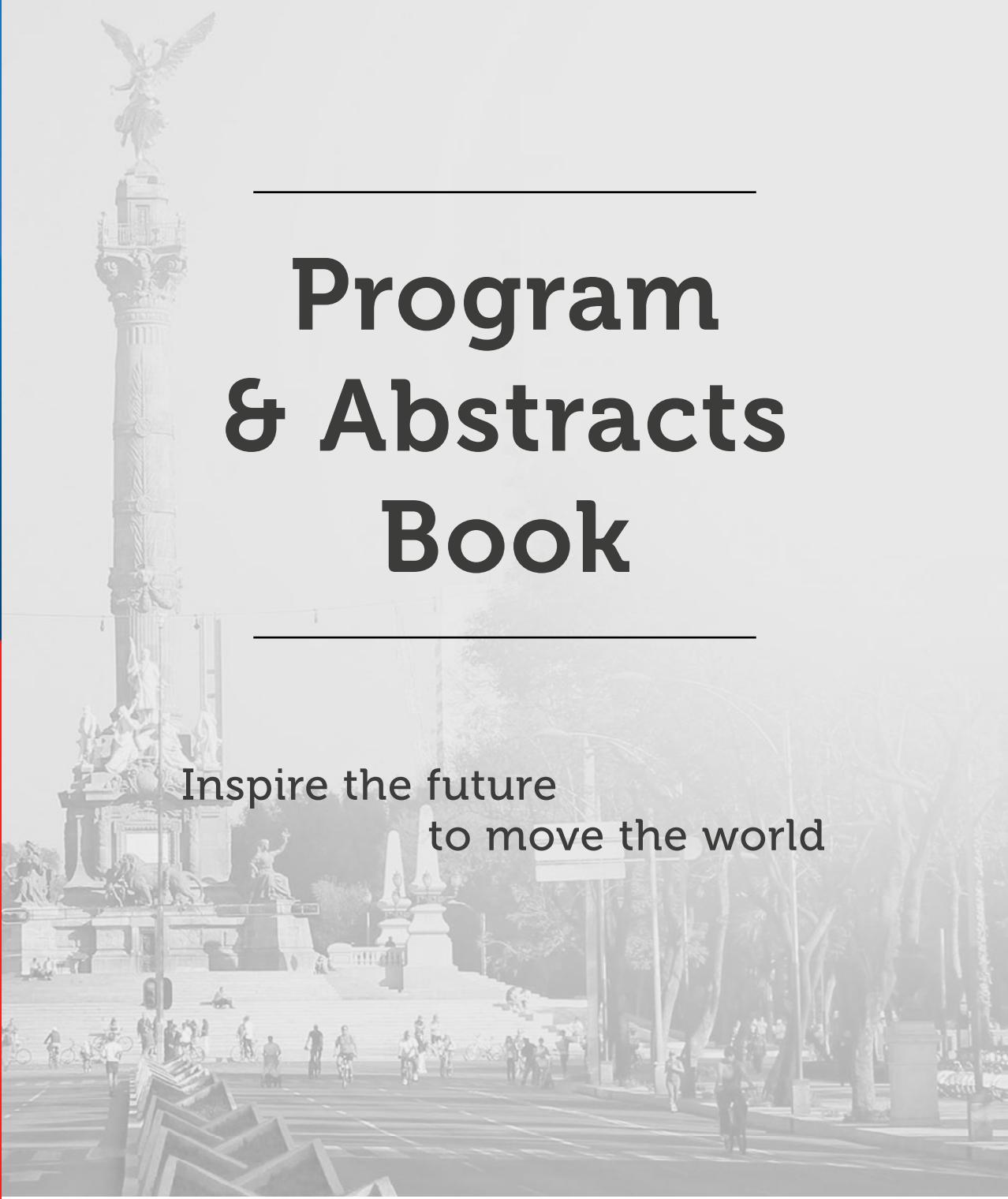




Program & Abstracts Book

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Foreword

Bioethics is a rather young academic inter-disciplinary field that has emerged rapidly as a particular moral enterprise against the background of the revival of applied ethics in the second half of the twentieth century. The notion of bioethics is commonly understood as a generic term for three main sub-disciplines: medical ethics, animal ethics, and environmental ethics. Each sub-discipline has its own particular area of bioethics, but there is a significant overlap of many issues, ethical approaches, concepts, and moral considerations. This makes it difficult to examine and to easily solve vital moral problems such as abortion, xenotransplantation, cloning, stem cell research, the moral status of animals and the moral status of nature (the environment). In addition, the field of bioethics presupposes at least some basic knowledge of important life sciences, most notably medicine, biology (including genetics), biochemistry, and biophysics in order to deal successfully with particular moral issues. This article also contains a discussion about the vital issue of moral status—and hence protection—in the context of bioethics, that is, whether moral status is ascribed depending on rationality, harm, or any other feature. For example, it might well be the case that non-sentient beings such as plants and unique stone formations, such as the Grand Canyon, do have a moral standing—at least, to some degree—and should not be deliberately destroyed by virtue of either their instrumental or intrinsic value for human beings. The last part contains a discussion of the main bioethical theories including their main line of reasoning and complex challenges in contemporary philosophy.

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Credits	218

Program

Program

Tuesday 24, June 2014

9.00 - 17.30	Satellite Meeting: Workshop for Early Career Bioethics Scholars	Doña Sol
9.00 - 17.30	Satellite Meeting: Revived Global Forum for Bioethics in Research	Don Americo
From 15.00	12 IAB WCB registration	Foyer Don Alberto
19.00 - 20.30	12 IAB WCB Welcome Cocktail	Foyer Don Alberto

Wednesday 25, June 2014

From 7.00	Registration	Foyer Don Alberto
8.30 - 9.30	Plenary Crossover FAB-IAB session Chair: Angus Dawson + Manuel H Ruiz de Chavez Ruth Macklin: What is Required to Improve Global Health: Research, Health Care, and Social Determinants Søren Holm	Don Alberto 1-4
9.40 - 10.40	Opening Session Manuel H Ruiz de Chavez, President of the Congress José Narro Robles, President of the National Autonomous University of Mexico Søren Holm, President of the International Association of Bioethics Mercedes Juan López, Secretary of Health of Mexico	Don Alberto 1-4
10.40 - 11.10	Performance by Son de Madera /coffee break parallel	Don Alberto 1-4
11.10 - 12.25	Plenary Session 1 Chair: Eduardo González Pier Tom Beauchamp: Why We Needed the System of Research Ethics We Have and How It Needs to Change Norman Daniels: How to respond to concerns about the judicialization of health Julio Frenk Mora: Ethical foundations of health policy Discussion/Forum	Don Alberto 1-4
12.25 - 13.25	Lunch	Foyer Don Alberto, Foyer Don Diego and Don Diego 1
12.25 - 13.25	IAB Board Meeting (only for board members)	Executive lounge, Floor 26
13.25 - 14.55	Symposia Parallel 1. Towards a global consensus on an ethical framework for medical products of human origin Marie-Charlotte Bouësseau, Caroline Clarinval, Dominique Martin, Farhat Moazam, Arturo Dib Kuri, Florencia Luna, Alex Capron	Don Alberto 1

Wednesday 25, June 2014

13.25 - 14.55	<p>The ethics of mitochondrial replacement therapy John Appleby, Stephen Wilkinson, Vardit Ravitsky, Annelien Bredenoord, Anthony Wrigley</p> <p>Iberoamerican Network: Bioética y laicidad Chair: Rodolfo Vázquez Cardozo</p> <p>The social value of research: Conflicts between science, society and individuals Seema Shah, Hans van Delden, David Wendler, Alan Wertheimer, Annette Rid</p> <p>Towards a normatively oriented empirical bioethics Ulrik Kihlbom, Hilde Lindeman, Jackie Leach Scully</p> <p>Control: duty and virtue, nightmare and fear; security and the role of the ethics committees. A Latin-American- EU Jim Dratwa, Inez de Beaufort, Jaime Burrows, Siobhan O'Sullivan</p> <p>Methods of bioethics Michael Selgelid, Vilhjálmur Árnason, John McMillan, Angus Dawson</p> <p>Should bioethicists be Activists: Do we need a translational bioethics? David Hunter, Iain Brassington, James Wilson</p> <p>Diabetes y la pobreza una paradoja de nuestra era, un análisis desde el punto de vista bioético Juan Manuel Granillo, Roberto Contreras García</p> <p>Patient death seen by the members of The Committee on Bioethics Hospitable, Hospital of Juárez México Dolores Delgado Ochoa, Cecilia Julieta González Ramírez, Octaviano Humberto Domínguez Márquez, Mónica Tejeda Romero, Leobardo Valle Molina, Clara Elena Hernández Bernal</p> <p>Biobanking in Africa Keymanthri Moodley, Eric Juengst, Ciara Staunton</p> <p>Ética en Investigación: Vulnerabilidad y protección Carla Saenz, Estela Quiroz, Carmen Alicia Cardoso, Dirce Guilhem</p>	<p>Don Alberto 2</p> <p>Don Alberto 3</p> <p>Don Alberto 4</p> <p>Don Diego 2</p> <p>Don Diego 3</p> <p>Don Diego 4</p> <p>Doña Adelita</p> <p>Don Genaro</p> <p>Don Julian</p> <p>Doña Socorro</p> <p>Doña Sol</p>
13.25 - 14.55	Abstract presentation session 1 1. Decision-making Chair: María de Jesús Medina	Don Americo
13.25 - 14.55	Poster session 1 Chair: Catherine Womack	Foyer Don Alberto
14:55 - 15:55	Coffee break	Foyer Don Alberto, Foyer Don Diego and Don Diego 1
15.55-17.40	<p>Plenary Session 2 Chair: Hans van Delden</p> <p>Christine Grady: The US Presidential Commission for the Study of Bioethical Issues and Compensation for Research Related Injury</p> <p>Juan Ramón de la Fuente: Medicine and human values</p> <p>Jonathan D. Moreno: Mind Wars: Brain Science and the Military in the 21st Century</p> <p>Amar Jesani</p> <p>Discussion/Forum</p>	Don Alberto 1-4

Wednesday 25, June 2014

17.50 - 19.05	Plenary Session 3 Chair: Inez de Beaufort Maria Casado: Ethics committees: From protector to legitimizers Peter Kemp: The Irreplaceable: A Fundamental Principle of Bioethics Juliana González: Philosophical Perspectives on Bioethics Discussion/Forum	Don Alberto 1-4
19.15 - 20.45	General IAB Meeting	Don Alberto 1-4
20.30 - 22.30	Speakers reception	Hilton Hotel

Thursday 26, June 2014

From 7.00	Registration	Foyer Don Alberto
8.30-9.45	Plenary Session 4 Chair: Alex Capron José Ramón Cossío: Derecho, Ciencia y Bioética Maria do Céu Patrão Neves: The new European Regulation on Clinical Trials Ruth Faden: HeLa Cells, Social Justice and the Ethics of Science Discussion/Forum	Don Alberto 1-4
10.00-11.15	Plenary Session 5 Chair: Simón Kawa Karasik Andrew Haines: Climate Change and Human Health- Ethical Challenges José Sarukhán: Elements of an ethical environmentally Evandro Agazzi: Bioethics as a new paradigm of ethics for contemporary world Discussion/Forum	Don Alberto 1-4
11.15-12.15	Coffebreak	Foyer Don Alberto, Foyer Don Diego and Don Diego 1
12.15-13.45	Symposia Parallel 2 Financial and other incentives for lifestyle: ethical issues Dick Willem, Inez de Beaufort, Hugh Whittall, Harald Schmidt, Becky Brown Social Determinants of Health and Research Ethics: Challenges of an EU funded Research (SDH-Net) Adolfo Martínez Palomo, Lucinda Cash-Gibson, Masuma Mamdani, Elis Borde, Manuel Urbina, Astrid Stuckelberger	Don Alberto 1 Don Alberto 2
12.15-13.45	Iberoamerican Network: Derechos sexuales y reproductivos. Nuevos formatos de familia. Chair: Joaquim Montauri Evidence-based research regulation? James Wilson, Simon Whitney, David Hunter, Annette Rid, Anant Bhan, Heike Felzmann From bioethics to bioart: The question about the limits I Ingeborg Reichle, Deborah Dorotinsky, Brandon Ballengée, Sebastián Lomelí Construction of knowledge in Bioethics I Carlos Viesca Treviño, León Olivé Morett, J. Alberto Campos	Don Alberto 3 Don Alberto 4 Don Diego 2 Don Diego 3

Thursday 26, June 2014

12.15-13.45	Place, care and bioethics Hilde Lindemann, Judit Illes, Joseph Fanning	Don Diego 4
	The islamic theory and principles of ethics within the global ethical diversity Omar Hasan Kasule, Muhammad Zuheir Alkawi	Doña Adelita
	An Ethical Evolution of Sexuality César Abarca-Garcia, Diana Buzo-Zarzosa	Don Julian
	Analysis of the Inter-American Court of Human Rights ruling on the case of Artavia Murillo et al. ("In Vitro Fertilization") vs. Costa Rica Manuel Ramos-Kuri, José Antonio Sánchez Barroso, Martha Tarasco	Doña Socorro
	Etnografía y Bioética: La experiencia de un grupo transfuncional Jorge Alberto Méndez Jiménez, Rodrigo Nava Diosdado, Adalberto de Hoyos, Sandra Lizárraga, Nelly F Altamirano Bustamante	Don Genaro
	Ethics of translational stem cell research: moving pluripotent stem cells to the clinic Annelien Bredenoord, Jeremy Sugarman, Michelle Habets	Don Americo
	Ethics of universal health coverage Daniel Wikler, Calvin Wai Loon Ho, Andreas Reis, Carla Saenz	Room B, Hotel Fiesta Inn Centro Histórico
	Special Session: "El final de la vida y El testamento vital I" organized by Universidad Autónoma del Estado de México Octavio Márquez Mendoza, Benjamín Herreros Ruiz Valdepeñas, Gregorio Jesús Palacios García-Cervigón, María Isabel Rivera Obando	Room C y D, Hotel Fiesta Inn Centro Histórico
12.15-13.45	Session Council CONBIOETICA	Executive lounge, Floor 26
13.45-14.45	Lunch	Foyer Don Alberto, Foyer Don Diego and Don Diego 1
14.45-16.15	Symposium	
	Integrity in medical research: Urgent as it is Medard Hilhorst, Inez de Beaufort, Leonardo D. de Castro, Søren Holm, Francisco Javier León, Wim Pinxte, Suzanne van de Vathor	Don Alberto 1
14.45-16.15	Abstract presentation parellel session 2-15	
	2. End of life Chair: Sigrid Sterckx	Don Alberto 2
	3. Genetics and Bioethics Network Chair: Darryl Macer	Don Alberto 3
	4. Social bioethics Chair: Peter Kemp	Don Alberto 4
	5. Clinical ethics Chair: Amar Jesani	Don Diego 2
	6. Global Health Chair: Tom Beauchamp	Don Diego 3
	7. Research ethics Chair: to be confirmed	Don Diego 4

Thursday 26, June 2014

14.45-16.15	8. Migration and Healthcare, Animal ethics & Neuro-ethics Chair: to be confirmed	Doña Adelita
	9. Special environmental ethics session Chair: James Dwyer	Don Americo
	10. Ethics and policymaking Chair: Inez De Beaufort	Don Genaro
	11. Clinical ethics Chair: David Hunter	Don Julian
	12. Global Health Chair: Ruth Faden	Doña Socorro
	13. Decision-making & Bioethics theory and methodology Chair: Camillia Kong	Doña Sol
	14. Bioethics theory and methodology Chair: James Wilson	Room B, Hotel Fiesta Inn Centro Histórico
	15. Research ethics Chair: Urban Wiesing	Room C y D, Hotel Fiesta Inn Centro Histórico
14.45-16.15	Poster session 2 Chair: Kasper Raus	Foyer Alberto
16.15-16.45	Coffebreak	Foyer Don Alberto, Foyer Don Diego and Don Diego 1
16.45-18.15	Abstract presentation parallel session 16 - 29	
	16. Global Health Chair: Alastair Campbell	Don Alberto 1
	17. Gender and health Chair: Wim Pinxten	Don Alberto 2
	Iberoamerican Network: Bioética de la relación con animales no humanos. Chair: Beatriz Vanda Cantón	Don Alberto 3
	18. ICT and ethics Chair: Andrew Haines	Don Alberto 4
	19. Reproductive technologies & End of life Chair: Medard Hilhorst	Don Diego 2
	20. Spanish session Chair: Gustavo Ortiz Millán	Don Diego 3
	21. Biobanks Chair: Graeme Laurie	Don Diego 4
	22. Enhancement Chair: John Harris	Doña Adelita
	23. Clinical ethics Chair: Daniel Fu-Chang Tsai	Don Americo
	24. Beginning of life Chair: Maureen Kelley	Don Genaro
	25. Ethics and policymaking Chair: to be confirmed	Don Julian
	26. Gender and reproduction Chair: Farhat Moazam	Doña Socorro

Thursday 26, June 2014

16.45-18.15	27. Teaching and bioethics Chair: Sarah Chan	Doña Sol
	28. Research ethics Chair: Ruth Macklin	Room B, Hotel Fiesta Inn Centro Histórico
	29. Bioethics and vulnerability Chair: to be confirmed	Room C y D, Hotel Fiesta Inn Centro Histórico
16.45-18.15	Poster session 3 Chair: John McMillan	Foyer Don Alberto
18.30-20.00	Symposia Parallel 3	
	Migrants, health care, and ethical responsibility James Dwyer, Verina Wild, James Wilson	Don Alberto 1
	Ethical issues in public health surveillance Andreas Reis, Abha Saxena, Michael Selgelid	Don Alberto 2
	Iberoamerican Network: Democracia participativa en Latinoamérica. Pobreza y hambre. Desnutrición y obesidad. Seguridad alimenticia Chair: Debora Diniz	Don Alberto 3
	The Tissue/Data Divide: Paradigms, property and privacy Hugh Whittall, Nayha Sethi, Graeme Laurie, Iain Brassington, Emily Postan,	Don Alberto 4
	Construction of knowledge in Bioethics II J. Alberto Campos, Javier Luna Orosco, Javier Sádaba, Carlos Viesca Treviño	Don Diego 2
	From bioethics to bioart: The question about the limits II María Antonia González Valerio, Rosaura Martínez, Nicole C. Karafyllis	Don Diego 3
	Regulation of research, efficiency and internationalization: Does one size fit all? David Hunter, Annette Rid, John McMillan, Calvin Wai Loon Ho	Don Diego 4
	Men and reproduction: some controversies on 'Fathering' Inez de Beaufort, Hafez Ismaili m'Hamdi, Wim Pinxten	Doña Adelita
	Cross-border stem cell therapies: International governance and harmonisation John Harris, María Medina, Rubén Lisker, Ricardo Tapia	Don Americo
	What can clinical bioethics offer to our mexican contemporary reality? Martha Tarasco, Robert Hall, Ma. Elizabeth de los Ríos Uriarte, Samuel Weingerz Mehl	Don Genaro
	Real time bioethics: axiology of clinical practice Myriam Altamirano-Bustamante, Nelly Altamirano- Bustamante, Alberto Lifshitz, Uria Guevara, Ximena Sueiras, Ana Serrano, Adalberto de Hoyos, Rodrigo Nava Diosdado	Don Julian
	Ethics, morality and evolution Ricardo Noguera-Solano, Rodrigo Bustillo-Ramírez, Susana Carapia-Vargas, Vivette García-Deister, Rosaura Ruiz Gutiérrez, Juan Manuel Rodríguez-Caso	Doña Socorro
	Iberoamerican Network: Género, sexualidad y bioética Chair: Florencia Luna	Doña Sol

Thursday 26, June 2014

18.30-20.00	Bioethics education 2.0: Advancing continuing professional development in ethics for healthcare professionals Jacqueline Chin, Nancy Berlinger, Michael Dunn, Farhat Moazam, Daniel Fu-Chang Tsai, David Rodríguez-Arias	Room B, Hotel Fiesta Inn Centro Histórico
	Special Session: "El final de la vida and El testamento vital II" organized by Universidad Autónoma del Estado de México Octavio Márquez Mendoza, Marcela Veytia López, Rosalinda Guadarrama Guadarrama, Sergio Ruiz Peña, Benjamín Herreros Ruiz Valdepeñas, Elba Margarita González Fabián, Gregorio Jesús Palacios García-Cervigón, María Isabel Rivera Ovando, Sergio Gerardo Martínez Pérez	Room C y D, Hotel Fiesta Inn Centro Histórico
20.00-22.00	Performance by the Ballet Folklorico of México of Amalia Hernandez	Biblioteca de México "José Vasconcelos"

Friday 27, June 2014

From 7:00	Registration	Foyer Don Alberto
8.30-9.45	Plenary Session 6 Chair: Dafna Feinholz Carlos Viesca Treviño Eduardo Matos: Biodiversidad en el Templo Mayor Azteca Patrick Johanson: The aztec cosmovision of death before the Conquest Discussion/Forum	Don Alberto 1-4
10.00-11.15	Plenary Session 7 Chair: Paulette Dieterlen Adolfo Martínez Palomo: Disability and the Universal Declaration on Bioethics and Human Rights Carlos Alonso Bedate: The triple helix for a Global Health Florencia Luna: Reproductive Rights; still a pending issue in Latin America Discussion/Forum	Don Alberto 1-4
11.15-12.15	Coffebreak	Foyer Don Alberto, Foyer Don Diego and Don Diego 1
12.15-13.45	Symposia Parallel 4 Revision of the CIOMS guidelines for biomedical research involving human subjects Annette Rid, Hans van Delden, Rieke van der Graaf, Anant Bhan, Ruth Macklin 'Vulnerability' in research involving human participants Calvin Wai-Loon Ho, Alastair Campbell, Abha Saxena, Seema Shah, Hugh Whitall	Don Alberto 1
	Iberoamerican Network: Neuroética y droga. Estado penal y salud. Drogas de uso ritual, recreativo y de abuso I Jorge E. Linares Salgado, Francisco Pellicer, Óscar Prospéro, Bia Labate	Don Alberto 2
	Current controversies in end-of-life ethics Jan L Bernheim, Kasper Raus, Sigrid Sterckx, Søren Holm, Alexander Capron	Don Alberto 3
	Iberoamerican Network: Bioética en Iberoamérica Chair: Eduardo Siqueira	Don Alberto 4
		Don Diego 2

Friday 27, June 2014

			Don Diego 3
12.15-13.45	Consent and assent in paediatric research: Global issues Phaik Yeong Cheah, Mark Sheehan, Paul Baines, Maureen Kelley		Don Diego 4
	Contemporary ethical challenges to organ transplantation in Asia Leonardo D. de Castro, Daniel Fu-Chang Tsai, Zohar Lederman, Ilhak Lee, Jacqueline Chin, Hitoshi Arima		Doña Adelita
	Bioethics and Security of the Patient Wellbeing and Human Rights Enrique Mendoza Carrera, Cristina Caballero Velarde, Jorge Alfonso Pérez Castro y Vázquez, Lidia Cote Estrada, Martha Tarasco		Don Julian
	Acts and omissions across bioethics Txetxu Ausín, David Rodríguez-Arias, Rosana Triviño, Elizabeth Téllez		Doña Socorro
	Bioethics and indigenous peoples: Public health and peace Darryl Macer, Alireza Bagheri, Martha Marcela Rodriguez Alanis		Room B, Hotel Fiesta Inn Centro Histórico
	Food choices, responsibility and bioethics David Hunter, Catherine Womack, Christian Munthe, Marcel Verweji		Room C y D, Hotel Fiesta Inn Centro Histórico
	Global bioethics and climate change: Science, society and individuals in Latin America and the Caribbean Cheryl Macpherson, Myriam Altamirano-Bustamante, Seetharaman Hariharan, Sean Philpott		Abstract presentation parellel session 30-31
	30. Global Health Chair: Jackie Leach Scully		Don Genaro
	31. Spanish session Chair: Maria Casado		Don Americo
12.15-13.45	Poster session 4 Chair: to be confirmed		Foyer Don Alberto
13.45-14.45	Lunch		Foyer Don Alberto, Foyer Don Diego and Don Diego 1
13.45-14.45	IAB Board Meeting (only for board members)		Executive lounge, Floor 26
14.45-16.15	Iberoamerican Network: Neuroética y droga. Estado penal y salud. Drogas de uso ritual, recreativo y de abuso II Maria Casado, José Luis Díaz, María Elena Medina Mora, Jorge González Olvera		Don Alberto 3
14.45-16.15	Abstract presentation parellel session 32 - 44		
	32. Special Enviromental ethics session Chair: James Dwyer		Don Alberto 1
	33. Ethics and policymaking Chair: Ulrik Kihlbom		Don Alberto 2
	34. Bioethics Education Network Chair: Darryl Macer		Don Alberto 4
	35. Bioethics theory and methodology Chair: Rieke van der Graaf		Don Diego 2

Friday 27, June 2014

14.45-16.15	36. Genetics Chair: Simon Kawa	Don Diego 3
	37. Multicultural ethics Chair: to be confirmed	Don Diego 4
	38. Spanish session Chair: Jorge E. Linares Salgado	Doña Adelita
	39. Decision-making Chair: Alireza Bagheri	Don Americo
	40. Animal ethics Chair: to be confirmed	Don Genaro
	41. Research ethics Chair: Annette Rid	Don Julian
	42. Global Health Chair: Michael Selgelid	Doña Socorro
	Iberoamerican Network: Desigualdad y políticas públicas. Chair: Roberto Luiz Dávila	Doña Sol
	43. Bioethics and transplants, Sexuality and bioethics & Food ethics Chair: Jacqueline Chin	Room B, Hotel Fiesta Inn Centro Histórico
	44. Pediatric research Chair: Suzanne van de Vathorst	Room C y D, Hotel Fiesta Inn Centro Histórico
14.45-16.15	Poster session 5 Chair: Marie-Charlotte Bouësseau	Foyer Don Alberto
16.15-17.15	Coffebreak	Foyer Don Alberto, Foyer Don Diego and Don Diego 1
17.15-18.45	Plenary Session 8 Chair: Angus Dawson Carlos María Romeo Casabona: New challenges for genetic information management in research and clinics Gilbert Hottois: Is transhumanism a humanism? John Harris: The Generic Nature of the Good Nicholas Agar: I want to sell Peter Singer some moral insurance	Don Alberto 1-4
18.45-20.00	Closing ceremony Chair: Manuel H Ruiz de Chavez President Lecture: Søren Holm Prizes: Guillermo Soberón, Poster & Abstracts awards Next Venue: Edinburgh Closing remarks	Don Alberto 1-4

Friday 27, June 2014

9:00-18:00	Conference on Bioethics, Public Health and Peace for Indigenous Peoples	UNAM Centro Cultural Tlatelolco
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Presentations

Presentations

Wednesday 25, June 2014

Room: Don Américo

Session 1 Decision making

TIME	ID	TITLE	AUTHOR	COUNTRY
13:25	198	Strengths and weaknesses of guideline approaches to safeguard voluntary informed consent of patients within a dependent relationship	Sara Dekking, University Medical Center Utrecht	Netherlands
13:40	258	Incidental Findings through Imaging in Population-based Research: Participant Perspectives	Lisa van Bodegom, Erasmus MC	Netherlands
13:55	384	Hanging on to some autonomy in decision-making in dementia – how do people with dementia and their carers do it?	Deirdre Fetherstonhaugh, ACEBAC, La Trobe University	Australia
14:10	435	To be or not to be involved in medical decisions concerning relatives	Michael Katz, Haifa University	Israel
14:25	516	Gender-dependent participation in cardiovascular genetic research: An analysis of consent forms reveals 'participant categories'	Charles Dupras, University of Montreal	Canada
14:40	622	Which Autonomy? Supportive Decision-Making in Mental Capacity Law and Philosophy	Camillia Kong, The Ethox Centre, University of Oxford	United Kingdom

Thursday 26, June 2014

Room: Don Alberto 1

Session 2 End of Life

TIME	ID	TITLE	AUTHOR	COUNTRY
14:45	12	Descriptive study on the opinion of members of the National Criminal and Civil (Family) Courts in cases of withholding or withdrawing life sustaining treatment I	Maria Susana Ciruzzi, Observatorio de Salud Facultad de Derecho UBA	Argentina
15:00	443	How broad is too broad? Justifying models of consent to research	Mark Sheehan, University of Oxford	United Kingdom
15:15	172	Medically Assisted Death. National Realities/ International Topics	Edith González Moreno, Universidad Michoacana de San Nicolás de Hidalgo	Mexico
15:30	304	Further Deliberating the Differences between Do-Not-Resuscitate and Allow-Natural-Death	Yen-Yuan Chen, National Taiwan University Hospital	Taiwan (Republic of China)
15:45	463	Physician-assisted dying in New Zealand: what do older persons think and why?	Phillipa Malpas, University of Auckland	New Zealand
16:00	662	Biopolitics of Euthanasia in Colombia	Yolanda Guerra, Universidad Militar Nueva Granada	Colombia

Thursday 26, June 2014

Room: Don Alberto 2

Session 3 Genetics and Bioethics Network

TIME	ID	TITLE	AUTHOR	COUNTRY
14:45	152	Genetics, Identity and Triparenting	Anthony Wrigley, Keele University	United Kingdom
15:00	210	Is there such a thing as personal utility in genomic testing?	Eline Bunnik, Erasmus MC	Netherlands
15:15	312	Defending the child's right to an open future concerning genetic information	Annelien Bredenoord, University Medical Center Utrecht	Netherlands
15:30	379	The Social and Ethical Consequences of Ambiguous Definitions of 'Population' in Community Resource Projects: The case of the 1000 Genomes Project	Santiago Molina, University of California Berkeley	United States
15:45	509	Why it is ethical to create children with three genetic parents using mitochondrial replacement therapies	John Appleby, King's College London	United Kingdom
16:00	750	Ethical Considerations in Genomic-based Personalized Medicine	Alan Warner, Mount Sinai Hospital	Canada

Room: Don Alberto 4

Session 4 Social bioethics

TIME	ID	TITLE	AUTHOR	COUNTRY
14:45	699	Twenty years of bioethics in UNESCO: what is the perspective for the coming years?	Dafna Feinholz, UNESCO	France
15:00	474	Bioethical aspects of intra-familiar relationship in the context of home care	Dirce Guilhem, University of Brasilia	Brazil
15:15	554	Science and Crime: The impacts of bioanthropological research in law and in contemporary society	Nilza Maria Diniz, State University of Londrina	Brazil
15:30	486	Beyond dichotomies: an informational approach to personal identities	Lais Lopes, Federal University of Minas Gerais	Brazil
15:45	675	Bioethical analysis of public policy designed to fight obesity and malnutrition in Mexico	Maria de los Angeles Marina Adame, Comisión Nacional de Bioética	Mexico
16:00	416	Is there an ethical obligation to think about one's health, and if so, should we use rewards or penalties for encouragement? The case of health screenings	Harald Schmidt, University of Pennsylvania	United States

Room: Don Diego 2

Session 5 Clinical Ethics

TIME	ID	TITLE	AUTHOR	COUNTRY
14:45	298	Parental autonomy and choice in the context of prenatal diagnosis. Views and attitudes of healthcare professionals and prospective parents	Sylvia Hübel, University College Brussels	Belgium
15:00	591	Qualitative determination of care ethics elements in Nursing in institutions in Mexico City	Claudia Villanueva Sáenz, Universidad Panamericana	Mexico
15:15	603	Building ethical sensitivity from the subjectivity of nursing students and professors	Bertha Alicia Alonso Castillo, Universidad Autónoma de Nuevo León	Mexico
15:30	665	Posteriorizing Marginally Beneficial Treatments – Practical Considerations	Daniel Friedrich, Institute for Ethics, History and Philosophy of Medicine	Germany
15:45	687	Implicit bias in health care professionals: a systematic review	Chloë Fitzgerald, Université de Genève	Switzerland
16:00	323	Children in clinical drug research: Why do they participate?	Krista Tromp, Erasmus Medical Center Rotterdam	Netherlands

Thursday 26, June 2014

Room: Don Diego 3

Session 6 Global Health

TIME	ID	TITLE	AUTHOR	COUNTRY
14:45	150	Separate Goals, Converging Priorities: On the Ethics of HIV Treatment as Prevention	Carla Saenz, Pan American Health Organization / WHO	United States
15:00	20	Quality of life related to Health: equivocal concept in a globalized world	Gilberto Alfonso Gamboa-Bernal, Universidad de La Sabana	Colombia
15:15	35	Public Health and Implementation Research in latin America	Claude Verges, Latin American Network of Research Ethics Committees	Panama
15:30	173	The responsiveness requirement revisited: global attention for global health needs and priorities	Rieke van der Graaf, University Medical Center Utrecht	Netherlands
15:45	177	The ethics of priority setting for health systems research in developing countries: Should global priorities drive national priorities?	Bridget Pratt, Johns Hopkins Berman Institute of Bioethics	United States
16:00	290	Ethical Considerations for a Tobacco Phase-Out	Yvette van der Eijk, National University of Singapore	Singapore

Room: Don Diego 4

Session 7 Research Ethics

TIME	ID	TITLE	AUTHOR	COUNTRY
14:45	638	The rise of direct-to-consumer genomic tests and its implications to science, society and the individual in the developing world. A case study in México	Miguel Angel Contreras Sieck, Instituto Nacional de Medicina Genómica	Mexico
15:00	78	Compensation For Research-Related Injuries – Whither Africa: The Contributory Collaborative Responsibility Approach – A Solution Based On The Traditional	Patrick Kamalo, University of Malawi	Malawi
15:15	108	Ethical Double Standards: What are they? What can be done about them?	David Wendler, US NIH Clinical Center	United States
15:30	265	Population studies and the ethics of representativeness	Hallvard Fosseheim, The Norwegian National Research Ethics Committees	Norway
15:45	423	Pandemic A H1N1 (2009) Preparedness Efforts, Compliance, and Some Ethical Considerations: A Retrospective Study on Hijli Rural Hospital (RH), Kharagpur I, West	Rhyddhi Chakraborty, Indian Institute of Technology Kharagpur	India
16:00	355	Human enhancement as a basic right	Brunello Stancioli, Federal University of Minas Gerais	Brazil

Room: Doña Adelita

Session 8 Migration and Healthcare, Animal ethics & Neuro-ethics

TIME	ID	TITLE	AUTHOR	COUNTRY
14:45	247	Does migration lead to unjustified disparities in health care? A factorial survey among physicians in Switzerland	Daniel Drewniak, University of Zurich	Switzerland
15:00	300	Migration o Elderly People in Need of Longterm Care and its Ethical Issues	Verina Wild, Center for Ethics of the University of Zurich	Switzerland
15:15	392	Balancing Burdens and Benefits in Neuroscientific Research using Non-Human Primates	Gardar Arnason, University of Tübingen	Germany
15:30	222	Will neuroscience become an apology for violence? Disability, law and the aggressive legal subject	Karen O'Connell, University of Technology	Australia
15:45	244	My brain made me not do it: Neurodeterminism and the negative sense of free will	Daniel Pallarés Domínguez, Universitat Jaume I de Castellón	Spain
16:00	631	Neuroethics of medical therapy in attention deficit disorder whit hyperactive	Marcela Patricia Vazquez Valenzuela, Colegio EDIA	Mexico

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Room: Don Americo

Session 9 Special environmental ethics session

TIME	ID	TITLE	AUTHOR	COUNTRY
14:45	393	GM Crops debate in China: from a confucian perspective	Zhen Cai, East China Normal University	United States
15:00	203	Ethics and climate change	Santiago Oton G., UNAM	Mexico
15:15	204	Ethical and political aspects of climate change	Ma. Teresa de la Garza, UNAM	Mexico
15:30	629	IPAT-ethics: Some normative considerations with respect to reducing humanity's aggregate environmental impact.	Wouter Peeters, University of Brussels	Belgium

Room: Don Genaro

Session 10 Ethics and Policymaking

TIME	ID	TITLE	AUTHOR	COUNTRY
14:45	125	Actors and arguments against surrogacy in Swedish public debate	Kjell Asplund, Swedish National Council on Medical Ethics	Sweden
15:00	167	Exploitation in International Surrogacy Arrangements	Stephen Wilkinson, Lancaster University	United Kingdom
15:15	209	Just what is just in public health emergency preparedness and response? Preliminary findings from a qualitative study of public health policy-maker perspectives	Maxwell Smith, University of Toronto	Canada
15:30	301	The Three Most Important Ethical Principles in the Prioritisation Debate	Bert Vanderhaegen, Ghent University Hospital	Belgium
15:45	329	Obesity prevention and tobacco control: similarities and differences	Céline Brassart Olsen, University of Copenhagen	Denmark
16:00	363	Intergenerational Harm: do we have an obligation to protect the health of future persons?	Isabel Karpin, University of Technology	Australia

Room: Don Julian

Session 11 Clinical Ethics

TIME	ID	TITLE	AUTHOR	COUNTRY
14:45	121	Bioethicist's Proactive Engagement In Clinical Rounds And Consultations, Hospital Risk Management And Quality Programs: Experiences Of The King Fahad Medical City	Omar Hasan Kasule, King Fahad Medical City	Saudi Arabia
15:00	186	When eating and drinking may be harmful: Perspectives of patients and speech pathologists	Belinda Kenny, University of Sydney	Australia
15:15	215	Accounting for illness in the medical encounter - a tailored account of autonomy	Rebecca Tock, Macquarie University	Australia
15:30	319	Integral perspective of a bioethical case	Jaime Villalba-Caloca, National Institute of Respiratory Diseases	Mexico
15:45	467	Regret in patients with acute and chronic conditions recruited to stem cell clinical trials	Katrine Bavnbek, University College London Hospitals	United Kingdom

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Room: Doña Socorro

Session 12 Global Health

TIME	ID	TITLE	AUTHOR	COUNTRY
14:45	305	Plain Packaging for Cigarettes: Where Public Health Ethics and Research Ethics Meet	Iain Brassington, University of Manchester	United Kingdom
15:00	352	Agency, identity and behavior change: shifting from an individual to a relational model	Norah Mulvaney-Day, Abt Associates	United States
15:15	354	The New EU Standards for Aesthetic Surgery Services	Diana Nacea, University of Copenhagen	Denmark
15:30	366	Autonomy: three suggestions for more applications in Costa Rica	Jimmy Washburn, University of Costa Rica	Costa Rica
15:45	401	A Framing Problem for Public Health Ethics: Addressing the basic Issue of Scope	Christian Munthe, University of Gothenburg	Sweden
16:00	563	Stigma, mental health and peace process in Colombia	Edwin Herazo, Human Behavioral Research Institute	Colombia

Room: Doña Sol

Session 13 Decision-making & Bioethics theory and methodology

TIME	ID	TITLE	AUTHOR	COUNTRY
14:45	255	Physician acquiescence, medical virtue, and evaluative conditioning in direct-to-consumer pharmaceutical advertising	Justin Oakley, Monash University	Australia
15:00	199	Bioethical considerations of informed consent or agreement in teen pregnancy	Samuel Weingerz, Hospital General Dr Manuel Gea Gonzalez	Mexico
15:15	315	Not a Lone(l)y Process: Healthcare Decision Making as a Relational Process	Anita Ho, University of British Columbia	Canada
15:30	55	Conscientious objection in Latinamerica and Spain	Maria de la Luz Casas Martinez, Panamerican University	Mexico
15:45	570	Does Human dignity have nothing to do with the physical body?	Han Yuehong, Kunming University of Science and Technology	China
16:00	72	Why Privacy is or not so important in Human Subject Protection: A comparative study between Chinese and American Patient Subjects	Haihong Zhang, Peking University Health Science Center	China

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Session 14 Bioethics theory and methodology

TIME	ID	TITLE	AUTHOR	COUNTRY
14:45	54	Voluntariness is not a component of valid consent	Michael Dunn, University of Oxford	United Kingdom
15:00	682	Ten criticism thesis about bioethics	Raúl Héctor Rodríguez Otero, CONBIOETICA	Mexico
15:15	114	The Globalisation of Clinical Trials: How the Market Shapes Law and Bioethical Discourse	Gerard Porter, University of Edinburgh	United Kingdom
15:30	171	Between the bioethical imperative and land ethics: The contributions of Fritz Jahr And Aldo Leopold for the consolidation of bioethical thought	Jailson José Gomes da Rocha, Universida de Federal da Paraíba	Brazil
15:45	446	Juridification and Regulationism in Human Pluripotent Stem Cell Research: The Re-Emergence of the State	Calvin Wai-Loon Ho, National University of Singapore	Singapore
16:00	465	Deafness as a form of health? Theoretical and ethical issues regarding the holistic understanding of health	Diana Aurenque, University of Tübingen	Germany

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Session 15

Research Ethics

TIME	ID	TITLE	AUTHOR	COUNTRY
14:45	193	The yardstick of the pharmaceutical regulation: which GCP issues may also be ethical issues?	Rosemarie Bernabe, University Medical Center	Netherlands
15:00	196	Patent on genetic information – discoveries, inventions, processes and products	Tom Andreassen, Norwegian University of Science and Technology	Norway
15:15	233	Editorial police what say you? Analysis of duplicate publications in PubMed	Mario Malicki, University of Split	Croatia
15:30	248	The ethics of sham interventions in an era of emerging biotechnology	Sophie Niemansburg, University Medical Center Utrecht	Netherlands
15:45	294	The mission of an ethics committee apropos social studies: the experience of the Ethics Committee for the Research on Human Beings and Animals of the Pontifical	Gisela Isabel Fernández Rivas Plata, Pontifical Catholic University of Peru	Peru
16:00	378	The ethical experiences of stakeholders in stem cell research	Michelle Habets, University Medical Center Utrecht	Netherlands

Room: Don Alberto 1

Session 16

Global Health

TIME	ID	TITLE	AUTHOR	COUNTRY
16:45	395	Public Health and the Influence of Incentives	Becky Brown, University of Aberdeen	United Kingdom
17:00	645	Bioethical issues in the resolutions of the Inter-American Court of Human Rights	Sandra Lizbeth Carrizosa, UNAM	Mexico
17:15	132	Direct to the consumer nocebo effects - the ethics of pharma advertising & informing	David Hunter, Flinders University	Australia
17:30	153	Valuing Stillbirths	Joseph Millum, National Institutes of Health	United States
17:45	318	Sen's capabilities approach as an ethical framework for nudging	Hafez Ismaili m'Hamdi, ErasmusMC	Netherlands
18:00	399	Should there be a right to 'absenteeism' for health care workers?	Søren Holm, University of Manchester	United Kingdom

Room: Don Alberto 2

Session 17

Gender and Health

TIME	ID	TITLE	AUTHOR	COUNTRY
16:45	3	On the Necessity of Universals in Bioethics	Mary C. Rawlinson, Stony Brook University	United States
17:00	670	Meanings of menopause. Body, gender and experience	Gabriela Pineda Hernández, Comisión Nacional de Bioética	Mexico
17:15	430	Women's ethical dilemmas at the intersection of labour migration and care drain	Sylvia Hübel, University of Leuven	Belgium
17:30	466	What is the role of cultural relativism in the case of hymen reconstruction?	Verina Wild, Institute of Biomedical Ethics	Switzerland
17:45	487	Early medical treatment of children with gender dysphoria: an empirical ethical study on arguments of proponents and opponents concerning early interventions	Martine de Vries, Leiden University Medical Center	Netherlands
18:00	80	Estimating the Social Priority of Addressing Violence Against Women	Randall Waechter, St. George's University	Grenada

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Session 18

ICT and ethics & Teaching and bioethics

TIME	ID	TITLE	AUTHOR	COUNTRY
16:45	246	Perceived benefits and barriers of telemedicine in Botswana: A preliminary study of two referral hospitals in Botswana	Rekha Kumar, University of Botswana	Botswana
17:00	545	Data from mobile devices and clinical healthcare decisions: a new paradigm?	Alexander Capron, University of Southern California	United States
17:15	96	Clinical photography and social media	César Palacios González, University of Manchester	United Kingdom
17:30	239	Acces to legal-bioethics data in networks	Sílvia Navarro, Observatori de Bioètica i Dret UB	Spain
17:45	571	Medical empathy in Iberoamerican physicians-in-training: Similarities and differences during their professional practice at a Teaching Hospital in Spain	Adelina Alcorta-Garza, Center for Biomedical Research of La Rioja	Spain
18:00	262	Experience from the bioethics committee, in a private hospital. CEMAIN Hospital, 5 years later.	Agustín Loría Argaiz, Hospital CEIMAN	Mexico

Room: Don Diego 2

Session 19

Reproductive technologies & End of life

TIME	ID	TITLE	AUTHOR	COUNTRY
16:45	168	Informed Consent previous to Assisted Reproduction: A National Inquiry	Antonio Cabrera Cabrera, Universidad Anáhuac	Mexico
17:00	705	Dysthanasia – The futile and/or useless medical treatment in Brazil: From the anguish of the decision to the serenity of the bioethical dialogue	Leo Pessini, Saint Camillus University Center	Brazil
17:15	268	Understanding decision-making in the setting of Mexican adolescents who died of cancer: preliminary results of a qualitative research study	Carlo Egisto Cicero-Oneto, Hospital Infantil de México	Mexico
17:30	256	Evaluation of the End-of-Life Clinic	Marianne Snijdewind, University of Amsterdam	Netherlands
17:45	74	The good death	Suzanne van de Vathorst, AMC	Netherlands
18:00	149	"I don't need my patients' opinion to withdraw treatment": Patient preferences at the end-of-life and physician attitudes towards advance directives in England	Ruth Horn, University of Oxford	United Kingdom

Room: Don Diego 3

Session 20

Spanish session

TIME	ID	TITLE	AUTHOR	COUNTRY
16:45	254	LET en Psicoterapia	Mercado Velázquez, Sanatorio San Francisco de Asís	Mexico
17:00	13	Justicia y escasez: el problema bioético de la distribución de recursos para la salud	Maria Elizabeth De los Rios, Universidad Anáhuac México Norte	Mexico
17:15	58	Problemas éticos y bioéticos apreciados por los estudiantes de Ciencias de la Salud desde el aula a la práctica hospitalaria	Mirtha Flor Cervera Vallerjos, Universidad Católica Santo Toribio de Mogrovejo	Peru
17:30	757	Reflexiones Bioéticas sobre la Condición de Identidad en Pacientes con Trastorno de Diferenciación Sexual (TDS)	Ana Lilia Higuera Olivo, UNAM	Mexico
17:45	212	Bioética, derecho e imparcialidad judicial. Análisis crítico a la Sentencia Artavia Murillo y otros vs. Costa Rica	Hugo Ramírez, Universidad Panamericana	Mexico
18:00	527	Aspectos éticos de la investigación sobre violencia de género y violencia familiar	Agueda Muñoz del Carpio Toia, Middleton International Fellows Association	Peru

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Room: Don Diego 4

Session 21 Biobanks

TIME	ID	TITLE	AUTHOR	COUNTRY
16:45	101	Solidarity in brain banking: a guiding value for a public good?	Shawn Harmon, University of Edinburgh	United Kingdom
17:00	302	Interpreting the body: bioinformation as a tool of self-conception	Emily Postan, University of Edinburgh	United Kingdom
17:15	751	The re-examination of the Council of Europe Biobank Recommendation: current status	Kristof Van Assche, Free University of Brussels	Belgium
17:30	686	Is this real promise or real dilemma? An Ethical Evaluation of Human Embryonic Stem Cells as a Therapeutic Agent	Mukadder Gun, Turkish Gendarmerie General Command	Turkey
17:45	588	Transforming conceptualization of Health and Disease: Bioethical and epistemological implications of the interaction Microbiome-Human	Ximena González-Grandón, Universidad Nacional Autónoma de México	Mexico
18:00	334	Religion as bioethical element that influences decision-making hospital	Francisco X González Garza, Instituto de Investigaciones en Bioética	Mexico

Room: Doña Adelita

Session 22 Enhancement

TIME	ID	TITLE	AUTHOR	COUNTRY
16:45	179	Fit for the future: misdiagnosing the need for moral enhancement	Felice Marshall, Victoria University of Wellington	New Zealand
17:00	358	Moral bioenhancement and virtues	Joanna Rozynska, University of Warsaw	Poland
17:15	406	Towards new possibilities of dignified personhood: superseding the homo sapiens	Daniel Ribeiro, Universidade Federal de Juiz de Fora	Brazil
17:30	144	Is biomedical enhancement a disenchantment of the world?	Anton van Niekerk, Stellenbosch University	South Africa
17:45	345	The ideal human as a guide to human enhancement?	Johann Roduit, University of Zurich	Switzerland
18:00	403	Designing the Best Possible Existence: The non-identity problem, genetics and our duties to future generations	Edgar René Ruiz-López, UNAM	Mexico

Room: Don Americo

Session 23 Clinical ethics

TIME	ID	TITLE	AUTHOR	COUNTRY
16:45	314	Ethical implications of surgical flow pro-action by anesthesia induction rooms: what's up for the patients?	Amitabh Dutta, Ganga Ram Institute for Medical Education & Research	India
17:00	372	Gathering up the Loose Ends of Dispute Settlement in Clinical Practice	Rodrigo Nava-Diosdado, IMSS	Mexico
17:15	482	Axiology of the ends of medicine	Perla Sueiras, IMSS	Mexico
17:30	500	Dysthanasia and/or Futile Care in the Intensive Care Units of a Specialty Hospital in El Bajío Region, in Mexico	Enrique M. Olivares-Durán, Hospital Regional de Alta Especialidad del Bajío	Mexico
17:45	607	Moral stress in health care professionals	Maria Teresa De Jesús Alonso Castillo, Universidad Autónoma de Nuevo León	Mexico
18:00	472	Autonomy principle into a counseling genetics service	Nilza Diniz, State University of Londrina	Brazil

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Session 24

Beginnig of life

TIME	ID	TITLE	AUTHOR	COUNTRY
16:45	697	Fate of cryopreserved human embryos produced by IVF: new scientific and bioethical and legal implications	Manuel J. Santos, Pontificia Universidad Católica de Chile	Chile
17:00	475	Neonatal health in Mexico. Analyzing challenges from the perspective of the vulnerability principle	Irma Alejandra Coronado-Zarco, Instituto Nacional de Perinatología	Mexico
17:15	636	Bonding and it's impact on public policy to decrease violence \ "Applied Bioethics	Jose Arturo Vela Staines, Colegio de Bioetica de N.L.	Mexico
17:30	700	Bioethical issues on the possibility of fetal pain	Maria Antonieta Flores Muñoz, UNAM	Mexico
17:45	702	Toward a Proper Comprehension of the Human Zygote	Manuel Ramos Kuri, Centro de Investigación Social Avanzada	Mexico
18:00	347	The moral status of embryos: the limits of the philosophical approach on abortion	Telma de Souza Birchall, Federal University of Minas Gerais	Brazil

Room: Don Julian

Session 25

Ethics and policymaking

TIME	ID	TITLE	AUTHOR	COUNTRY
16:45	556	A Concept of 'Legitimate Coercion' for the Regulation of Access to Emerging Biotechnologies	Kyle Edwards, University of Oxford	United Kingdom
17:00	674	International Cooperation in HIV/AIDS from a bioethics perspective Bonding and it's impact on public policy to decrease violence \ "Applied Bioethics	Raquel Child	Chile
17:15	287	Rocky Mountain spotted fever in Sonora: an epidemiological problem or an ethical neglect?	Gerardo Álvarez Hernández, Universidad de Sonora	Mexico
17:30	576	Pain Relief is a Human Right	Michel Daher, Lebanese National Committee for Ethics and Bioethics	Lebanon
17:45	611	The latest version of the Declaration of Helsinki: Changes and Challenges	Urban Wiesing, Institute of Ethics and History of Medicine	Germany
18:00	122	Ethics of Non-communicable Diseases: A Perspective from India	Chhanda Chakraborti, Indian Institute	India

Room: Doña Socorro

Session 26

Gender and reproduction

TIME	ID	TITLE	AUTHOR	COUNTRY
16:45	130	Consensus conferences on gestational surrogacy: autonomy, procreative rights and gender	Yun-Hsien Diana Lin, National Tsing Hua University	Taiwan (Republic of China)
17:00	333	What is parenthood? What is the moral scope of parenthood?	Rachel Warren, University of Manchester	United Kingdom
17:15	37	Shared roots of oppression between species and gender	Fabio Oliveira, Federal University of Rio de Janeiro	Brazil
17:30	451	Epigenetics, maternal responsibility and neurological development	Hens Kristien, Maastricht University	Netherlands
17:45	730	The achievement of the parental Project by plural families through the use of assisted human reproduction	Valeria Silva Galdino Cardin, UNICESUMAR	Brazil

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Session 27

Teaching and bioethics

TIME	ID	TITLE	AUTHOR	COUNTRY
16:45	107	An Assessment of the Knowledge, Attitude and Practice of Research Ethics Amongst the Postgraduate Students of the Faculty of Clinical Sciences, Obafemi Awolowo	Cornelius Ewuoso, University of Ibadan	Nigeria
17:00	205	How to promote integrity in research through bioethics committees at university level	Itziar De Lecuona Ramírez, University of Barcelona	Spain
17:15	533	Teaching ethical standards for the performance of healthcare professionals	Mary Ana Cordero Diaz, Tecnologico de Monterrey	Mexico
17:30	592	The initial experience of interactive tutorials in the diffusion of Bioethics at the Medical College of Peru in 2013	Ana Maria Montañez Mendoza, Comite Nacional de Bioetica del Consejo Nacional de Salud Peru	Peru
17:45	652	Narratives of health and disease, illness and care	Lucia Galvagni, Bruno Kessler Foundation	Italy
18:00	376	The Elephant in the Operating Room: A qualitative study on disclosing senior colleague's medical errors	Jian Tang, Peking University	China

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Session 28

Research ethics

TIME	ID	TITLE	AUTHOR	COUNTRY
16:45	389	An Analysis of Transfer Process of Stored Human Biological Materials to Bio-repositories: A Practical Understanding of the 2012 Revision of the Bioethics and Sa	Young-Mo Koo, University of Ulsan College of Medicine	Korea, Republic of (South Korea)
17:00	444	Unpacking the Social Value of Research-Generated Knowledge	Danielle Wenner, Carnegie Mellon University	United States
17:15	449	Mandatory neurotechnological interventions: Ethical issues	Farah Focquaert, Ghent University	Belgium
17:30	462	The immorality of research exploiting unhealthy living conditions in a population	Marcel Verweij, Wageningen University	Netherlands
17:45	497	Stratifying risk in research regulation and oversight	Annette Rid, King's College London	United Kingdom
18:00	633	Developing Ethical Guidelines for Nanotechnology in Sri Lanka	Anuja Fernando, National Science Foundation	Sri Lanka

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Session 29

Bioethics and vulnerability

TIME	ID	TITLE	AUTHOR	COUNTRY
16:45	99	Seniors, vulnerability and power relations: Bioethical conflicts when giving up treatment	Carolina Consejo y Chapela, UNAM	Mexico
17:00	640	How can we demonstrate inequity in distributive justice in patients with spina bifida?	Sergio Francisco Camacho Gutiérrez, CRIC Puebla	Mexico
17:15	650	Child abuse detection by bioethics committee	Claudia Vilchis, Instituto Politecnico Nacional	Mexico
17:30	624	Vulnerability: Considerations on the Appropriate use of the Term in Bioethics	Martha Tarasco, Universidad Anáhuac México Norte	Mexico
17:45	664	Competent research participants: vulnerable or powerful?	Heike Felzmann, National University of Ireland	Ireland
18:00	142	Bioethical dilemmas and possible solutions in Pediatric Intensive Care in the Federal District of Mexico	Maria Cristina Caballero, Academia Nacional Mexicana de Bioética A.C.	Mexico

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Session 30

Global Health & Ethics and policymaking

TIME	ID	TITLE	AUTHOR	COUNTRY
12:15	691	Ethical presentation of AIDS in Africa	Baraka M. Morris, Muhimbili University of Health and Allied Sciences	Tanzania
12:30	635	Applying a health ethics policy framework to the case of healthcare user fee exemption in West Africa	Renaud Boulanger, McGill University	Canada
12:45	415	Kant's Political Philosophy and Its Contribution to Public Health	Diego Silva, St. Michael's Hospital	Canada
13:00	690	Biotechnological Challenges to the Conceptual Foundations of the Right to Life under the Constitution of India	Kelly A. Dhru, Gujarat National Law University	India
13:15	694	Review of Instruments for Assessing Decision-Making Capacity in Senior Adults: A Legitimate Need	Lorna Luco, Universidad del Desarrollo	Chile
13:30	566	Inequality in political philosophy and in epidemiology (a remarriage)	Carla Saenz, Pan American Health Organization	United States

Room: Don Americo

Session 31

Spanish session

TIME	ID	TITLE	AUTHOR	COUNTRY
12:15	201	Bioética multiculturalidad y cáncer en mujeres zapotecas del Istmo de Tehuantepec	Alma Rosa Fuentes Valdivieso, Centro de Estudios de Prevención del Cáncer A.C.	Mexico
12:30	19	Bioética contracorriente	Daniel Piedra-Herrera, Comité Nacional Cubano de Bioética	Cuba
12:45	716	Aspectos éticos de la investigación sobre violencia de género y violencia familiar	Maria Isabel Rivera, Universidad Santiago de Chile	Chile
13:00	760	Cuatro facetas de valoración en ética y metodología en las investigaciones en seres humanos	Rafael Bustos-Saldaña, Universidad de Guadalajara	Mexico
13:15	683	Enseñanza-aprendizaje de la bioética basada en problemas	Fabio Alberto Garzón Díaz, Universidad Militar Nueva Granada	Colombia

Room: Don Alberto 1

Session 32

Special enviromental thics session

TIME	ID	TITLE	AUTHOR	COUNTRY
14:45	213	Climate Change, health problems and anthropocentrism that overpopulates.	Lizbeth Sagols Sales, UNAM	Mexico
15:00	235	Bioethics and Health in the Changing Caribbean Environment.	Cheryl Macpherson, St George's University	Grenada
15:15	632	Climate change and obligations of justice	Andries De Smet, Ghent University	Belgium
15:30	761	The Role of Bioethics in the Resolution of Ethics Environmental Conflicts	Jaime Escobar, Universidad El Bosque	Colombia
15:45	112	Population explosion, distributive justice and environmental sustainability	Peter Osimiri, University of Lagos	Nigeria

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Session 33

Ethics and policymaking

TIME	ID	TITLE	AUTHOR	COUNTRY
14:45	532	Interpretation of Article 4.1: Review and analysis of the ulterior practice of states members of the American Convention on Human Rights	Aracely Ornelas Duarte, Center for Advanced Social Research	Mexico
15:00	557	Direct-To-Consumer Information: An Insidious Means of Drug Familiarization leading to Therapeutic Misconception	Jean-Christophe Bélisle Pipon, Université de Montréal	Canada
15:15	676	Bioethics and Islamic Government: Iran Experience	Ehsan Shamsi Gooshki, Iran Medical Assosiation	Iran (Islamic Republic of)
15:30	668	Principals and principles: utility, duties, and justice in the H5N1 case	David Koepsell, Delft University of Technology	Netherlands
15:45	404	Post-trial obligations towards research participants: a critical assessment of the Declaration of Helsinki 2013	Ignacio Mastroleo, National Scientific and Technical Research Council	Argentina
16:00	765	The reality in bioethics	Martha Franco Espejel	Mexico

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Session 34

Bioethics Education Network

TIME	ID	TITLE	AUTHOR	COUNTRY
14:45	134	Cultivating integrity: some experiences and obstacles in ethics teaching	Medard Hilhorst, Erasmus University Medical Center Rotterdam	Netherlands
15:00	282	Bioethics Education for Ecological Researchers	Gillian Crozier, Laurentian University	Canada
15:15	459	Introducing an E2 (Evaluation & Enhancement) Social Accountability Framework for Medical Schools	Jeffrey Kirby, Dalhousie University	Canada
15:30	535	The Bioethics in the Biomedical University Teaching	Antero Enrique Yacarini Martínez, Santo Toribio de Mogrovejo Catholic University	Peru
15:45	539	Bioethics Experts? Criticism, necessity and revisions for our future IRBs	Ana Cristina Ramírez Barreto, Universidad Michoacana de San Nicolás de Hidalgo	Mexico
16:00	60	Teachers of religious education and practice of human values	Rosa Elvira Bazalar-Whu, Santo Toribio de Mogrovejo Catholic University	Peru

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Session 35

Bioethics theory and methodology

TIME	ID	TITLE	AUTHOR	COUNTRY
14:45	543	The institutional bioethics in Mexico: perspectives and future	Beatriz Eugenia Cárdenas-Morales, Universidad Autónoma Benito Juárez de Oaxaca	Mexico
15:00	593	From Kant's categorical imperative to Fritz Jahr's bioethical imperative: toward an ethics of globalization	Maria Isabel Cornejo Plaza, University of Chile	Chile
15:15	614	Faithful bioethical judgements: negotiating personal, social and faith group norms	Jackie Leach Scully, Newcastle University	United Kingdom
15:30	680	Individual human existence in the light of bioethics	Boris Yudin, Moscow State University	Russian Federation
15:45	429	Grounded Normative Theory as a Methodology for Empirical Law and Ethics	Jean Frédéric Ménard, University College London	United Kingdom
16:00	375	Bioethics as transdisciplinary science	Jorge Aguirre, Instituto de Investigaciones en Bioética	Mexico

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Room: Don Diego 3

Session 36

Genetics & Pediatric ethics

TIME	ID	TITLE	AUTHOR	COUNTRY
14:45	407	United Nations Declaration on Human Cloning: 10 years on	Chamu Kuppuswamy, University of Sheffield	United Kingdom
15:00	355	Ethical aspects on mitochondrial replacement – reflections from the Swedish Ethics Council	Karin Wilbe Ramsay, The Swedish National Council on Medical Ethics	Sweden
15:15	394	Using new genetic sequencing methods in children: Should context matter?	Ainsley Newson, University of Sydney	Australia
15:30	590	Genomics, Commercialization and Benefits in Africa	Subhashini Chandrasekharan, Duke University	United States
15:45	762	Morally relevant differences in vulnerable groups of research subjects	Karin Jongsma, Erasmus Medical Centre	Netherlands
16:00	434	Ethical requirements in research involving children affected by acute lymphoid leukemia	Luciana Matos, University of Brasília	Brazil

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Session 37

Multicultural ethics

TIME	ID	TITLE	AUTHOR	COUNTRY
14:45	118	Reading Caplan in Karachi	Farhat Moazam, Center of Biomedical Ethics and Culture	Pakistan
15:00	653	Cross-Cultural and Global Bioethics: The Elements of a Transcultural Approach.	Jing-Bao Nie, University of Otago	New Zeland
15:15	654	Informed Consent process in intercultural contexts.	Marcia Mocellin Raymundo, Hospital de Clínicas de Porto Alegre	Brazil
15:30	754	Bioethics and interculturality	José Gilberto Rodríguez Rodríguez, Comisión Estatal de Bioética e Investigación de Jalisco	Mexico
15:45	755	Proposal for the analysis of issues bioethical dilemma	Rafael Rivera Montero, Comisión Estatal de Bioética e Investigación de Jalisco	Mexico
16:00	9	Attitudes of Healthcare Providers Towards Family Presence during Resuscitation: A Cross-Cultural Comparison.	Zohar Lederman, National University of Singapore	Singapore

Room: Doña Adelita

Session 38

Spanish session

TIME	ID	TITLE	AUTHOR	COUNTRY
14:45	286	Hacia una epistemología de la bioética	José Antonio Sánchez Barroso, Universidad Panamericana	Mexico
15:00	93	El mejor interés en Pediatría	Fernanda María Ledesma, Hospital Nacional de Pediatría	Argentina
15:15	160	Aspectos éticos en la paciente con cáncer de mama.	Roberto Contreras, Universidad Autónoma de Chihuahua	Mexico
15:30	185	Bioética y asedio grupal (Mobbing) en el trabajo	Rocío Fuentes Valdivieso, Instituto Politécnico Nacional	Mexico
15:45	243	Reproducción Asistida y Neoparentalidad un Dilema Ético	Jorge Carreño Meléndez, Instituto Nacional de Perinatología	Mexico
16:00	283	Pertinencia de los componentes éticos de la ciencia biomédica para la investigación social en salud mental	Liliana Mondragón, Instituto Nacional de Psiquiatría	Mexico

Friday 27, June 2014

Room: Don Americo

Session 39 Decision-making

TIME	ID	TITLE	AUTHOR	COUNTRY
14:45	679	Justice in health decision making	Ixchel Itza Patiño González, UNAM	Mexico
15:00	477	On the Ethics of Dynamic Consent	Bettina Schmietow, European Institute of Oncology	Italy
15:15	684	Perceptions of informed consent by patients from four areas of health care in Bogota, Colombia 2013	Maria Teresa Escobar Lopez, Universidad Militar Nueva Granada	Colombia
15:30	184	Obstetrics and gynaecology residents' knowledge of the informed consent process and its practice in their training institutions	Patrick Okonta, Delta State University Teaching Hospital	Nigeria
15:45	245	A shared understanding? Attitudes of stakeholders to newborn screening consent practices	Stuart G. Nicholls, University of Ottawa	Canada
16:00	322	Newer practice of Informed Consent Process in India	Barna Ganguly, P.S.Medical College	India

Room: Don Genaro

Session 40 Animal ethics

TIME	ID	TITLE	AUTHOR	COUNTRY
14:45	126	Legal and ethical issues around human-animal chimera research	Laura Cabrera, Institute for Biomedical Ethics	Switzerland
15:00	218	Against Pedigree: The Ethics of Artificial Selection in Dogs	Gustavo Ortiz-Millán, National Autonomous University of Mexico	Mexico
15:15	410	The legal status of animals in Brazil	Carolina Maria Nasser Cury, Federal University of Minas Gerais	Brazil
15:30	572	Animal research and the three Rs, updates in legislation in South America	Carmen Alicia Cardozo, Universidad de Chile	Chile
15:45	418	Factory Farming , Global Bioethics and Public Health: New Challenges	Fabiola Leyton, University of Barcelona	Spain

Room: Don Julian

Session 41 Research ethics

TIME	ID	TITLE	AUTHOR	COUNTRY
14:45	641	Ethical implications of research ethics review of social science research	Karolyn White, Macquarie University	Australia
15:00	651	The moral discourse of uncertainty in clinical genomics.	Jennifer Marshall, University of Toronto	Canada
15:15	441	Perception and Attitudes of Patients, Relatives, Health Professionals and Regulators on Bioethical Issues: The Case Study of the Brazilian Multiple Endocrine Ne	Maria Sharmila Alina de Sousa, Universidade Federal de São Paulo	Brazil
15:30	515	Bioethics, Donation of medicines and disease of poverty. Analysis of a case of Public Health	Katya Rodriguez, CEISEB	Ecuador
15:45	634	Real-time responsiveness and disaster research ethics	John Pringle, George Mason University	United States
16:00	667	Encouraging Conscientiousness in Risk Associated Areas of (Medical) Research	Jan-Ole Reichardt, University of Münster	Germany

Friday 27, June 2014

Room: Doña Socorro

Session 42 Global Health

TIME	ID	TITLE	AUTHOR	COUNTRY
14:45	2	Allocating limited humanitarian resources fairly: an ethical framework to assist humanitarian actors in their decision-making process.	Caroline Clarinval, Institute of Biomedical Ethics	Switzerland
15:00	431	Vector Borne Diseases and Community Based Participatory Research in Colombia: Empowerment to Establish Sustainable Solutions	Nadia Lorena Gonzalez Cifuentes, Catholique de Louvain	Belgium
15:15	678	Factors that inhibit and factors favoring the exercise of autonomy in health sector	Cuauthémoc Mayorga Madrigal, Centro Médico de Occidente	Mexico
15:30	455	Ontological Exploration of Vulnerability using a Conceptual Model beyond its Epistemological Limitations	Nabeel Mangadan Konath, Public Health & Bioethics Consultant	India
15:45	547	Ethical aspects of the move towards Universal Health Coverage: focus on LMICs	Anant Bhan	India
16:00	599	Use of Rapid Ethical Assessment to Improve Health Research Informed Consent Processes in a Low-Income	Adamu Addissie Nuramo, Addis Ababa University	Ethiopia

Room: B, Hotel Fiesta Inn Centro Histórico

Session 43 Bioethics and transplants, Sexuality and bioethics & Food ethics

TIME	ID	TITLE	AUTHOR	COUNTRY
14:45	277	Dialling international for consent to deceased donation – ethical hazards in family consultation	Dominique Martin, University of Melbourne	Australia
15:00	454	Determining validity of consent given by organ vendors for transplantation: the significance of regret in output-oriented assessment	Leonardo de Castro, National University of Singapore	Singapore
15:15	565	Ethical implications in the allocation of organs targeted the elderly	Itzel Villa Páez, UNAM	Mexico
15:30	565	Are ethics local or universal? The case of homosexuality in Africa and Elsewhere	Godfrey Banyuy Tangwa, University of Yaounde	Cameroon
15:45	504	The Ethics of Introducing GMOs into sub-Saharan Africa: Saharan African Theory of Ubuntu	Ana Komparic, University of Toronto	Canada
16:00	327	Contamination of food	Marta Alicia Bigliardi, Colegio Público de Abogados de la Capital Federal	Argentina

Room: C y D, Hotel Fiesta Inn Centro Histórico

Session 44 Pediatric research

TIME	ID	TITLE	AUTHOR	COUNTRY
14:45	180	Are parents ethically entitled to refuse fertility preservation procedures for their child with cancer?	Rosalind McDougall, University of Melbourne	Australia
15:00	95	A lens on current documentation of Research Ethics Committees in South Africa which guide ethics review of research involving children as participants: a document	Blanche Pretorius, Nelson Mandela Metropolitan University	South Africa
15:15	200	Best interests in paediatric intensive care decisions - what can practical understandings tell us?	Giles Birchley, University of Bristol	United Kingdom
15:30	433	Age Threshold and Assent in Paediatric Research.	Marcin Waligora, Jagiellonian University	Poland
15:45	522	Empowering Children and Caregivers in Pediatric HIV Disclosure: Insights from Kenya.	Maureen Kelley, University of Washington	United States
16:00	140	The Child's right to autonomy: dilemmas arising in a multicultural society	Adalberto De Hoyos, UNAM	Mexico

Wednesday 25, June 2014

Foyer Alberto

Poster session 1

TIME	ID	TITLE	AUTHOR	COUNTRY
13:25	263	Neglected bioethics on health research of NDNP	Fernando Andrade-Narvaez, Universidad Autnoma de Yucatan	Mexico
13:31	749	Differences in perception of the acquisition of ethical values in College students in a Mexican Campus	Sandra Anguiano Serrano, UNAM	Mexico
13:37	505	Moral education about the students of odontology in FESI UNAM and their conduct code	Jorge Alberto Calderón Martínez, UNAM	Mexico
13:43	503	Building a list of the basic functionings for transgender people	Cristiane Maria Amorim Costa, Universidade do Estado do Rio de Janeiro	Brazil
13:49	582	Pulmonary diseases and ethics issues	Jose Luis Sandoval Gutierrez, Instituto Nacional de Enfermedades Respiratorias	Mexico
13:55	498	Does Bioethics need or not to accept a foundation of human rights?	José Pedro García Scougall, Universidad Panamericana	Mexico
14:01	538	Perceptions of justice in health care: a theoretical and empirical analysis	Yareni Monteón, UNAM	Mexico
14:07	531	End of life decisions in the Perinatal Medical Care	Patricia Grether, Instituto Nacional de Perinatología	Mexico
14:13	371	Cross-functional Analysis of Ethical Dilemmas in Pain Treatment and Palliative Care	Uria Guevara, Universidad Benito Juarez de Oaxaca	Mexico
14:19	562	Complaints about health services	Sandra Inés Flores, Universidad Antonio Ruiz de Montoya	Peru
14:25	92	Advance Research Directives in Dementia Research: What does it solve?	Karin Jongsma, Erasmus Medical Centre	Netherlands
14:31	701	Fining the Flab: Should Weight Loss be Mandatory for the Obese?	Sophie Joury, University of Birmingham	United Kingdom
14:36	182	Normalcy and normativity	Richard Joyce, Victoria University of Wellington	New Zealand
14:42	464	Memory project: history, research and ethics	Dirce Guilhem, University of Brasilia	Brazil
14:48	507	Identifying dilemmas in pediatric cancer patients and their admission to intensive care units	Sandra Luz Lizarraga-Lopez, Instituto Nacional de Pediatría	Mexico

Thursday 26, June 2014

Foyer Alberto

Poster session 2

TIME	ID	TITLE	AUTHOR	COUNTRY
14:45	649	Biobank research and (potential) duties of researchers'. On beneficence, research-care distinction and therapeutic misconception in era of incidental findings	Kristi Louk, University of Tartu	Estonia
14:51	169	Construction of citizenship in health care space: between frustration and indifference	Maria Isabel de Fátima Luengas Aguirre, Universidad Autónoma Metropolitana	Mexico
14:57	16	Organization and functioning of the National Bioethics Council of Colombia since a global vision	Víctor Márceles, Universidad de la Costa	Colombia
15:03	365	Effect of bioethics program in developing moral judgment of nursing	Sofía Guadalupe Medina Ortiz, UANL	Mexico
15:09	325	New family configurations	Gricelda Moreira, Grupo Bioética Argentina	Argentina
15:15	211	The human genome: an open door to our intimacy?	Ana Guadalupe Olvera Arellano, Perspectiva Jurídica	Mexico
15:21	259	Bioethics in Mexican Law	Alejandro Pacheco Gomez, Comision de Bioetica del Estado de Hidalgo	Mexico

Thursday 26, June 2014

Foyer Alberto

Poster session 2

TIME	ID	TITLE	AUTHOR	COUNTRY
15:27	625	The network of human research Ethics Committees in Cali, Colombia: Protecting Human Subjects	Gloria I. Palma, CIDEIM	Colombia
15:33	229	Individual interests and research with no prospect benefit involving incompetent subjects	Jan Piasecki, Jagiellonian University	Poland
15:39	285	Ethical reflections on the Social Commitment of University Knowledge	Juan-Guillermo Figueroa-Perea, El Colegio de México	Mexico
15:45	279	Informed assent in pediatric dentistry	Maria De Los Angeles Salazar Cruz, Observatorio Mexicano de Bioética	Mexico
15:51	445	Conscientious objection in the medical migration context: cultural interference	Elena Toader, Gr. T. Popa University of Medicine and Pharmacy	Romania
15:57	280	Blood donors and healthcare workers' perspectives on notification process of permanent deferral: preliminary results	Valente Moisés Serrano-Delgado, UNAM	Mexico
16:03	655	The field concept in contemporary and "subjective processes" of the person: reflections from the thought Reyes Mate and Giorgio Agamben	Carolina Velasco, Pontificia Universidade Católica do Rio de Janeiro	Mexico
16:09	284	The use of animals in biology sciences	Elizabeth Téllez, Universidad Nacional Autónoma de México	Mexico

Poster session 3

TIME	ID	TITLE	AUTHOR	COUNTRY
16:45	223	Community Advisory Boards: the need to expand their involvement from advisors to true partners in the design of research studies	Alwyn Mwinga, ZAMBART Project	Zambia
16:51	432	Bioethics education: Prospects in medical education of Bangladesh	Fariha Haseen, Bangabandhu Sheikh Mujib Medical University	Bangladesh
16:57	514	Identification of values toward work, in medical staff of a unit pediatric intensive care	Maria Luisa Diaz García, Instituto Nacional de Pediatría	Mexico
17:03	549	Exploring research participants' perceptions and comprehension of the informed consent process in a pre-exposure HIV prevention study in Zimbabwe: A case study	Sitembile Ruzario, Meidcal Resaerch Council of Zimbabwe	Zimbabwe
17:09	257	Ethics in scientific practice of a biobank	Pollyana Gontijo, Alberto Cavalcanti Hospital	Brazil
17:15	764	Ethical analysis of health services in patients with rare diseases in Ecuador	Yuri Jesús Marimón Díaz, Centro de Salud Jambihiusi	Ecuador
17:21	400	When Ethics Committee Generate Government Revenue!	Martin Anu Nkematabong, National Ethics Committee	Cameroon
17:27	133	Implementation of Assisted Reproductive Techniques in Single Women	Eray Serdar Yurdakul, Gülhane Military Medical Academy	Turkey
17:33	137	Concept of What Constitutes a Difficult Ethical Problems in Military Medicine: Malingering	Fatih Namal, Gülhane Military Medical Academy	Turkey
17:39	151	Determination the success of Informed Consent Before Surgery that Patients Undergoing Surgical Operation? An Example Of a Training Hospital	Engin Kurt, Gulhane Military Medical Faculty	Turkey
17:45	166	Development of an instrument for early detection of psychopath behavior, based on hare's test	Luz Richardson, Panamerican University	Mexico
17:51	336	The Patient's Physically Protection of Privacy and the Responsibility of Physicians: An Assessment Reflected in the Media Through Examples	Mesut Ersoy, , Gulhane Military Medical Faculty	Turkey
17:57	380	Discrimination that suffer Mexicans who have epilepsy in the Field of Work	Amparo Ponce, Universidad Panamericana	Mexico
18:03	508	Constitutional responsibility , individual and group of bioethics in the promotion and quality health	Gabino Yescas Buendía, Instituto Nacional de Perinatología	Mexico
18:09	585	Spanish regulatory approach for Biobanking	Carlos Alonso Bedate, Instituto de Salud Carlos III	Spain

Friday 27, June 2014

Foyer Alberto

Poster session 4

TIME	ID	TITLE	AUTHOR	COUNTRY
12:15	82	Facing Facebook: Ethical challenges for medical professionals	Aamir Jafarey, Centre of Biomedical Ethics and Culture	Pakistan
12:21	356	Scientific Integrity in Brazil: analysis of the scientific literature	Gabriela Cristina Cantisani, University of Brasília	Brazil
12:27	364	Effects of course of ethics in the development of moral judgment of nursing students	Leticia Vázquez Arreola, Universidad Autónoma de Nuevo León	Mexico
12:33	601	Implementing normative and regulative documents for ethical control in research at Campeche, Mexico	Eduardo Garcia-Solis, Secretaria de Salud, Campeche	Mexico
12:39	518	Experts' Legal Knowledge on Personalized and Genomic Medicine and Its Ethical Implication in South Korea	Sungkyoung Choi, Yonsei University	Korea, Republic of (South Korea)
12:45	162	Neuroethics and neurosciences in (for?) developing countries	Jorge Alberto Álvarez-Díaz, Universidad Autónoma Metropolitana	Mexico
12:51	413	The reality of transsexuals in Brazil	Valéria Silva Galdino Cardin, UNICESUMAR	Brazil
12:57	439	Opinion of university students on management of genetic information	Berenice Perez-Cavazos, Universidad de Monterrey	Mexico
13:03	759	Bioethical Issues Considered in Human Research at the University South Center in University of Guadalajara	Eduardo Ramirez-Soltero, Universidad de Guadalajara	Mexico
13:09	646	Discussion about ethics of the placebo use in clinical trials for chronic pain	Daniela Caputo Dorta, World Clinical Trials	Brazil
13:13	238	Flexibilization of the norms for research: the case of Brazil	Gerson Zafalon Martins, The Brazilian Federal Council of Medicine	Brazil
13:19	221	Attitudes of geneticists and ophthalmologists regarding genetic counseling for retinoblastoma in Mexico	Paula Morelos-Herrera, Universidad Panamericana	Mexico
13:25	627	Inequidad en el campo colombiano: un problema de justicia social	Gilma Rodriguez, Universidad El Bosque	Colombia
13:31	628	Violencia contra las mujeres en Colombia: un desconocimiento de su dignidad	María Victoria, Rodríguez, Universidad El Bosque	Colombia

Poster session 5

TIME	ID	TITLE	AUTHOR	COUNTRY
14:45	116	Medical Tourism and Bioethics	Pablo Villarreal, Universidad de Monterrey	Mexico
14:51	621	Re-identification risk from Genome Wide Association Studies (GWAS)	Carlos Alonso Bedate, Instituto de Salud Carlos III	Spain
14:57	369	Teenagers attributes on sociomoral reasoning as a building process of bioethical competences	Martha Marcela Rodriguez Alanis, Instituto de Investigaciones en Bioética	Mexico
15:03	643	Privacy and trust in Biobanks for research – the Portuguese context	Cíntia Aguas Pereira, National Council of Ethics for the Life Sciences	Portugal
15:09	396	Designing a public system for the research ethics consultation service in Japan	Kuniko Aizawa, National Cerebral and Cardiovascular Center	Japan
15:15	502	From object to subject: the adolescent as actor of his health care	Blanca Bórquez, University of Barcelona	Spain
15:21	453	To profile adolescents and women who underwent legal termination of pregnancy in Brasília	Maria da Graça Camargo Neves, Universidade de Brasília	Brazil
15:27	525	Informed Assent. Minors as Research Subjects	Eloy Cardenas-Estrada, Universidad Autónoma de Nuevo León	Mexico
15:33	647	The contribution of movies to bioethical reflections	Rosane Figueiredo Estevao, CLION	Brazil
15:39	309	Ethical and Bioethical issues in Football	Francisco X González Garza, Instituto de Investigaciones en Bioética	Mexico

Friday 27, June 2014

Foyer Alberto

Poster session 5

TIME	ID	TITLE	AUTHOR	COUNTRY
15:45	669	Non-Invasive Prenatal Testing: an "option" to test or a "pressure" to test?	Haizar Haidar, University of Montreal	Canada
15:51	362	Bioethics in physician - patient relationship and development of the medical record	Adriana Mejia Estrada, Universidad Michoacana de San Nicolás de Hidalgo	Mexico
15:57	291	Influence of the emotional sphere on the ethical attitudes in the health care professional	Maria Aurea Mendoza Olvera, Instituto Mexicano del Seguro Social	Mexico
16:03	145	Captain America: Technopressive Avenger? The problem of the superhero for the bioconservative position on enhancement	David Lawrence, University of Manchester	United Kingdom
16:09	523	The national survey of the Medical Decision-making Process in the End-of-Life care in the Republic of Korea	Ilhak Lee, Yonsei University	Korea, Republic of (South Korea)

Sympsium Presentation

Symposium Presentation

Abstract number: 1 Migrants, Health Care, and Ethical Responsibility
ID: 7 James Dwyer, Verina Wild, James Wilson
Symposium United States, Upstate Medical University

Key Words: migrants, health care, bioethics, justice, and responsibility
People move around. They move to escape war, persecution, poverty, and environmental degradation. They move to find better opportunities, provide more support for their families, and build better lives. These migrants include refugees, asylum seekers, immigrants, undocumented workers, and other groups. The people include men, women, children, agricultural workers, domestic workers, computer programmers, health care professionals, and many others. This symposium will focus discussion on one important issue about migration: Do societies have an ethical responsibility to provide health care for undocumented migrants, documented migrants, and citizens on an equal basis? Three speakers will address this issue. The first speaker is Jim Dwyer from the Department of Bioethics and Humanities at Upstate Medical University, in the United States. He will give an overview of human migration, describe some cases of undocumented migrants, and sketch one approach to the ethical cases and issues. The second speaker is James Wilson from the Department of Philosophy at University College London, in the United Kingdom. He will examine whether refusal to provide healthcare to undocumented migrants on terms of equality to those of citizens amounts to wrongful discrimination, and whether rich countries also have extensive moral duties to provide healthcare for noncitizens outside their territory. The third speaker is Verina Wild from the Institute of Biomedical Ethics at the University of Zurich, in Switzerland. She will critically examine four common counterarguments to the idea that countries that provide universal health coverage for citizens and legal residents should provide the same health care for all migrants. The three speakers will limit their talks to a total of 60 minutes; 30 minutes of the symposium will be devoted to discussion. The speakers will invite comments and questions that allow people from different countries to share their perspectives, concerns, and experiences.

Abstract number: 2 Towards a normatively oriented empirical bioethics
ID: 15 Ulrik Kihlbom, Prof Hilde Lindeman, Prof Jackie Leach Scully
Symposium Sweden, Centre for Research & Bioethics, Uppsala University

Empirical bioethics has developed substantially over the last few years, both in terms of number of publications and in the range of methods used. However, the theoretical underpinnings of empirical ethics remain relatively thin, and have been widely criticized for their failure to relate the empirical to the normative, for disregarding the Is-Ought problem, and for leading inevitably to relativism.

In this interactive panel we will show how three theoretical bases for an empirically oriented bioethics—moral particularism, naturalized moral epistemologies, and phenomenological hermeneutics—answer the standard criticisms. The papers will provide provocative contributions to the further theoretical and normative development of empirical bioethics.

- Ulrik Kihlbom: Particularist bioethics, and the charge of relativism
- Hilde Lindeman: Naturalized bioethics, and the Is-Ought problem
- Jackie Leach Scully: Phenomenological hermeneutic bioethics, and relating the empirical to the normative

Literature

- “How to Relate the Empirical to the Normative. Toward a Phenomenologically Informed Hermeneutic Approach to Bioethics”, Christoph Rehmann-Sutter, Rouven Porz, and Jackie Leach Scully. Cambridge Quarterly of Healthcare Ethics 21, 436–447 (2012).
- Naturalized Bioethics: Toward Responsible Knowing and Practice. Hilde Lindemann, Marian Verkerk, and Margaret Urban Walker (eds.). New York: Cambridge University Press, (2009).
- “Toward a Naturalized Clinical Ethics.” Hilde Lindemann & Marian Verkerk, Kennedy Institute of Ethics Journal, 22: 289–306 (2012).
- “Naturalism” Hilde Lindemann & Marian Verkerk, in The Encyclopedia of Bioethics. Bruce Jennings (ed.). 4th ed. New York: Macmillan Reference USA, (forthcoming 2014).

Organising Group

- Ulrik Kihlbom ulrik.kihlbom@crb.uu.se, The Centre for Research Ethics & Bioethics at Uppsala University (CRB)
- Jackie Leach Scully jackie.scully@newcastle.ac.uk, Policy Ethics and Life Sciences Research Centre, Newcastle University (PEALS)
- Hilde Lindemann hlinde@msu.edu, The Department of Philosophy, Michigan State University (MICH)

Abstract number: 3

ID: 17

Symposium

The Tissue/Data Divide: Paradigms, Property, & Privacy

Nayha Sethi (University of Edinburgh), Professor Graeme Laurie (University of Edinburgh), Dr. Iain Brassington (University of Manchester), Emily Postan (University of Edinburgh)

Chaired by: Hugh Whitall (Nuffield Council on Bioethics)

United Kingdom, University of Bristol (co-organisers University of Edinburgh)

Key contact : Nayha Sethi – nayha.sethi@ed.ac.uk

Format/Methodology: 90 mins long with a panel of about 5 members. The format of the session would be very discursive with panel member giving about 10 mins of comment/thoughts and the rest of the time focused on debate with each other and the audience.

Abstract : "There is currently a mismatch between the way law and regulatory systems construct rights and protections around certain 'objects'. Of particular concern is the mismatch between how the uses of data and tissue are governed, particularly for research purposes. This is of interest because data for research is often either derived from or linked to tissue samples, yet they are disharmoniously conceptualized and thus subject to two different regulatory paradigms (privacy and property). Recently the Nuffield Council on Bioethics has launched a consultation (The Linking and Use of Biological and Health Data), prompted by the increasing use of health and biological data. Furthermore, recognising that "technological progress and globalisation have profoundly changed the way our data is collected, accessed and used", the European Commission has proposed a set of comprehensive reforms of its data protection rules. These do not, however, make explicit linkages to the source of certain data (i.e. biomaterials). While the focus in relation to data is often on privacy, increasingly human biomaterials are being viewed through a proprietorial lens. This symposium aims to investigate this tissue/data divide. It will ask what the different regulatory regimes governing tissue and data (usage) protect, and what they ought to protect. The panellists (together with the attendees) will also examine whether and how these systems could better reflect ethical perspectives, and how ethical insights could improve regulatory practices. The high-level aim is to ask whether a harmonised regulatory approach is desirable to govern the uses of both data and tissue and to map out what this might look like. This is important because of the globalised research contexts in which both data and biomaterials are used."

Abstract number: 4

ID: 18

Symposium

Evidence-based research regulation?

Rid Annette, James Wilson, Simon Whitney, David Hunter, Anant Bhan, Heike Felzmann

United Kingdom, King\’s College London, Department of Social Science, Health & Medicine

Research involving human participants, particularly medical research, is now regulated in most jurisdictions via some system involving research ethics committees. Nonetheless these regulatory systems face a substantial justificatory challenge. They are primarily designed to protect participants' rights and interests, but many argue that they cause more harm than they prevent by distorting, delaying, and stopping research. This claim is often presented with an analogy to evidence-based practice in health care, with authors pointing either to the cost of research regulation for investigators and sponsors or the potential harm to future patients.

This symposium, organised by the IAB Network on Research Ethics, will explore the following issues:
1) What do we know about the issues that research regulations aim to address?

2) What do we know about the impact of research regulatory systems?

3) How can we measure the risks and benefits of regulation, especially when most potential criteria for evaluating research ethics review are neither consensual nor easily operationalized?

4) What (if anything) is lost if we take an evidence-based perspective on research regulation?

5) How are evidence arguments used in controversies surrounding research regulation?

Plan

James Wilson, University College London (United Kingdom) Introduction (5 min)

Annette Rid, King's College London (United Kingdom) What are the risks of study participation, and how important is this question for research regulation? (12 min)

Simon Whitney, Baylor College of Medicine (United States) The harms of ethical review (12 min)

David Hunter, Flinders University (Australia) Is research ethics regulation really killing us? (12 min)

Anant Bhan, Bioethics and Global Health, Pune (India) Evidence and research ethics activism: impact on regulatory reform in India (12 min)

Heike Felzmann, National University of Galway (Ireland) REC deliberation and evidence-based decision-making: an intrinsic tension? (12 min)

Discussion with audience (25 min)

Keywords: evidence, research regulation, ethical review

Contact:

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Abstract number: 5

ID: 22

Symposium

Cross-border Stem Cell Therapies: International Governance and Harmonisation

John Harris, Ricardo Tapia, Ruben Lisker, María Medina

United Kingdom, University of Manchester

Stem cell therapies (SCT) are a rapidly growing area of stem cell (SC) science and are likely to present significant ethical challenges within this controversial field. Early reports of successful SCT have promoted public confidence, spurred scientific interest and attracted the attention of industrial biotech. Amidst this enthusiasm, the ethical and regulatory problems such therapies may pose must be considered. E.g.:

How should experimental SCT be regulated? What mechanisms are needed to manage risk and ensure safety and efficacy?

METHODOLOGY:

This symposium will consist in the presentation of research papers as a result of an international partnership and mobility scheme project focused on the analysis of transnational ethical and regulatory issues in stem cell therapies. Members of the research project (Mexico and UK) will present for 15 minutes, at the end of the presentations we will open a 15 minutes for discussion.

Participants:

Ricardo Tapia I. Professor UNAM, leader of the project in Mexico

María de Jesús Medina-Arellano, Senior Lecturer, Autonomous University of Nayarit (15 minutes)
"Neuroethics of the beginning of life and the use of stem cells"

(15 minutes) "Regulate to innovate: principled-based approach to regulation for stem cell science in Mexico" (taking lessons from the established framework in UK)

Sarah Chan, Institute for Science Ethics and Innovation, The University of Manchester (iSEI / UoM)
(15 minutes) "Bench to Bedside: ethical and legal issues in the development of novel stem cell treatments and neurotherapies"

John Harris, Institute for Science Ethics and Innovation, The University of Manchester (iSEI / UoM)
(15 minutes) "Stem cells, chimeras and dignity"

Rubén Lisker, Universidad Nacional Autónoma de México (UNAM) (15 minutes) "Some bioethical issues in stem cell research"

ABSTRACTS AND PARTICIPANT BIOGRAPHIES

"NEUROETHICS OF THE BEGINNING OF LIFE AND THE USE OF STEM CELLS"

Ricardo Tapia

The spectacular advances in the neurosciences, molecular biology and genetics have changed the ideas on the nature of mankind. The human species is only one among millions of other animal species, but it is the only one that is conscious of its position in nature and can modify it. Although we are only beginning to understand how the human brain functions, we have learned enough on several basic aspects of the cellular and molecular mechanisms that determine many brain functions, and so we have been able to understand the pathophysiology of several diseases of the nervous system. However, the cause and mechanisms of neurodegenerative diseases, characterized by the death of specific types of neurons inside the brain or the spinal cord is still unknown and

there is no effective treatment. One promising approach is the therapeutic use of stem cells, which can be obtained from human blastocysts or from induced pluripotent stem cells. The use of the former implies the destruction of the blastocyst, and this creates an ethical problem because it is believed by many that the blastocyst is already a person possessing all human rights. The aim of this work is to show evidence, based on the knowledge on the physiology and development of the nervous system, that is not reasonable to maintain that blastocysts are persons and that it is unethical not to use the non implanted blastocysts obtained from in vitro fertilization, that are kept frozen and eventually will be destroyed, for investigating the potential therapeutic effect of the human embryonic stem cells, especially for diseases of the nervous system.

Ricardo Tapia is Professor Emeritus at the División de Neurociencias, Instituto de Fisiología Celular, Universidad Nacional Autónoma de México. His research over more than 50 years on several neurochemical and neurophysiological mechanisms of brain function includes work on epilepsy, neurotransmission, memory and neurodegeneration, and has been published in more than 160 articles in international journals and books. He has been Editor of several neurochemical journals and of *Frontiers in Cellular Neuroscience*, and has also published over 150 articles and 6 books in Mexico on neuroscience, science policy, science teaching and bioethics. He has imparted many courses and lectures in many countries.

"REGULATE TO INNOVATE: PRINCIPLES-BASED APPROACH TO STEM CELL SCIENCE REGULATION IN MEXICO"

María de Jesús Medina-Arellano

The aim of this paper is to advocate for the adoption of a flexible mechanism to regulate the innovative area of stem cell science (SCS) in Mexico. The proposal advance in this paper for Mexico is to adopt some of the paradigmatic features of the UK's system of SCS governance. It is acknowledged that although it may not be feasible to adopt completely such a liberal system, some of its elements could be emulated, such as the enactment of a principles-based regulatory approach to SCS, learning from the experience of the UK model some lessons about how to enforce it effectively.

María de Jesús Medina Arellano is a qualified lawyer graduating from the University of Nayarit, Mexico (2004). After finishing her degree she decided to move to Mexico City to continue her studies in the Philosophy of Law. In January 2008 she graduated with the equivalent of an MPhil (with honours) from the Postgraduate Law Division at the National Autonomous University of Mexico (UNAM). During her postgraduate degree she focused on the new paradigm of Health/Medical Law and Human Rights in Mexico. In December 2008 she was awarded with the silver medal "Alfonso Caso" for outstanding achievements during her postgraduate studies at UNAM. She obtained her PhD in Bioethics and Medical Jurisprudence in July, 2012, from the School of Law/Institute for Science, Ethics and Innovation in the University of Manchester are currently concerned with the regulation of stem cell research in developing countries (Mexico as a case study) under the supervision of Prof John Harris, Dra. Anne-Maree Farrell, Dr. David Gurnham and Dr. Sarah Devaney.

"BENCH TO BEDSIDE: ETHICAL AND LEGAL ISSUES IN THE DEVELOPMENT OF NOVEL STEM CELL TREATMENTS AND NEUROTHERAPIES"

Sarah Chan

As stem cell treatments and neurotherapies begin to move from the realm of theoretical possibility to the reality of clinical application, new ethical and regulatory challenges arise regarding the various possible routes by which these therapies might be developed and the effects this will have on the provision and availability of treatments. In this paper I consider the issues associated with different modes of developing novel stem cell and neurotherapies, and discuss their implications for possible pathways to provision; effective clinical application and scientific progress; and access to treatments, both by individual patients and wider 'markets', local and global. I suggest a number of policy approaches that will be required to achieve the ultimate goal of developing safe and effective treatments that are available on a fair and equitable basis.

Sarah Chan is a Research Fellow in Bioethics and Law with the Institute for Science, Ethics and Innovation (iSEI) at The University of Manchester. She was educated at the University of Melbourne, Australia, where she received degrees in law and biological science, and spent a number of years as a research scientist in a molecular biology laboratory before moving to work in the area of science policy and stem cell ethics. In 2005 Sarah took up a Research Fellowship at the Centre for Social Ethics and Policy, University of Manchester, where she also completed a Master's degree and PhD in Health Care Ethics and Law. She has been a Research Fellow at iSEI since the Institute's foundation in 2008 and in 2009 was appointed Deputy Director of the Institute. Her research interests and publications cover areas including the ethics of gene therapy and genetic information, enhancement, research ethics, stem cells, animal ethics, transhumanism, and the ethics of science and innovation.

"STEM CELLS, CHIMERAS AND DIGNITY"
John Harris

Different kinds of human-nonhuman chimeras can be created through stem cell research. Among these, it is the creation of human-nonhuman chimeras with dignity related capacities that has caught the ethicists' attention. One of the arguments advanced against the creation of such entities comes from a human dignity standpoint. In this paper I present a detailed criticism of the dignity related arguments against the creation of human-nonhuman chimeras. My main claim is that the human dignity arguments presented so far cannot ground a prohibition against creating human-nonhuman chimeras with dignity related capacities. At best some of such arguments would provide grounds to prohibit the creation of human-nonhuman chimeras that would have wrongful lives. I conclude that all dignity related arguments that have been advanced make one, or more, of the following mistakes: a) they confuse the creation of chimeras with how such creatures would be treated in a laboratory context; b) they misrepresent how a being could be treated solely as means towards others' ends; and c) they fail to characterise the moral responsibilities that moral agents have towards other moral agents.

John Harris FMedSci, is Director of The Institute for Science, Ethics and Innovation and of the Wellcome Strategic Programme in The Human Body, its Scope Limits and Future, School of Law, University of Manchester, where he is Lord Alliance Professor of Bioethics. He is joint Editor-in-Chief of The Journal of Medical Ethics and has been a member of The United Kingdom Human Genetics Commission since its foundation in 1999 and is a Member of the Medical Ethics Committee of the British Medical Association. Recent Books Include: Clones Genes and Immortality. Oxford University Press, 1998. John Harris Ed. Bioethics. Oxford Readings in Philosophy Series, Oxford University Press, 2001. Justine C. Burley and John Harris Eds. A Companion To Genetics: philosophy and the genetic revolution. Basil Blackwell, Oxford. 2002. (Blackwells Companions to Philosophy series) and On Cloning, Routledge, London, 2004. Enhancing Evolution was published by Princeton University Press in 2007.

In September 2006 The Independent included John Harris in The Good List, purportedly a list of the fifty men and women who make our world a better place. On the 6th September 2008 John Harris featured in The Times Lifestyle 50: The top fifty people who influence the way we eat, exercise and think about ourselves. The Times citation noted his book Enhancing Evolution is hugely influential. Harris has also appeared (as himself) as a minor character in novels by authors as diverse as Alexander McCall Smith (The Careful Use Of Compliments, Leslie Brown, 2007) and Dean Koontz (One Door Away from Heaven, Headline, London 2001), and is one of Nick Baker's Groovy Old Men. (Nick Baker's Groovy Old Men Icon Books Ltd, London 2008)

"SOME BIOETHICAL ISSUES IN STEM CELL RESEARCH"
Ruben Lisker

We begin by analyzing the different types of stem cells, their relationship to cloning and the possibility of transforming them into different tissues to be used as specific transplants to treat diseases which are at present untreatable by any means, such as diabetes mellitus type I or Alzheimer's disease. Arguments are presented to invalidate the objections to human embryonic stem cell research posed by conservative groups, which at best are of a religious nature, that have no place in a secular government system like ours.

Ruben Lisker is a former hematologist and human geneticist, that for the last 25 years has been interested in ethical issues of the practice of medicine. From 1993 to 1997 was a member of UNESCO International Bioethics Research Committee. He has published around 200 research papers that have changed in time from clotting disorders to human population genetics, to the clinical relevance of lactase "deficiency" in our species. His recent publications refer to empirical work on the opinions of medical students and physicians on ethical issues at the beginning and end of life. At present he is Research Head of the Instituto Nacional de Ciencias Medicas y Nutricion Salvador Zubiran and has been named Professor Emeritus at the Universidad Nacional Autonoma de Mexico and other institutions such as the Secretaria de Salud.

ACKNOWLEDGMENTS

This symposium is supported by an International Partnership and Mobility grant from the British Academy; we thank them for their generous support of our project. We also acknowledge the Wellcome Trust Strategic Programme on "The Human Body: Its Scope, Limits and Future" (WT087439) for providing additional support for international collaboration of participants. Finally we would like to thank the Universidad Nacional Autónoma de México (UNAM) for providing logistical support for the event.

Transnational differences in regulation, availability and cost of SCT may lead to 'health tourism', as patients travel to receive SCT that are unapproved or unaffordable elsewhere. What are the

implications of this and how should it be addressed?

What are the effects of commercialising SCT? How should this be regulated in the global health market?

We will examine ethical and policy issues associated with novel SCT, especially those arising from transnational regulatory differences. We will compare regulation of SC science and therapy in the UK within the wider European context, with the situation in Mexico and its implications within the North / Central American context; and aim to use our findings to inform national and international policy.

We will address these questions through an international collaboration involving researchers in SC ethics and law from the UK (a highly regulated jurisdiction, active in SC science, situated within the wider EU regulatory context) and Mexico (a developing country that is a prime site for SC-related health tourism, but where such treatments remain largely unregulated).

Abstract number: 6 **The Social Value of Research: Conflicts between science, society, and individuals**

ID: 24 Seema Shah, Annette Rid

Symposium United States, U.S. National Institutes of Health

The Social Value of Research: Conflicts between science, society, and individuals

Social value is widely accepted, but rarely questioned as a benchmark of ethical research. National and international research ethics guidelines and regulations presume that the value of research to society is critically important for selecting study populations, justifying risk imposition, and determining the acceptable level of net risk. Yet, there is little discussion of whether social value should be considered a necessary requirement for ethical research, what makes research socially valuable (in addition to scientifically valuable), the uncertainty involved in making social value determinations, the difficulty in identifying the right stakeholders to make these judgments, and the challenges of determining social value as applied to particular groups. This panel aims to clarify questions surrounding the concept of social value in research and research ethics, its normative status and potential practical implications, as well as setting a future research agenda.

Plan

Hans van Delden, Utrecht University (Netherlands)
Introduction (5 min)

David Wendler, National Institutes of Health (United States)

Alan Wertheimer, National Institutes of Health (United States)

Social value as an ethical requirement for research: for and against (2 x 10 min; 2 x 3 min. for rebuttal)

Annette Rid, King's College London (United Kingdom)
Conceptualizing social value and its relation to risk (10 min)

Seema Shah, National Institutes of Health (United States)

Applying social value to particular vulnerable populations (10 min)

Paul Ndebele, Medical Research Council of Zimbabwe (Zimbabwe)

Ensuring local social value of research ("responsiveness"): Challenges for policymakers in low- and middle-income countries (10 min)

Discussion with audience (29 min)

Keywords: Social value, international research ethics, responsiveness

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Abstract number: 7	Food choices, responsibility and bioethics
ID: 27	<u>David Hunter</u>
Symposium	Australia, Flinders University

Food choices, responsibility and bioethics

It is clear that the food we choose both for ourselves and for our families has a profound impact on our health, and hence considerable effort is put into public health policies to regulate the content and safety of food, and to health promotion policies to promote healthy eating. However given the rising levels of obesity it must be acknowledged that these strategies aren't working. One reason for this is that these policies are directly against the interests of Big Food, and hence they directly campaign against such policies, as well as undermining them in other ways. A central plank of the argument used against both regulation and health promotion is the notion that food choices are made by free individuals and as such they are the responsibility of those individuals. This relies on a particular liberal, autonomy focused conception of responsibility and bioethics which this symposium aims to unpack and examine:

1. Are people really free and autonomous decision makers when it comes to food?
2. Does respect for autonomy forbid interference with food choices?
3. What sorts of interferences with food choices are compatible with respecting people?

Running Order:

Catherine Womack (Bridgewater State University) Accommodating diversity in food choices and policies: Reframing the debate between Public Health and Big Food (15 minutes)

Christian Munthe (University of Gothenburg) - Structure, responsibility and the goals of public health: how decision competent consumers may mostly be incapable of taking responsibility for population health (15 minutes)

Marcel Verweij (Wageningen University) - Preventing obesity: a matter of individual responsibility AND social solidarity (15 minutes)

David Hunter (Flinders University) - Reconceptualising responsibility and autonomy as freedom from domination - implications for health policy and promotion (15 minutes)

Audience discussion: How should we conceptualise the relationship between food choices and responsibility? (30 minutes)

Keywords:

Obesity, responsibility, autonomy

Abstract number: 8	Should Bioethicists be Activists: Do we need a translational bioethics?
ID: 28	<u>David Hunter, James Wilson</u>
Symposium	Australia, Flinders University

The International Network for Philosophy and Bioethics (INPAB) has spent several sessions trying to understand what methodologies are legitimate in bioethics, but perhaps this was a mistake. Perhaps the point isn't to understand the world, but to change it. In this symposium we will engage with the question of what ethical obligations bioethicists have - in particular are we obliged to be activists for whichever cause we write about, or whether we should see our role as dispassionate observers sticking strictly to our (often) philosophical skill sets and commenting on issues without actively trying to implement change. This session will discuss both the obligations bioethicists may have to be advocates, as well as the risks inherent in them taking up specific causes.

Improving the health of patients is the taken-for-granted goal of medical research and practice; and much blood has been spilled on the question about whether we are translating theoretical advances into patient benefit as effectively as possible. This session asks whether we now need a translational bioethics and what would this look like?

Running Order

David Hunter, will argue that bioethicists need to take on greater advocacy roles and use their talents and expertise in pursuit of social justice. (15 minutes)

Iain Brassington, University of Manchester will respond (10 minutes)

Roundtable discussion - Should ethicists be advocates? (25 minutes) – Chaired by Catherine Womack

James Wilson, University College, London. From bioethics to politics (15 minutes)

Roundtable discussion - what skills, knowledge and experience make for good translational bioethics? (25 minutes)

Keywords: bioethics, activism, translational

Abstract number: 9	'Vulnerability' in Research Involving Human Participants
ID: 29	<u>Calvin Wai-Loon Ho</u> , Abha Saxena (WHO), Seema Shah (NIH), Hugh Whittall (Nuffield Council), Alastair Campbell (Singapore)
Symposium	Singapore, National University of Singapore

The role and contribution of transnational ethical guidelines for biomedical research in low- and middle-income countries (LMICs) are widely recognised, although their effectiveness and, in certain cases, relevance have been questioned. For instance, while there are many different sets of guidelines, there is no realistic means of giving effect to their potentially conflicting requirements. Persistent inadequacies in LMICs include deficient governance systems, underdeveloped clinical and healthcare infrastructure, lack of transparency, and insufficient community engagement. More fundamentally, guidelines fail to identify the very people that they attempt to protect. The recent revision to the Declaration of Helsinki reframes the responsiveness requirement (i.e., the requirement that research be responsive to health needs and/or priorities) towards vulnerable groups. This is a departure from the previous approach of focusing on host communities, an approach that is still recommended by the CIOMS ethical guidelines. Notions of 'vulnerability' remain highly contestable. There has been a general shift away from thinking about this term categorically (e.g. as particular types of people such as children), and towards a more pluralistic assessment, so that different safeguards are required for different types of vulnerability. Such a move is sensible in theory, but questionable if ethics review bodies in developing countries do not have the resources and capability to engage in more rigorous evaluations of the vulnerability of research populations and appropriate safeguards. In the context of these broader ethical deliberations on the conduct of biomedical research, particularly research involving children in LMICs, this symposium will explore different ways of defining 'vulnerability,' what the implications are of using one safeguard to cover all vulnerable groups, and propose more constructive ways to operationalise the concept in order to better secure the interests of both research participants and the scientific enterprise.

(288 words)

Key Words:

Vulnerability, Low-Resource Settings, Children

Primary contact for Symposium Proposal: Dr Calvin WL Ho, Assistant Professor, Centre for Biomedical Ethics, Yong Loo Lin School of Medicine, National University of Singapore

Format: Symposium - 90 minutes

Schedule:

Introduction and Framing of the Problem: Professor Alastair Campbell (5 Minutes)

Chair: Professor Alastair Campbell

Director

Centre for Biomedical Ethics

Yong Loo Lin School of Medicine

National University of Singapore

Paper Presentations:

1. Concept of vulnerability in international health research – the experience of WHO

Abha Saxena, MD

Coordinator, Global Health Ethics;

Secretary, Research Ethics Review Committee,

World Health Organization, Geneva

2. Different Types of Vulnerability and the Responsiveness Requirement

Seema Shah, JD

Department of Bioethics, Division of AIDS at the National Institutes of Health, USA

3. Research Involving Children

Hugh Whittall

Director

Nuffield Council on Bioethics, UK

4. The Resource Question in Research: Perspectives from East Asian Countries

Calvin WL Ho, JSD MSc

Assistant Professor, Centre for Biomedical Ethics,

Yong Loo Lin School of Medicine, National University of Singapore;

Research Associate, Ethox Centre, University of Oxford, UK.

Each Paper will be Allocated 15 Minutes

25 Minutes for Panel Discussion on a case involving pneumococcal vaccine trial in a middle-income country. Issues discussed will include different ways of defining 'vulnerability' and the distinction between vulnerable groups and communities.

Panel Chair: Professor Alastair Campbell (Singapore)

Panel Discussants: Abha Saxena (WHO), Andreas Reis (WHO), Seema Shah (NIH),

Abstract number: 10 Revision of the CIOMS guidelines for biomedical research involving human subjects
ID: 30 Johannes (Hans) J.M. van Delden, Annette Rid, Ruth Macklin, Rieke Van der Graaf
Symposium Switzerland, Council for International Organizations of Medical Sciences

The CIOMS guidelines for biomedical research involving human subjects have a unique status among international ethical guidance documents for human subjects research. The CIOMS guidelines not only offer specific guidance, but also a commentary that serves as a practical approach and working tool for all involved. The CIOMS guidelines are widely considered as valuable, in particular in contexts where legal protection of human beings in research is absent.

In 2010 CIOMS decided that its ethical guidelines needed to be revised, amongst others because the WMA proposed to revise its Declaration of Helsinki (now completed), to which the CIOMS guidelines are closely related. The last revision of the CIOMS document dates from 2002.

In this symposium, Working Group members and advisors to the Working Group will present and discuss key issues in the revision process. Additional members will be present for panel discussions, with Annette Rid MD PhD (member of the Working Group) functioning as the chair. This symposium will also serve as one element of CIOMS' international consultation process regarding the proposed revisions.

1. Title: The CIOMS revision process

Speaker: Hans van Delden MD, PhD (President of CIOMS, chair of the revision Working Group)

Duration: 10 minutes presentation, 10 minutes panel discussion

2. Title: Major revisions to the CIOMS guidelines: reasons for change

Speaker: Ruth Macklin PhD (Working Group Member)

Duration: 20 minutes presentation, 10 minutes panel discussion

3. Title: Proposed and potential new CIOMS guidelines

Speaker: Rieke van der Graaf PhD (Secretary CIOMS Working Group)

Duration: 10 minutes presentation, 10 minutes panel discussion

4. Title: The CIOMS guidelines in Low- and Middle Income Countries

Speaker: Aissatou Toure PhD (Working Group Member)

Duration: 10 minutes presentation, 10 minutes panel discussion

Abstract number: 11 The ethics of mitochondrial replacement therapy
ID: 31 John Appleby, Stephen Wilkinson, Vardit Ravitsky, Annelien Bredenoord, Anthony Wrigley
Symposium United Kingdom, Centre of Medical Ethics and Law, The Dickson Poon School of Law, King's College London

Mitochondrial DNA (mtDNA) disorders are among the most commonly inherited neuromuscular diseases and can cause immense suffering and death. The development of new technologies (e.g. pronuclear transfer and maternal spindle transfer) may lead to the replacement of mitochondria carrying harmful mtDNA mutations with 'healthy' mitochondria from donated eggs. These experimental techniques will be beneficial to some parents who are likely to pass on mtDNA disorders to their children, as they will provide the option of having a genetically related child without an mtDNA disorder. However, such technologies raise important ethical issues.

The panel consists of four short (10–15 minutes) papers from speakers, each addressing a key ethical question. A 30-minute moderated discussion will follow with audience engagement.

Chair: Professor Stephen Wilkinson (Department of Politics, Philosophy and Religion, Lancaster University, UK).

Title: 'Mitochondrial replacement: the role of the media in shaping the public debate'

Speaker: Professor Vardit Ravitsky (Bioethics Program, School of Public Health, University of Montreal, Canada).

Description: A heated public debate has been emerging surrounding mitochondrial replacement and the coverage of this debate in the media has been extensive. What are the various portrayals of this technology in the media and how do different framings shape the public debate?

Title: Mitochondrial replacement: ethics from bench to bedside

Speaker: Dr Annelien Bredenoord (Department of Medical Humanities, University Medical Centre Utrecht, Netherlands).

Description: Are these 'radical' technologies ethical to use when 'safer' reproductive alternatives (e.g. egg donation) exist? When would it be ethically acceptable to take the leap from bench to bedside?

Title: Mitochondrial replacement: ethics and identity

Speaker: Dr Anthony Wrigley (Centre for Professional Ethics, Keele University, UK).

Description: To what extent is mitochondrial replacement identity-affecting? If successful, would it be therapy or a form of selective reproduction?

Title: Is mitochondrial replacement eugenic and incompatible with human dignity?

Speakers: Dr John Appleby (The Dickson Poon School of Law, King's College London, UK) and Professor Stephen Wilkinson (Department of Politics, Philosophy and Religion, Lancaster University, UK).

Description: Mitochondrial replacement has been attacked for being inconsistent with human dignity, eugenics and a form of germ-line modification. These objections are critically assessed.

Abstract number: 12

ID: 34

Symposium

Acts and omissions across bioethics

Txetxu Ausín,

Spain, Consejo Superior de Investigaciones Científicas

Background: The acts/omissions distinction underlies some of the most prominent and traditional controversies in bioethics, including debates about killing and letting die; causing and enabling harms; and positive vs negative forms of eugenics. In bioethics, different approaches to the acts/omissions distinction determine and elicit different understandings of what is deemed to be justifiable in the relationship between health professionals and patients (clinical bioethics), in the relationship between individuals and healthcare institutions (organizational bioethics), and in the relationship between individuals or health institutions and global populations (global bioethics).

Objective: To explore the acts/omissions distinction and its practical and moral relevance for bioethical debates.

Methods: A draft paper on "Candidate criteria for, and objections against the acts/omissions distinction in bioethics" will be circulated before the symposium. Speakers will apply their view on the distinction -whether supportive or critical- to a particular case or debate in bioethics. Presentations will last 10 minutes, followed by a general discussion.

Research questions: Is the acts/omissions distinction morally relevant in bioethics? Which criteria can account for its moral relevance? Are such criteria justifiable and useful? Can they be consistently applied to a wide range of bioethical debates?

Contributions:

- David Rodríguez-Arias (CSIC) and Carissa Véliz (CUNY): Doing, Allowing and Enabling Harm in the Context of Global Justice and Poverty Alleviation
- Txetxu Ausín: The Cost of Omissions in Precautionary Policies
- Rosana Triviño (CSIC): Are Positive Conscientious Objections in Healthcare Acceptable?
- Teresa López de la Vieja (USAL): Health care and women's rights
- Omar García Zabaleta and Antonio Casado da Rocha : (UPV-EHU): Doing vs Not Doing in the Promotion of Autonomy and Mental Health
- Ion Arrieta Valero and Antonio Casado da Rocha (UPV-EHU) : Conceptualizing Autonomy in Bioethics: The Role of Actions and Omissions

Abstract number: 13

ID: 79

Symposium

Biobanking in Africa

Keymanthri Moodley, Prof Eric Juengst (Univ North Carolina) Dr Ciara Staunton (Stell Univ)

South Africa, Centre for Medical Ethics and Law, Department of Medicine, Stellenbosch University

For decades biological samples have been exported from Africa for storage in biobanks abroad. This has raised suspicion amongst researchers and research participants and generated significant debate on future use and validity of consent. The establishment of biorepositories in Africa as part of the Human Heredity and Health in Africa (H3Africa) project funded by the National Institutes of Health (NIH) and the Wellcome Trust is therefore extremely timely. This initiative will serve to promote research within Africa and support international collaborations. However, this project has raised poignant questions about ethics, governance and sustainability. In resource limited settings sustainability of biobanks will be an ethical imperative beyond the grant funding period. We will collectively explore economic, environmental and social factors that impact on sustainability.

This symposium will comprise a short introduction, 3 talks and an interactive session with participants to explore options for sustainability.

1. H3 Africa and Genomic Sovereignty
Prof Eric Juengst (USA)

The H3Africa project is hailed as a departure from traditional Euro-American models of international genomic research funding because of its focus on scientific capacity building in Africa and the willingness of its funders to allow African scientists to control its design and implementation. But Africa is not a single sovereign state: its populations are of scientific interest precisely because of the genetic diversity that results from its history of socio-political divisions and internal diasporas. Already, claims to "genomic sovereignty" by particular African polities are complicating the ambitions of H3Africa to create a pan-African genomic research infrastructure. These complications illuminate critical conceptual and ethical challenges to attempting to govern genetic information as national natural resources, which mirror the problems with patenting genes as scientists' intellectual property.

2. Governance and Sustainability of Biobanks in South Africa.
Prof Keymanthri Moodley (South Africa)

A biorepository represents a viable business entity that must be managed with short and long term strategic goals to maximise impact. Principles of good governance – transparency, accountability, responsibility, fairness, discipline and social responsibility – must be applied in daily management to achieve institutional legitimacy and to remain economically viable. In Africa, environmental sustainability of biobanks is critical in terms of ensuring alternate sources of energy and disposal of samples. Social responsibility must be demonstrated via consideration of stakeholder community interests.

3. Community Engagement in Biobanking in Africa
Dr Ciara Staunton(South Africa), Dr Alwyn Mwinga (Zambia)

Unlike in western societies where autonomy, self-determination and individual informed consent are the focus, in African cultures, the community plays a much greater role in the lives of its members. Individual informed consent may thus need to be accompanied by community consent. Engaging the community to determine their views on genetic research will likely be crucial to the success of the H3Africa project. Yet despite this clear need, there is a paucity of research on community views on genetic research and a lack of guidelines for researchers on community engagement (CE). This paper will seek to identify these challenges and provide recommendations for guidelines.

Abstract number: 14
ID: 113
Symposium

Bioethics Education 2.0: Advancing Continuing Professional Development in Ethics for Healthcare Professionals
Jacqueline Chin, Dr Nancy Berlinger, Dr Michael Dunn, Dr Farhat Moazam , Dr Daniel Fu-Chang, Dr David Rodriguez-Arias
Singapore, Centre for Biomedical Ethics, National University of Singapore

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Dr David Rodriguez-Arias

Dr Jacqueline Chin is the primary contact:

Abstract

Continuing professional development (CPD) activities in ethics are less well-developed than ethics programmes for medical students. Advancing CPD in ethics faces a number of challenges. Junior healthcare professionals may have limited educational opportunities for the integration of ethics within their training programmes than in medical school. These professionals may also lack the 'safe spaces' or 'dedicated time' required to engage in ethical reflection about their work, and they are unlikely to embrace training materials that do not parallel issues of ethics or professionalism that they face.

Bioethics Education 2.0 refers to new possibilities that web-based technologies can offer to developing educational materials in ethics for professionals-in-training. The educational, ethical and practical challenges that arise in developing them will be considered in this symposium. Focusing on educational activities, one web-based educational project will be introduced as the starting point for discussions: a new online ethics casebook developed in Singapore for its professional healthcare community by three bioethics centres (the Centre for Biomedical Ethics in Singapore, The Hastings Center in New York and the Oxford Ethox Centre).

Methodology

The symposium will consist of three parts:

1) An introductory presentation will set the scene with a tour of the content and navigational features of Making Difficult Decisions with Patients and Families, the web-based ethics teaching casebook made by, and for, practising clinicians. (15 minutes)

2) A presentation of key discussion questions.

Chin: Why a web-based casebook? Developing teaching and learning resources for clinician education in a digital nation and a globalized region. The project in Singapore developed in response to empirical findings suggesting a need for clinically and culturally relevant continuing bioethics education. We considered questions concerning the users and audiences that could benefit from setting out ethics materials in a web-based casebook format, and potential teaching and learning contexts in globalised clinical education. (15 minutes)

Berlinger: Pedagogical Challenges in Bioethics 2.0. What are some of the most important principles of adult learning that apply to the design of continuous professional development? How do those principles translate into the strategies available to designers of CPD? What are some of the limitations of web-based learning and how might they be overcome? (15 minutes)

Dunn: Practical and ethical challenges in Bioethics Education 2.0. In writing a web-based CPD casebook, what are some important considerations for ensuring clinical realism and reliability? What privacy and confidentiality requirements should be adhered to for an open-access, web-based work based on realistic cases? (15 minutes)

3) An audience discussion. Clinician educators and bioethicists, Dr Farhat Moazam (Pakistan) and Dr Daniel Tsai (Taiwan), and Dr David Rodriguez-Arias (Spain) will respond to the presentations. The audience will be asked to share perspectives on meeting continuing education needs for clinicians and healthcare professionals in their own societies, and how the internet might offer new opportunities and challenges in their educational activities. (30 minutes)

Expected outputs: This symposium hopes to establish an on-going forum for deepening exploration of the idea of Bioethics 2.0, and such future educational initiatives.

Abstract number: 15
ID: 141
Symposium

Real time bioethics: axiology of clinical practice

Myriam M Altamirano-Bustamante, Nelly Altamirano-Bustamante, Alberto Lifshitz, Uria Guevara-López, Ximena Sueiras, Ana Serrano, Adalberto de Hoyos, Rodrigo Nava-Diosdado Mexico, Instituto Mexicano del Seguro Social

Key Words – Values based medicine, axiology, Translational bioethics, Translational bioethics real time bioethics, clinical ethics, cultural capacities, palliative care.

Abstract:

A globalized world, whose changing rhythm has startled us, offers medicine new challenges in the social, scientific and technological arenas; which are central themes of the IAB's World Congress. The last century witnessed the development of a very effective clinical practice strongly based in

evidence, where data and clinical test where most important. However, conflicts emerged when the ethical values that guide the practice were neglected, these have to give sense to a mindful practice to offer solutions to the ethical dilemmas that arise. The clinical dilemmas that arise to the healthcare systems are often related to problems of justice because it is increasingly hard to offer adequate health care to a growing population, which is also acquiring a more complex age and epidemiological configuration. This symposium offers an amalgam of methodologies to study these phenomena; from triangulation concurrent mixed methods, qualitative and hermeneutical analysis among others.

Healthcare cannot be a technical or political subject, since it is about men and women who suffer illnesses, that can understand them and offer elements for their better treatment; people whose life plans and capabilities have to be protected. The attention to vulnerable groups is important, since it is of them who have least

access to these services. World population is aging and this trend will continue, therefore it is important to offer extensive care to geriatric patients, as well as the access to palliative care. Cultural, linguistic and religious minorities have to be included in a constant dialogue so that their point of view may be considered in their treatment. All of these modifications require a change in focus, so that medicine may offer a better quality of life. The results of this group of researches shows that values such as honesty and respect tend to be basic; and values such as self-transcending and openness to change are eminent for the clinical practice. In order to promote these values it is necessary to train the students of healthcare careers in a solid clinical ethics tradition, making this discipline not only a theoretic subject, but an everyday way of practicing medicine.

The speakers will be addressing matters along the following lines:

- Real time bioethics: the pairing of Evidence-based medicine and Values-based medicine (Myriam M. Altamirano Bustamante, Centro Médico Nacional Siglo XXI, IMSS)
 - Translational bioethics (Alberto Lifshitz, Fac. Medicina UNAM)
 - Geriatrics & palliative care (Uria Guevara, UABJO, Oaxaca)
 - Axiology of the ends of medicine (Ximena Sueiras, Universidad Iberoamericana)
 - Gathering up the Loose Ends of Dispute Settlement in Clinical Practice (Ana Serrano, Rodrigo Nava Diosdado, Instituto de Investigaciones Filosóficas, UNAM.)
 - Justice, multicultural societies and healthcare (Adalberto de Hoyos, FES Acatlán, UNAM)
- Goals:
- Establish crossfunctional groups as a vector in strengthening the pairing of Evidence-based medicine and Values-based medicine.
 - Analyze the axiology of clinical practice and the influence it poses to the decision making
 - Note the main ethical dilemmas and the values of the Mexican clinical practice
- Methodology
- Panel speakers (10 minutes x 6 panelists=60 mins)
 - Dialog with audience participants (25 mins)
 - Closing comments (5 mins)

Abstract number: 16
ID: 157
Symposium

Towards a global consensus on an ethical framework for medical products of human origin
Marie-Charlotte Bouësseau,
Switzerland, World Health Organization

Over the past decade important international initiatives have been taken by scientific societies and governmental organizations to address ethical issues related to the donation and use of medical products of human origin (MPHO). In 2008, the declaration of Istanbul was adopted during the International Summit on Transplant and Organ Trafficking convened by the Transplantation Society and International Society of Nephrology; in 2009 a joint United Nation/Council of Europe study on organ, tissue and cell trafficking was published; in May 2010, the World Health Assembly endorsed a resolution which includes 10 guiding principles on Human Cell, Tissue and Organ Transplantation. These principles are an update of the WHO guiding principles adopted 20 years before, they constitute a reference for countries willing to create or modify their domestic laws. In addition many national ethics committees have contributed to the debate publishing statements and reports on ethical challenges related to the development of therapeutic measures that involve

the use of MPH0; in 2010 and 2012 this topic was discussed by delegates of the Global Summit of National Ethics Committees. Nevertheless there is still a need for more discussion to build a global consensus and harmonize practices around the world. The World Health Organization (WHO) is now taking an initiative including all products of human origin and aiming to agree on common governing principles to protect the donors, the recipients and the society at large. The symposium will convene experts from different regions of the world and facilitate exchange of experiences around a large scope of ethical questions related to the donation and use of MPH0. Ethical aspects common to all MPH0 such as safety and vulnerability of recipients and donors ; self-sufficiency as a way to contribute to equitable access and universal health coverage will be presented; specific topics such as transplant tourism, organ trafficking, stem cell therapy will be open to the discussion; a special attention will be given to country experiences (e.g. Pakistan and Argentina). The main goals of the symposium are: to review ethical issues to be addressed in an ethical framework on MPH0 and to formulate recommendations for the development of such guidance. The symposium will consist of six brief presentations of 10 minutes each, followed by a general discussion; a background paper will be developed before the Congress and distributed to the participants during the symposium. The symposium will be part of a vast consultation process conducted by WHO on these issues. The confirmed speakers are: Nikola Biller, Switzerland; Arturo Dib-Kuri , Mexico; Florencia Luna, Argentina; Dominique Martin, Australia; Farhat Moazam, Pakistan; M-C Bouësseau and L. Noël, WHO.

- Opening: Marie-Charlotte Bouesseau
- Panel:
 - Caroline Clarinval
 - Dominique Martin
 - Farhat Moazam
 - Arturo Dib-Kuri
 - Florencia Luna
- Discussion
- Concluding: remarks: Alex Capron

Abstract number: 17
ID: 165
Symposium

Diabetes y la pobreza una paradoja de nuestra era un análisis desde el punto de vista bioético
Juan Manuel Granillo, Roberto Ignacio Contreras
Mexico, Facultad de Medicina Universidad Autónoma de Chihuahua

Palabras Clave.- Diabetes, Pobreza, Derechos humanos y bioética
Autor.- Dr. Juan Manuel Granillo Saláis
Coautor.- Dr. Roberto Contreras García
La presentación es para 15-20 minutos
Preguntas.- 10 minutos
Tópicos a abordar.- Diabetes Mellitus y su relación con la pobreza, derechos humanos y bioética.

Este ensayo analiza los diferentes aspectos que actualmente se están presentando alrededor de la diabetes, siendo uno de ellos la pobreza y lo paradójico que es, ya que en la etiología de la diabetes uno de los factores predisponentes más importantes es la comida abundante y una de las enfermedades que más frecuentemente la predisponen, es la obesidad.

Este análisis consiste en observar el comportamiento de la Diabetes y la pobreza siendo un problema creciente y social ya que se está presentando cada vez más en poblaciones vulnerables y de más bajos recursos.

En diferentes estudios se describe como antiguamente a la Diabetes se le consideraba de alcurnia, se presentaba más frecuentemente en niveles sociales altos, la pobreza no le permitía a la población darse los lujos que tenían estas clases y gran parte de sus enfermedades eran de etiología infecciosa o por desnutrición.

Si bien es cierto que existen poblaciones y países con un gran nivel de riqueza en donde hay alta frecuencia de diabetes, los países en desarrollo que tienen poblaciones pobres también tienen una mayor frecuencia de esta enfermedad.

Se suele observar por un lado la opulencia de las clases adineradas y al otro lado de la región la pobreza extrema.

En México tenemos como ejemplo el Estado de Guerrero, en donde hay regiones que observan riqueza pero el pueblo se mantiene con sueldos bajos , viviendo humildemente y a pesar de ello también se detecta esta patología.

En el Estado de Chihuahua, se presenta en general cierto nivel de progreso y de recursos, sin embargo en las zonas conurbadas de las ciudades más importantes hay pobreza y también se observan patologías crónico degenerativas como la diabetes y no se diga las zonas serranas en donde la tala inmoderada, la sequía y las desigualdades sociales impiden el progreso; ello redunda en bajos salarios y conlleva a pobreza extrema, como le sucede a nuestros tarahumaras en donde se están detectando también enfermedades metabólicas.

La Diabetes ha rebasado las clases sociales, los recursos para su atención cada vez son más altos, aunado al precio de los medicamentos, agregándose a esta entidad otras alteraciones, como la dislipidemia y la hipertensión, con lo que aumenta el gasto ante el mayor número de fármacos, siempre y cuando el paciente aun no presente complicaciones, y de presentarse, los costos se elevan estratosféricamente.

Esta historia real que estamos observando atenta directamente los derechos humanos, obliga a plantearse. Qué estamos haciendo desde el punto de vista bioético, social y médico y como debemos de abordar esta situación la cual será más problemática, porque aún hay poblaciones a las cuales no llega la suficiente atención médica, los recursos y la educación tampoco es suficiente, lo que ocasiona que este binomio DIABETES/POBREZA sea un gran problema regional y mundial.

Se Contemplan algunas alternativas de solución.

El Nombre de los ponentes son:

Dr. Juan Manuel Granillo Salais
Dr. Roberto Ignacio Contreras García
Dra. Matilde Rodríguez Rico
Dra. Sara Chávez Prieto
Dr. Octavio Martínez Pérez

Abstract number: 18

ID 183

Symposium

Place, Care, and Bioethics

Lisa Eckenwiler

United States, George Mason University

This panel, comprised of selected members of an interdisciplinary bioethics research consortium, examines the significance, for care, of place. Most work in bioethics reckons with our embodiment and interdependence, including the necessity of relations of care and dependence. However, it typically overlooks the importance of our implacement, or locatedness, and in particular, the need for fit between our bodies and our environments. Once we take seriously the significance of place in our identities and prospects for well being, it becomes integral to a proper understanding of our responsibilities in caring for one another, through clinical care, public health, and global health policies and practices. The first speaker will focus on place and care in the clinical setting. He will critique the standard understanding of clinical 'pathways', and summarize findings from a mixed-method pilot study conducted last year in a regional Burn Center in the southeastern United States that examined how the design of the unit shaped patients', families' and health care teams' hopes, expectations, and decisions about the future course of care. The second panelist will examine the significance of place for long-term care by analyzing three case studies of innovative dementia care environments, the Eden Alternative and the Greenhouse Projects in the United States, and the Hogewey Alzheimer's Village in the Netherlands. She will argue that the creation of physical environments promotes better care for persons with dementia by enhancing their sense of well-being and enabling them to remain physically and socially active, allowing them to maintain a connection to the natural world. The third speaker highlights the significance of place for health equity. She proposes and defines a new ethical concept, 'ethical place-making', as a normative foundation and organizing idea for addressing the societal determinants of health that generate inequities. Alongside the examples of her co-panelists, she presents one from urban planning and another involving health worker migration. A moderator will synthesize the panelists' presentations and facilitate discussion between participants and panelists.

Abstract number: 19

ID: 191

Symposium

Men and reproduction: some controversies on 'fathering'

Inez de Beaufort, Dr. Wim Pinxten and Hafez Ismaili m\Hamdi MA

Netherlands, ErasmusMC, department Medical Ethics and Philosophy

Future father, semen provider, partner of the pregnant woman, second father: the different roles and responsibilities of men in the variety of ethical decisions regarding reproduction can be negligible, controversial, or unclear. The complexity of moral issues has increased through modern

reproductive technologies . This symposium will discuss some controversial issues regarding the responsibility of (future) fathers.

Different introductory talks followed by a debate with the audience on the moral issues and possible policy-implications, chaired by Inez de Beaufort.

'Images of the father': a general introduction based on novels and movies Frans Meulenbergh (ErasmusMC Rotterdam)

'The role of fathers before the conception' Measures to improve the health of future children are predominantly associated with the health and life-style of prospective mothers. But what about future fathers? Do they have a moral duty to reproduce responsibly and if so, what does this entail? Hafez Ismaili m'Hamdi (ErasmusMC Rotterdam)

'It is my child as well: the role of fathers in decisions regarding prenatal diagnosis. Which rights and duties do fathers have in decisions regarding prenatal diagnosis, possibly followed by an abortion. Wim Pinxten(University of Hasselt. Belgium)

'Two fathers: Adoption by homosexual couples' Though easier through reproductive technologies, in some countries adoption by homosexual couples is widely accepted, in other countries it is very difficult or forbidden. This has to do with deeply engrained cultural values. 3 speakers (to be invited from those who attend the IAB *) will present differing perspectives (5 minutes) and underlying arguments.

Panel debate with the audience, leading to suggestions for the agenda for future ethical debate and research.

*We realize this is unusual, but given the sensitivity of the subject, it is easier for people to address it if that is not the particular reason for attending the IAB.

Abstract number: 20 **Euthanasia and Physician-Assisted Suicide for Mental Suffering**
ID: 242 Kasper Raus, Sigrid Sterckx
oral Belgium, Ghent University

[This presentation is part of a symposium proposed by prof. Jan Bernheim entitled 'Current controversies about end-of-life ethics']

A common image in the euthanasia and physician-assisted suicide (PAS) debate is that of a patient with intense physical suffering of somatic origin, requesting an end to her suffering. Indeed, in the countries where euthanasia, PAS or both are legal, empirical data indicate that euthanasia and PAS are indeed used mainly (e.g. in Belgium, The Netherlands and Luxembourg) or even solely (in the US states of Oregon and Washington) for patients suffering from somatic diseases (mostly cancer). Nevertheless, there is considerable debate as to whether suffering of psychological or psychiatric origin can in some cases also be accepted as an indication for PAS or euthanasia, either in combination with somatic suffering or even as the sole type of suffering. Euthanasia laws in Belgium, The Netherlands and Luxembourg already allow euthanasia in the case of unbearable suffering due to diagnosable psychiatric illnesses (such as, for example, schizophrenia), but such cases are extremely rare.

We will look more closely into the issue of euthanasia and PAS for patients suffering from mental suffering or psychiatric illness. We will analyze whether the arguments commonly given for euthanasia or PAS can also be applied to these types of suffering. Next, we will assess the reasons that are commonly given for viewing psychological suffering as morally different from somatic suffering. More specifically, we will address the question of whether mentally ill patients can give valid consent and whether a psychological or psychiatric condition can ever be judged incurable (a central requirement in the Dutch and Belgian euthanasia law).

Abstract number: 21 **What can Clinical Bioethics offer to our Mexican contemporary reality?**
ID: 250 Martha Tarasco, Dra. María Elizabeth de los Ríos, Dr. Robert Hall, Dr. Samuel Weingerz
Symposium Mexico, Universidad Anáhuac México Norte

This research questions has the clear intention to enrich the discussion on the possibility to establish Clinical Bioethics in Mexico City taking into consideration the cultural, economic and territorial situation of the country.

Therefore, this symposium explores the opportunities to implement clinical bioethics in Mexico that support the Bioethics Committee taking as an example of success the service provides by the Cleveland Clinic in Cleveland Ohio in its Department of Bioethics.

It also discusses different methodologies of Clinical Bioethics in order to compare them and analyze its convenience to Mexican reality.

Also, the educational factor concerning the ignorance towards Clinical Bioethics in our Country is studied here pursuing the purpose of reinforcing the educational function of Committees as a central organism to promote a correct discernment and analysis of medical facts and their relation to human life.

Lastly, this symposium discusses the difficulties and dares that the conformation of the Bioethics Committees has faced in our country to identify vulnerable areas and generate schemes of special attention and emission of recommendations with efficiency in the making of ethical decisions.

Esta pregunta pretende fomentar la discusión en torno a la posibilidad de la Bioética Clínica en México partiendo de un análisis de la realidad territorial, cultural y financiera del país.

Así pues, se exploran las áreas de oportunidad para la implementación de servicios de consulta ética que apoyen las funciones de los Comités Hospitalarios de Bioética tomando como ejemplo el modelo norteamericano y, concretamente, el modelo del departamento de Bioética de la Cleveland Clinic.

También se discuten distintas metodologías de la Bioética Clínica para la emisión de recomendaciones bioéticas, comparándolas y resaltando su adecuación o no a la realidad mexicana.

De igual forma, se problematiza el aspecto educacional del desconocimiento e ignorancia de la Bioética en nuestro país y se acentúa la función educativa de los integrantes de los Comités y de éstos mismos como eje rector de un acertado discernimiento y análisis ético de los fenómenos médicos y su relación con la vida humana.

Se abordan también los retos y desafíos a los que se ha enfrentado el proceso de conformación de los Comités Hospitalarios de Bioética en nuestro país y se identifican áreas vulnerables para generar patrones de atención y emisión de recomendaciones más eficaces y rápidos para la toma de decisiones clínicas.

"El papel de médicos y representantes en los casos clínicos"

Dr Robert Hall PhD (20 minutos)

"La Bioética Clínica : Retos y Desafíos para México"

Dra. Ma Elizabeth de los Ríos Uriarte PhD (20 minutos)

"Dificultad para funcionar en la práctica los comités hospitalarios de Bioética en México"

Dr. Samuel Weingerz Mehl (20 minutos)

"Límites de los Comités Hospitalarios de Bioética y la Bioética Clínica"

Dra. Martha Tarasco Michel MD PhD (20 minutos)

Abstract number: 22

ID: 251

Symposium

Ethical issues in public health surveillance

Andreas Reis, Abha Saxena, Michael Selgelid

Switzerland, World Health Organisation

Schedule:

Speaker/Facilitator

- Introduction.

Abha Saxena. 10 minutes

- Privacy and The Duty to Protect: Addressing the Tensions in the Ethics of Public Health.

Ron Bayer, Amy Fairchild. 30 minutes.

- Standards of Care (with a particular focus on the case of MDRTB surveillance surveys).

Michael Selgelid. 15minutes.

- Report on WHO's recent international meeting.

Andreas Reis. 15 minutes.

- Discussion. 20 minutes.

Goals of the symposium:

- To raise awareness for ethical issues in surveillance
- To report on WHO's recent international consultation
- To solicit recommendations from the audience which will feed into current policy-making in this area

Surveillance, often referred to as "the eyes of public health," is widely recognized as a fundamental public health activity. It often requires physicians, health care institutions, or laboratories to report not only numbers of cases but also the names of those with a disease or condition, both infectious and chronic. Tuberculosis reporting, for example, is a long tradition; diabetes surveillance is new to

many industrialized nations. Disease notification has received new emphasis in the WHO's revised International Health Regulations (2005).

As critical as surveillance is to the practice of public health—enabling officials to map epidemics, treat cases, and target resources—it may also conflict with individual rights claims. Often, given the need to control disease at the population level, it is undertaken without informed consent, one of the most central requirements of research ethics. Likewise, it sometimes creates profound privacy concerns. In some instances, individuals worry about the stigma and discrimination that may result from the disclosure of personal information. In others, they fear the loss of liberty or autonomy if surveillance has the potential to trigger measures like quarantine or mandatory treatment. These kinds of tensions may be magnified in countries where electronic medical records are increasingly used.

Surveillance has also been at the center of controversy over the technical distinction between research, which requires ethical oversight, and public health practice, whose limits are typically a function of law, policy making, and public debate. There are also important issues related to tissue sampling and sharing of specimen and infectious agents (such as virus-sharing).

Remarkably, while there have been some efforts to craft surveillance guidelines for specific diseases, WHO Member States currently lack a comprehensive normative framework and specific guidelines on public health surveillance. WHO has been working with partners to develop guidance on this issue and organized a consultation in May 2014. The main findings of this consultation will serve to highlight the key issues.

Abstract number: 23

ID: 267

Symposium

Global Bioethics and Climate Change: Science, Society, and Individuals in Latin America and the Caribbean

Cheryl Macpherson, Myriam Altamirano, Seetharaman Hariharan, Sean Philpott
United States, St George's University School of Medicine (SGU)

Key Words - Global bioethics; Climate change; Latin America & the Caribbean

Abstract (361 words)

No topic is more connected to IAB's 2014 theme than climate change- a global problem confronting science, society, and individuals. Leading health and economic organizations, including the WHO and World Bank, are investing in research and education about the increasingly prevalent health impacts of climate change. Climate change harms health by contributing to increasingly frequent and severe heat waves and extreme weather events, and by reducing environmental resources including safe food, water, land, and air, and by allowing for the increased spread of infectious diseases. Scarcity of these resources ultimately also reduces the options available for tests, medications, and procedures designed to improve health. Many health scientists and leaders define climate change as the biggest health threat of the 21st century but few bioethicists work on related topics. Bioethicists are based primarily in wealthy nations and benefit significantly from policies that generate large amounts of carbon emissions. Many, however, disregard their own direct and indirect contributions to those policies. Despite bioethics relative inattention to these and the related injustices, its renewed interest in Van Rensselaer Potter's concept of global bioethics is growing. Potter's construct of global bioethics is concerned with sustaining environmental resources for health now and in the future, and with serving as a bridge between experts from diverse disciplines that facilitates their collaborative explorations of ways to do this. This symposium addresses the neglected issue of bioethics and climate change in the Latin American and Caribbean region, demonstrates the significance of regional context, and highlights regional considerations about cause and effect that bear on national or institutional responsibilities therein. The symposium will engage bioethicists and others in dialog about their responsibilities to respond to climate change and the value of bringing climate change into their research, teaching, and policy work. Expert panelists will present the following topics and pose questions to generate dialog with participant stakeholders.

- Global Bioethics and Climate Change (Cheryl Macpherson, Grenada)
- Health Impacts of Climate Change: Latin America and the Caribbean (Myriam Altamiranto, Mexico)
- Health Economics and Climate Change in Latin America and the Caribbean (Seetharaman Hariharan, Trinidad)
- Intersecting Vulnerabilities: El Nino Impacts and Uneven Development in Latin America and the Caribbean (Ivan J Ramirez, USA)
- Infectious Disease and Climate Change: Latin America and the Caribbean (Sean Philpott, USA)

Methodology

Panel speakers (10 minutes x 5 panelists=50 mins)

Panel discussion of each others work (15 mins)

Dialog with audience participants (20 mins)

Closing comments (5 mins)

Abstract number: 24

ID: 273

Symposium

Ethics, Morality and Evolution I

Ricardo Noguera-Solano, Juan Manuel Rodriguez-Caso, Susana Carapia-Vargas, Rodrigo Bustillo-Ramirez, Vivette Garcia Deister, Rosaura Ruiz Gutiérrez.
Mexico, UNAM

The human species, like all other species, has been the result of an evolutionary process that began about 3.8 billion years ago, and through which it has accumulated unquantifiable amount of genetic information. Portions of this information are part of the inheritance of all living beings, others have a more recent history in different lineages, but in the background, all now living species, including the human species is the product of a history that began billions of years ago.

The moral capacity, as all the features of our species was generated through a long evolutionary process which resulted of biological and cultural factors. Therefore, it is considered that biology, in particular evolutionary biology can provide valuable insights for the study of ethics and morality, through understanding how moral capacity was acquired and in particular as it has enhanced in our species the ability to build ethical codes.

The symposium is divided in 3 presentations that emphasize historical and philosophical aspects of this discussion. The first presentation argues that in the works of Jean Baptiste Lamarck: *Recherches sur l'organisation des corps vivans* (1802), *Philosophie Zoologique* (1809) and *Système des connaissances analytique positives de l'homme* (1820), can explain the natural and evolutionary origin of the moral capacity in humans, for Lamarck the "zoological philosophy" was ultimately a research proposal for understanding the nature of human beings.

The second presentation the moral ideas developed by major authors who built the Synthetic Theory of Evolution (Julian Huxley, Ernst Mayr, GG Simpson, GL Stebbins and Th. Dobzhansky) is analyzed. Each of them at different times extended their evolutionary explanations to the evolution of human beings, including human moral capacities.

In the last presentation argues that: morality exists because emotions exist. Hence it is necessary to explain and understand the fundamental role of emotions in our moral behaviour as a species and as individuals.

Rethink ourselves as historical products that are the result of evolutionary processes has strong implications for all, and has strong implications in the assessment of ethical issues that run the full spectrum of human society.

Abstract number: 25

ID: 276

Symposium

An Ethical Evolution of Sexuality

Cesar Abarca-Garcia, Diana Buzo-Zarzosa
Mexico, UAM-Lerma

Since Darwin's seminal work regarding the origin of species, published more than one hundred and fifty years ago, many evolutionary biologists have demonstrated that all living beings, including humans, are descendants from a common ancestor. As a consequence of this biological process, all species share many characteristics. If we are capable to recognise it, we will understand better why many main aspects of our own ancestral behaviour are in constant conflict with ethics. Sexuality is a polemic example of the above, and we intend to examine it as an interaction between our shared biology and culture. First, we propose that sexual behaviour in humans, including different aspects as polygamy or mate choice, could be partially explained by the theory of sexual selection in a similar way than in other dimorphic animals. Second, in this symposium we will discuss particularly how religion, politics and education have been used to modify moral patterns of sexuality in different social contexts. One of our main objectives is showing why, when and where, sexuality becomes an ethics' concern, even more important than other standing topics of moral as medicine or feeding. Finally, with a collaborative team of multidisciplinary specialists, we can comprehend our sexuality in a better way than through disciplinary approaches and, therefore, reduce or avoid the negative effects of moral on natural sexual behaviour as homosexuality or multiple sexual mates. Our symposium was thought and designed as a result of an Ethics and Evolution seminar; we want to present our main conclusion of this reflective exercise in a very free and integrative discussion between researches of different areas of science and humanities.

Background: Numerous factors make bioethical debate an especially challenging activity: bioethics is an applied discipline that is meant to provide practical guidance; bioethical questions often, at least partly, turn on empirical matters (which are often quite complicated and/or involve uncertainty); bioethical questions also turn on questions about values (rather than facts); contributors to bioethics come from a wide range of disciplinary backgrounds (and thus often bring different approaches to argument, sometimes with different standards of reasoning); and the policy relevance of bioethics adds a political dimension. This symposium thus focuses on questions regarding bioethics methodology: i.e., what methods of argument are appropriate, or not, for meeting the unique kinds of challenges enumerated above?

Programme:

1. Professor Vilhjálmur Árnason, University of Iceland

Title: Pitfalls of Critical Thinking in Bioethics

Abstract: As a philosophical discipline, a primary method in bioethics is critical thinking which implies critical evaluation of concepts, positions and arguments. It is argued in this paper that philosophical bioethics which restricts its critical role to critical thinking of this type often suffers from other intellectual flaws (partly because of pride in the excellence of the approach). Three examples will be taken to demonstrate this: premature criticism, uncritical self-understanding of theoretical assumptions, and narrow framing of bioethical issues. This can lead both to unfair treatment of authors and to uncritical discussion of topics.

2. Professor Michael J. Selgelid, Monash University

Title: Bioethics and Burden of Proof (co-authored with Julian Koplin)

Abstract: A common strategy in bioethics is to put forward *prima facie* reasons in support of one policy, and to then claim that the burden of proof (that this policy should be rejected) falls on those with opposing views. If the burden of proof is not met, it is claimed, then the policy in question should be accepted. This paper illustrates, and critically evaluates, use of this strategy in debates about human enhancement, reproductive cloning, and the sale of organs (by live donors). Highlighting general problems with this style of argument, and particular problems with its use in specific cases, it concludes that the burden is on policy makers to chose policy supported by the best reasons.

3. Professor John McMillan, University of Otago

Title: When argument fails: how to reason publicly with those who are being unreasonable (co-authored with Nikki Kerruish)

Abstract: In 2012 the editors of the Journal of Medical Ethics and the authors of a paper on postnatal abortion were subjected to threats and calls for their resignations. More recently New Zealand bioethicists were subjected to a social and national media campaign following the publication of a paper in the New Zealand Medical Journal on prenatal testing. Given that Bioethics is in part an exercise in public reason, how can we respond when argument fails? This paper describes some argumentative strategies that can be used when reason fails. While these strategies fail in the sense that they will not convince opponents they can: clarify the key assumptions within a debate and demonstrate in a public domain 'unreasonableness' of some opponents.

4. Professor Angus Dawson, University of Birmingham

Title: Is the 'real world' a constraint on policy ethics?

Abstract: How should we conceptualise the way that moral theory links to framing policy? One model is that we do the real work at the level of theory and then try and squeeze as much of that through to policy as possible. This approach tends to see policy making as imposing a series of pragmatic constraints on our 'ideal' moral theory. An alternative model to policy making begins with the situational context and sees the 'real world' not as a constraint, but as where we have to work. In this paper I outline each model and suggest reasons to prefer the latter approach.

5. General Discussion

Proposed method for audience participation:

- 15 minute presentations, each followed by 5 minutes of discussion
- 10 minutes general discussion at conclusion of the session

Abstract number: 27
ID: 296
Symposium

Integrity in Medical Research: Urgent as it is
Medard Hilhorst,
Netherlands, Erasmus University Medical Center Rotterdam

Panel:

Inez de Beaufort (chair, The Netherlands), Leonardo De Castro (Singapore), Søren Holm (United Kingdom), Francisco Javier León (Chile), Wim Pinxten (Belgium), Suzanne van de Vathorst (The Netherlands).

Theme:

There is an increasing awareness of misconduct in medical research all over the world. Studies show a lack of trust among the population and we see significant concerns within the research communities and scientific institutions themselves.

Practices can be clearly illegal, corrupt and fraudulent, but can also hide dubious behaviour with regard to sponsors, interests, handling of scientific data, authorships, and role of media. Various conditions and circumstances can give rise to a questionable attitude, and this may differ from country to country.

In a Panel discussion we will exchange ideas cross-cultural and discuss key issues on integrity in medical research in vivid interaction with the audience. Short contributions or brief statements by the members of the panel, e.g. Conflicts of interests – some delicate cases for review boards (De Castro); More cases (Heesters; Pinxten); Concerns expressed by PhD-students, results from questionnaires (Holm and Van de Vathorst); Research integrity, Lessons from Latin America (Léon). We will deal with questions like: is medicine more susceptible to misconduct than other areas of research; do we talk about isolated cases or a wider phenomenon; what are the underlying factors that contribute to compromising integrity and undermining trust; can we draw strict lines between what is morally acceptable and not acceptable, decent and not decent; what can philosophy teach us and how can integrity be taught and fostered; should we focus on professional conduct or on personal virtues; be concerned about regulation, about context and culture, or about individual attitudes and skills?

Biographical information panellists:

- Inez de Beaufort, Professor of medical ethics at Erasmus University Medical Center, Rotterdam (The Netherlands), and member of the European Group on Ethics in Science and New Technologies
- Leonardo D. de Castro, Editor-in-Chief Asian Bioethics Review and Senior Research Fellow, Centre for Biomedical Ethics, School of Medicine, National University of Singapore, Singapore
- Soren Holm, Professor of Bioethics, The University of Manchester (United Kingdom)
- Francisco Javier León, Philosopher, Director of Universidad Central de Chile, Bioethics Center and President of the Latin American Federation of Bioethics Institutions (FELAIBE), Santiago (Chile)
- Wim Pinxten, Assistant professor of Medical Ethics, Hasselt University (Belgium)
- Suzanne van de Vathorst, Lecturer on integrity issues, Erasmus University Medical Center Rotterdam and Professor of medical ethics, e.g. quality in the final phase of life and dying, Academic Medical Center Amsterdam (The Netherlands)
- Ann Munro Heesters, Associate Director of Bioethics, University Health Network, member Rehabilitation Science and Medicine Research Ethics Board (Vice chair) and bioethicist at the Joint Centre for Bioethics, University of Toronto (Canada).

Abstract number: 28
ID: 297
Symposium

Regulation of research, efficiency and internationalization: Does one size fit all?
David Hunter, Annette Rid, John McMillan, Calvin Ho
Australia, Flinders University

Internationally the regulation of research is increasingly driven by the pressure to cut costs for sponsors and researchers and remove unnecessary barriers to conducting high quality research. In this context several key concepts have been used to refine existing systems, such as “proportionality” of review to risk, the exclusion of “low risk” studies from prospective ethical review, the reduction of “redundant review”, the sharing and streamlining of best practices, and the move towards a “learning healthcare system” that efficiently integrates clinical care and research.

The intention behind these approaches is laudable: Who would object to speeding up and making research ethics review more efficient? However, before fully embracing the efficiency agenda, several questions need to be addressed:

- 1) Efficiency of what and for whom?
- 2) Will strategies that have worked in one country be effective in another country? Or were

they successful because of particular aspects of the system in the original country?
Will moves to integrate clinical care and research put patients at unjustified risk?
This symposium aims to look at these questions through the lens of several countries' experiences of reforming their regulatory system to increase efficiency.

Symposium Outline

1. Introduction – David Hunter (5 minutes)

2. Presentations (50 minutes)

Annette Rid, King's College London (United Kingdom)

Risk-adapted regulation in the UK: recent developments

David Hunter, Flinders University (Australia)

Moving to a single review for the country model in Australia: Potential pitfalls

John McMillan, University of Otago (New Zealand)

The recent research ethics reforms in New Zealand

Angela Ballantyne, University of Otago (New Zealand)

Improving management of surgical innovation - a case study for challenging the research-treatment distinction.

Calvin Ho National University of Singapore (Singapore)

The cost of innovation: who should pay and benefit?

3. Workshop (20 minutes)

We will break the audience into small groups to workshop the questions outlined above. Each presenter will work with one small group to record their insights and experience.

4. Roundtable discussion (15 minutes)

Rather than have oral feedback from each small group we will ask participants to use the insight from their small group to address the overarching research question: when is acceptable to reduce the quality of review to increase efficiency?

Abstract number: 29

ID: 311

Symposium

Ethics of translational stem cell research: moving pluripotent stem cells to the clinic

Annelien Bredenoord,

Netherlands, University Medical Center Utrecht

Pluripotent stem cells, such as human embryonic stem cells (hESCs) and induced pluripotent stem cells (iPSCs), have the capacity to self-renew and to differentiate into any cell type of the human body. Though these features have great potential for regenerative medicine, research related to pluripotent stem cells has been accompanied by marked ethical and political debate. There is however a set of ethical questions that received scant attention: the ethical issues associated with translating basic pluripotent stem cell research into cellular treatments. The world's first hESC-based trials have been launched and the first iPSC trial is announced to start in 2014. In this symposium we will discuss whether and how we can ethically justify and launch first-in-human pluripotent stem cell trials.

The proposed panel consists of four short (15 min) papers from confirmed speakers, followed by a 30-minute moderated discussion with the audience.

1.Title: Translational pluripotent stem cell research: the ethical agenda

Speaker: Annelien Bredenoord (Department of Medical Humanities, University Medical Center Utrecht) (confirmed)

Content: The inherent uncertainty of first-in-human trials combined with the technical complexity of pluripotent stem cells make early-phase pluripotent stem cell trials ethically very challenging. What are the ethical issues when moving pluripotent stem cells into patients?

2.Title: Stem-cell based innovation

Speaker: Jeremy Sugarman (Johns Hopkins Berman Institute of Bioethics) (confirmed)

Content: The clinical translation of stem cells could either follow a traditional research pathway or an innovation pathway that is sometimes used in clinical practice. What is the appropriate route towards clinical translation?

3.Title: Social value in pluripotent stem cell research

Speaker: Michelle Habets (Department of Medical Humanities, University Medical Centre Utrecht) (confirmed)

Content: Research participants, especially in innovative medical fields such as stem cells, are in general not expected to gain direct benefit in early phase trials. Could the concept of social value justify exposing participants to possible harms?

4.Title: Global challenges in stem cell research

Speaker: Michael Parker (Ethox Center, Oxford University) (confirmed)

Content: International research collaboration in general raises various ethical challenges. What are global challenges specifically in stem cell research?

Abstract number: 30

ID: 320

Symposium

Financial and other incentives for lifestyle: ethical issues

Marieke ten Have, Inez de Beaufort, Hugh Whittall, Harald Schmidt, Becky Brown
Netherlands, Centre for Ethics and Health

Keywords: Incentives, Nudging, Solidarity

Background

The impact of people's lifestyle on their health status is well documented. Governments are taking all kinds of measures and initiatives to inform the population and promote healthy lifestyles. As not everybody seems equally susceptible to these calls, alternative and more individual strategies are being explored. In that context the use of financial incentives – both positive and negative – is being discussed to make citizens more conscious and responsible for their health. Another approach that is frequently discussed is nudging.

However, both approaches raise a range of ethical questions. How do these more individual strategies affect societal values in health, such as solidarity? Knowing that health inequalities to a large extent are rooted in broader social health determinants and health literacy also varies among groups with different social and economic background, to what extent can individuals be held accountable for their health? But also more practical questions of feasibility need to be addressed. How effective are financial incentives to change health behavior? How to control individual lifestyles and how may this intrude on citizens' privacy? Where does nudging ('making the healthy choice the easy choice') slip into paternalism?

Objectives

This symposium will explore the delicate balance between solidarity and responsibility in health. The symposium is a sequel of an earlier policy dialogue (Nov 6 2013, The Hague), organized by the European Observatory on Health Systems and Policy and the Dutch Centre for Ethics and Health (CEG).

Based on evidence and experiences in various countries, the symposium intends to

- Review the existing international experience with financial and nudging incentives – both positive and negative – in changing health behaviour;
- Discuss the various arguments – pro and contra - that have to be taken into account when considering the implementation of incentive schemes;
- Assess the role of different actors, including health insurers, private sector and civil society;
- Explore alternative policy options and priorities, including scope for further international cooperation and knowledge sharing in this area.

Programme

The programme of the symposium consists of 4 15 minutes' talks, followed by a discussion with the participants.

1. Public health between solidarity and responsibility

Dick Willems, Professor of Medical Ethics, Academic Medical Centre, University of Amsterdam and Centre for Ethics and Health, the Netherlands

2. Blame and shame: individual versus corporate responsibility for unhealthy lifestyles

Inez de Beaufort, Professor of Medical Ethics and Philosophy of Medicine, Erasmus Medical Centre, Erasmus University Rotterdam, the Netherlands

3. Nudging and judging in public health: balancing solidarity, fairness, efficiency and proportionality

Hugh Whittall, director Nuffield Council on Bioethics, UK

4. Rewards and penalties for health behavior: an ethical framework for policy

Harald Schmidt, Assistant Professor of Medical Ethics & Health Policy, Center for Health Incentives and Behavioral Economics, University of Pennsylvania, US

5. Financial incentives for a healthy lifestyle: ethics and effectiveness

Becky Brown, Researcher, Health Services Research Unit, University of Aberdeen, UK

Chairperson: Marieke ten Have, PhD, Senior Advisor, Centre for Ethics and Health, the Netherlands.

Introduction: broader context

In the past century, science, not the least medical science, and societal developments have vastly increased humans' control over their existence. This applies to the beginning and the end of life. For the beginning of life, the medical sciences have provided assisted procreation and effective family planning to enhance loving care for one's progeny. At the other end, life expectancy has doubled and many diseases which in the past were rapidly fatal, have become chronic. Thus, the quantity of suffering at the end of life has increased. On top of that, the inevitability of suffering is no longer accepted by many. It is on this backdrop that in some countries with a liberal tradition prioritizing individual autonomy, laws allowing and regulating assisted dying in cases of refractory suffering at the end of life have been enacted. These developments run contrary to most religious doctrines and to the letter of the Hippocratic tradition.

The IAB has a tradition of addressing contentious bioethical issues, and this symposium will endeavor to reflect an important one.

Objections to legal euthanasia, the concept of futility of some palliative care (PC) and the e.g. Belgian model of 'integral palliative care' embracing euthanasia are both ideological and pragmatic. Brussels' (Belgium) Jan Bernheim, Kenneth Champaere and Luc Deliens' Objections to legal euthanasia revisited: the Benelux experience reviews the epidemiological data from the countries where the end of life has been most extensively studied. The developments in the Benelux countries, where legal regulation of euthanasia was accompanied by highly successful efforts towards universal access to PC can assuage the pragmatic, not the fundamental ethical objections against legal euthanasia.

Lars Materstvedt (Trondheim, Norway) opposes euthanasia and physician-assisted suicide in Caring and killing in the clinic: an empirical and ethical analysis. He finds the empirical data not conclusive and analyzes the Belgian "integral palliative care" from the theoretical perspectives of John Locke, Immanuel Kant, and Robert Nozick. . For him the empirical evidence is far from conclusive, and the ethical justifications are lacking.

Two special cases in assisted dying are then discussed.

Kasper Raus and Sigrid Sterckx (Gent, Belgium), ask whether suffering of psychological or psychiatric origin can qualify as an indication for physician-assisted suicide (PAS) or euthanasia. Can mentally ill patients express valid requests of PAS or euthanasia? Can a psychological or psychiatric condition ever be considered irreversible (as legally required in the Benelux countries?

Sören Holm (Manchester, UK) evaluates the ethics of Terminal Sedation, the alternative to PAS or euthanasia propagated by mainstream palliative care. He critically distinguishes terminal sedation with and without maintenance of hydration and nutrition. The former is not irreversible and not a form of active or passive euthanasia, and does not rely on any use of potentially problematic double effect reasoning. The latter is ethically largely similar to euthanasia and should similarly be regulated to prevent misuse.

Format: 15-minute presentations followed by 5 minutes of specific discussion. Ten minutes for panel discussion.

Nowadays, the world and the problems arising in it are becoming more complex; thus, it is of high importance that the ways and means to deal with them evolve according to the needs involved. A response to this issue is the formation of working groups in order to find the required answers that explain specific questions of each situation. For this reason, there is endless research related to working groups; studies and articles that attempt to approach the content of what they are, how they work, their key concepts, the conceptualization of different types of working groups, the epistemic problems and systemic paradigms that could arise, among many other topics related to the formation of working groups. As there are multiple spectra and fields of work, there are many disciplines that appeal to this way of developing a research, working in groups when carrying it out.

Therefore, trying to outline a novel concept as \"Interdisciplinarity\" in the health sector entails risks. When addressing such a hard issue, we intend to establish the interdisciplinary as a new working group dynamic that deals with bioethical studies. The work we propose is complex, as there is no background of research groups in the field of humanities that use this methodology.

Our purpose, then, is to introduce some considerations and general views that facilitate the understanding of a \"new manner and form\" to establish working groups that provide us the opportunity to find the answers of the contemporary problems faced by researchers. The proposal announced has many aspects as well as other working methods (multidisciplinarity and interdisciplinarity), that does not mean that we have not established a starting point yet, but the working group itself (its members) characterizes its methodology and redefines it according to its interests. The aim of this study is to shed traces on ways of interdisciplinary work through the description of an interdisciplinary group in clinical ethics.

Abstract number: 33

ID: 411

Symposium

The Ethics of Universal Health Coverage

Calvin Wai Loon Ho, Andreas Reis, Carla Saenz

Singapore, National University of Singapore, Harvard School of Public Health, PAHO, WHO, University of Bergen

Universal Health Coverage (UHC) is based on the 1948 constitution of the World Health Organization (WHO), and on the Health for All agenda set by the Alma-Ata declaration in 1978. It is defined as all people receiving quality health services – prevention, promotion, treatment, rehabilitation and palliation – that meet their needs without exposing them to financial hardship in paying for them. UHC underscores the capability of a population to be productive and actively contribute to their families and societies. Financial risk protection that is entailed relates directly to the preservation of this capability, particularly where people have to pay for health services out of their own pockets. This symposium discusses UHC as an ethical initiative that is being implemented in many low and middle-income countries. It focuses on a set of guidelines recently published by the WHO on decision-making by its member states regarding fairness and equity that arise on the path to UHC. These values have a crucial role in ordering the priority of certain services, distributing benefits and burdens by policy-makers, and expanding health coverage (through means such as reducing barriers to access and financial risks). More specifically, the WHO guidelines propose three guiding considerations for choices made in implementing UHC:

- (1) Fair distribution of services, with priority to the worst off;
- (2) Cost-effectiveness, in that services demonstrating this attribute should be prioritised; and
- (3) Fair contribution, based on ability to pay rather than on health needs.

Within an analytical framework anchored by these three considerations, certain decisional trade-offs have been proposed as ethically acceptable or not. The meaning of these three considerations, their application within the proposed framework, and their ethical implications for policy-makers are critically analysed in the collection of presentations in this symposium.

Keywords: Universal Health Coverage, Fairness and Equity, Cost-effectiveness
Primary Contact for Symposium Proposal:

Professor Daniel Wikler PhD, Department of Global Health and Population , Harvard School of Public Health (wikler@hsph.harvard.edu); and Dr. Calvin WL Ho, Centre for Biomedical Ethics, Yong Loo Lin School of Medicine, National University of Singapore; Research Associate, Ethox Centre, University of Oxford, UK (medhwlc@nus.edu.sg)

Format: Symposium – 90 minutes

Schedule:

Introduction and Framing of the Problem:

Chair: Professor Daniel Wikler, PhD

Department of Global Health and Population
Harvard School of Public Health

Paper Presentations:

1. Universal Health Coverage as an Ethical Initiative of the WHO

Dr. Andreas Reis, MD MPH

Technical Officer for Ethics and Health

World Health Organization

2. Making fair choices on the path to universal health coverage: Key Messages

Dr. Trygve Ottersen, PhD, MD; and Professor Ole Frithjof Norheim, PhD, MD

Department of Global Public Health and Primary Health Care

University of Bergen

3. The concept of 'Universality' in Universal Health Coverage

Professor Daniel Wikler, PhD

Department of Global Health and Population

Harvard School of Public Health, USA

4. Latin American Experiences with Universal Health Coverage and the Right to Health

Dr. Carla Saenz, PhD

Bioethics Regional Advisor, Pan American Health Organization

5. Accelerating Equity through Universal Health Coverage in East Asia

Dr. Calvin WL Ho, JSD, MSc

Assistant Professor, Centre for Biomedical Ethics,

Yong Loo Lin School of Medicine, National University of Singapore;

Research Associate, Ethox Centre, University of Oxford, UK

Total allocated time for all presentations will be 65 minutes, and another 25 minutes will be reserved for general discussion involving all symposium attendees.

Abstract number: 34

ID: 442

Symposium

Consent and assent in paediatric research: global issues

Phaik Yeong Cheah, Mark Sheehan, Paul Baines, Maureen Kelley

Thailand, Mahidol University

Many international guidelines require that children provide assent for participation in medical research in addition to their parent's consent. However, whilst assent usually indicates the importance of seeking agreement from someone who is not competent to provide consent, the concept lacks clarity resulting in a great deal of uncertainty and disagreement about its definition and application. In this symposium we propose to outline the current international debate surrounding the roles of paediatric consent and assent, and explore the important challenges arising when involving children in the decision making process. Of central importance to this debate is the claim that children who are able to understand and retain relevant information, weigh this information in making a mature judgment, come to a decision and communicate the decision, should be able to consent for themselves regardless of their age. Two proposals might follow from the acceptance of this claim: (1) where the decision about whether to participate in a study is of comparable complexity to the decisions the child is used to making in other aspects of his or her life, it should be made by the child; and (2) in the case of children who are judged to lack this level of competence, assent should be sought from the child in addition to parental consent. Assent is here defined as involving the child to the extent compatible with his or her maturity as well as with cultural norms and not as obtaining the child's permission to proceed. These proposals will be discussed in the context of seeking consent and assent to research in low-income settings where there are differences in childhood responsibilities, literacy levels and parenting norms. The discussion will also explore some of the practical challenges, counter arguments and safeguards from abuse that should be in place before implementing these proposals.

For this symposium a panel to be chaired by Professor Michael Parker (University of Oxford, UK) will be convened. There will be four 15 minute presentations:

(1) Mark Sheehan, University of Oxford, UK: Justifying Assent to Research

(2) Paul Baines, Alder Hey Hospital, UK: Assent has not yet been coherently formulated, but even if it were, it would not be the right thing to do

(3) Maureen Kelley, University of Washington, US: Orphans and vulnerable children in research: Prioritizing support over assent

(4) Phaik Yeong Cheah, Mahidol University, Thailand: Assent and consent in paediatric research-challenges in low-income settings

These will be followed by a 30 minute interactive

Abstract number: 35

ID: 447

Symposium

From Bioethics to Bioart: The Question About the Limits

Ingeborg Reichle

Mexico, National Autonomous University of Mexico

Chair: Prof. Dr. María Antonia González Valerio (National Autonomous University of Mexico, Mexico City, Mexico) and PD Dr. Ingeborg Reichle (Humboldt University, Berlin, Germany)

Date and Time: Thursday, June 26, 12.15–13.45 (Panel I), 18.15–19.45 (Panel II)

Venue: Hotel Hilton Reforma, Av. Juarez #70, Colonia Centro, Mexico City, Distrito Federal, 06010, Mexico, Tel.: 52-55-5130-5300

From a philosophical point of view a limit is that which enables something to exist, for an entity can only exist — and develop and evolve — within certain boundaries. The limits, then, are an ontological matter that allows us to think in terms of shapes and figures, morphologies, transformations, and even names.

Life is something that comes into being only in the presence of certain limits or constraints, regardless of their plasticity and ever changing capacity. The fragility and the power of life lie within these limits, boundaries, and frontiers. However, it is not only a question of biological limits: For example, within which framework is life biologically possible? It is also a question about conceptual limits, models of knowing, epistemological boundaries, and so on. Life is also a concept, a concept that has changed dramatically due to the arrival of biotechnology within the frame of technoscience. To reflect on these limits, from biology to philosophy and art (such as bioart), seeks first and foremost to propose arguments about what life is within the flexibility of the limits that we are experiencing nowadays in the realm of technoscience.

In these terms, not only science but also art has an important role, because historically the latter has been a human activity that constantly configures and refigures the limits of the sensible world. In this panel we intend to organize a debate from the viewpoint of various disciplines about life and its limits in the crossovers between bio arts, ethics, sciences, and philosophies.

Speakers:

- Brandon Ballangée (New York, United States)
- Deborah Dorotinsky (Mexico City, Mexico)
- Sebastián Lomelí (Mexico City, Mexico)
- Ingeborg Reichle (Berlin, Germany)

Program (Panel I)

Thursday, June 26, 12.15–13.45

(12.15–12.20) Introduction, María Antonia González Valerio (National Autonomous University of Mexico, Mexico City, Mexico) and Ingeborg Reichle (Humboldt University, Berlin, Germany)

(12.20–12.40) Portraiture, Limits, Returns, Deborah Dorotinsky (National Autonomous University of Mexico, Mexico City, Mexico)

(12.40–13.00) The Art, Science, and Ecological Ethics of Deformed Amphibians: A Practitioner's Perspective Brandon Ballengée (School of Visual Arts, New York, NY, USA and McGill University, Montréal, QC, Canada)

(13.00–13.20) Debating Non-normative Approaches in BioArt Practices against the Prospect of a Bioscience-based Economy, Ingeborg Reichle (Humboldt University, Berlin, Germany)

(13.20–13.40) Liminal Portraits: The Embodiment of Other Ways of Living, Sebastián Lomelí (National Autonomous University of Mexico, Mexico City, Mexico)

(13.40–13.45) Closing Remarks

Program (panel II)

Thursday, June 26, 18.15–19.45

(18.15–18.20) Introduction, María Antonia González Valerio (National Autonomous University of Mexico, Mexico City, Mexico) and Ingeborg Reichle (Humboldt University, Berlin, Germany)

(18.20–18.45) The Freudian Psychic Apparatus: A Lifedeath Bioartifact, Rosaura Martínez (National Autonomous University of Mexico, Mexico City, Mexico)

(18.45–19.10) Bioethics or Ethics of Biotechnology? Reflecting the Limits of Evaluating Biofacts from an Ethics Perspective, Nicole C. Karafyllis (TU Braunschweig, Braunschweig, Germany)

(19.10–19.35) Teleology, Functionality, and Instrumentality in Biology: An Approach from the Artifacts and Aesthetic Ontology, María Antonia González Valerio (National Autonomous University of Mexico, Mexico City, Mexico)

(19.35–19.45) Closing Remarks

The Art, Science, and Ecological Ethics of Deformed Amphibians: A Practitioner's Perspective
Brandon Ballengée (School of Visual Arts, New York, NY, USA and McGill University, Montréal, QC, Canada)

Hind limb deformities (sometimes called "malformations") in natural populations of amphibians have been an important environmental issue for several decades. The most commonly reported abnormalities in North America, Europe, and Australia are those featuring missing, partial, or truncated hind limbs, yet specific causes for this phenomenon have remained unclear. Only recently have aquatic predators such as dragonfly nymphs (Odonata) and some fishes have been linked to tadpole injuries resulting in these types of limb abnormalities. Here I present evidence from both field and laboratory studies demonstrating that selective predation by Odonate nymphs may play a significant role in inducing limb deformities in natural populations of anuran amphibians.

Transdisciplinary art and participatory science programs were utilized during these studies to engage public volunteers (citizen scientists). Participants achieved increased awareness of amphibian conservation issues through direct participation in primary scientific studies. Art inspired from these research experiences has been exhibited internationally with the intention of furthering a message of amphibian conservation. An ecological ethical framework (derived from the ideas of John Muir, Aldo Leopold, Rachel Carson, Richard Louv, and others) underlies these combined art, science, and environmental practices, which will be discussed.

CV:

Brandon Ballengée is an artist, biologist, and conservationist; he creates transdisciplinary artworks inspired from his ecological field and laboratory research. Ballengée's art has been exhibited internationally, and in the summer of 2013 the first career survey of his work debuted at the Château de Chamarande in Essonne (France), and recently travelled to the Museum Het Domein in Sittard (Netherlands) in 2014. Recent solo exhibitions have been the Alden B. Dow Museum of Art and Science (Midland; USA: 2014); Schuylkill Center for Environmental Education (Philadelphia, USA: 2013); Ronald Feldman Fine Arts (New York City, USA: 2012); Longue Vue House and Gardens (New Orleans, USA; 2011); PAV, Centro d'Arte Contemporanea (Turin, Italy: 2010); Nowhere Gallery (Milan, Italy: 2009); Yorkshire Sculpture Park (Wakefield, England: 2008); Central Park's Arsenal Gallery (New York City, USA: 2007); Peabody Museum of Natural History (Yale University, New Haven, USA: 2007); and others. His works have been included in several international biennials and festivals including: Documenta 13 (Germany: 2012); Prospect 2 New Orleans (USA: 2011); Transmediale 11 (Germany: 2010); 3rd Moscow Biennale (Russia: 2009); Biennale for Electronic Arts Perth (Australia: 2007); Venice Biennale (Italy: 2005); Geumgang Nature Art Biennale (South Korea: 2004); and others. In 2011 he was awarded a conservation leadership fellowship from the National Audubon Society's TogetherGreen Program (USA). He is currently a professor at the School of Visual Art in New York, NY, and a Visiting Scientist at McGill University in Montréal, Quebec.

Portraiture, Limits, Returns

Deborah Dorotinsky (Instituto de Investigaciones Estéticas, National Autonomous University of Mexico, Mexico City, Mexico)

Historically, one of portraiture's central tasks has been the representation of the alleged identity of the model. Within nineteenth-century anthropological practices, and even more so after the invention of photography (1839), the anthropometric and ethnographic portrait not only became "research data" but also served to establish the moral, social, and biological worth of ethnic populations. Identification photography thus served a purpose in both defining types of subjects, and literally subjecting populations to different power/knowledge regimes.

The case study I will approach here is a photographic series, Genetic self-portrait created by South African artist Gary Schneider between 1997 and 1998. In this series, Schneider presents us with close-ups of his body made with different visualization techniques used in laboratories, but printed using antique photographic techniques. It would seem that the artist abandons the tradition of portraiture as conceived in art historical terms by presenting us with microscopic parts of his own body: a sperm, a hair follicle, a mitochondrion, intestinal flora – all of them printed in large format and installed in New York's Center for Creative Photography.

This paper will explore how portraiture and self-portraits operate as devices that explore the limits of representation of subjects by making use of historical photographic techniques. I am particularly interested in pinpointing boundaries in self-portraiture figuration processes as well as the return to or revival of historic or antique photographic techniques as strategies for making scientific images "artistic" while at the same time contesting the ethical scope of identification images. Since the nineteenth century, identification photographs have played an instrumental role in law enforcement, medicine, and schooling. They served to establish identifiable images of normality and deviation, health and illness, civility, and barbarity. They were part of eugenic approaches and biotypes. In using historical processes to print laboratory images, does Schneider evade the negative ethical connotations ascribed to identification photographs? Does he make these issues more salient and thus puts forward a critique of these images, which according to John Tagg bear "the burden of representation"? How do these historic photographic printing techniques present us with a paradox? What are the new premises that images like Schneider's allow us to imagine for the problematic representation of human diversity? These are some of the questions this paper will attempt to address.

CV:

Deborah Dorotinsky is an anthropologist, who turned to art history. She is chair of the Graduate Art History program at the National Autonomous University of Mexico (UNAM) since 2011, and full time researcher at Instituto de Investigaciones Estéticas in UNAM since 2004. She holds an MA and PhD in art history from UNAM and a BA in cultural anthropology from UC Berkeley. Her research

centers on issues involving racism and gender constructions. She has dealt with the photographic representation of indigenous peoples of Mexico and the construction of gender in Mexican visual culture between 1900 and 1940. She has published extensively on the history of Mexican Photography in the journals *Luna Córnea* and *Alquimia*. Her book, *Viaje de sombras. Fotografías del Desierto de la Soledad y los indios lacandones en los años cuarenta*, 2013, (*Voyage of shadows. Photographs of the Desierto de la Soledad and the Lacandon Indians in the 1940s*) traces the visual and conceptual genealogy of the photographic representation of both the Lacandon rainforest and its inhabitants, the Lacandon Indians, as seen since the nineteenth century to the 1940s to unravel how this natural area and its inhabitants were construed as the zero degree of civilization in Mexican territories. She is a member of the Arte+Ciencia research group and has participated in the art collective BIOS Ex machinA and its first bioart exhibition, *Sin origen/Sin semilla* in 2012. She is a partner in the Getty Foundation project, "Unfolding Art Histories in Latin America, the long 19th century," a joint venture with Universidad Estadual do Rio de Janeiro, Brazil, Universidad Nacional San Martín in Argentina, and UNAM in Mexico.

Teleology, Functionality, and Instrumentality in Biology: An Approach from the Artifacts and Aesthetic Ontology

María Antonia González Valerio (Faculty of Philosophy and Literature, National Autonomous University of Mexico, Mexico City, Mexico)

Epistemological models in contemporary biology tend to criticize teleological explanations, since, in general, it is understood that teleology belongs to a worldview where the cosmos has a purpose. Taking the physics paradigms as granted, where explanations through necessary and sufficient conditions are the basis, biology discusses the pertinence of functionality as a non-teleological explanation model – or at least allegedly.

It is said, then, that functionality is different from teleology, and therefore many explanations in biology are built through functions and functionality, from genetics to ecology. Nevertheless, it is necessary to at least distinguish between functionality in ontological terms, and in operational terms. If it is understood in ontological terms, and then functionality is used to explain the existence of something, the idea of purpose usually appears. Teleology and ontological functionality have to deal with the idea of purpose, whether it is an immanent or transcendent one.

My contention here is that rethinking teleology, functionality, and instrumentality from the artifacts, especially the artwork, provides us with different arguments to understand the idea of purpose and functionality.

Purpose can be thought of without the notion of an ending and without chronological organizations; it can be understood from the perspective of limits, posited as that ontological condition from whence something comes to be. Art is a producer of these limits. But life is also a producer. Art and life can only exist within these limits, which are flexible and in a state of constant change. These limits are also purposiveness, and within them life and death come to be. If functionality is an important model to understand biological processes, it is also because death, non-being, ceasing to be, are determinants of life. If physics can operate with epistemological models where functionality and purposiveness are out of the frame, it is because its limits do not include death and conclusion of a life term.

CV:

María Antonia González Valerio is a philosopher working in the fields of aesthetics and ontology, with a focus on biotechnologies and the arts. She is full professor at the Faculty of Philosophy, National Autonomous University of Mexico (UNAM). She is the author of two books: *Un tratado de ficción. Ontología de la mimesis* (Herder, 2010) and *El arte develado* (Herder, 2005). She is co-editor of five books, the most recent is: *Prós Bion: Reflexiones naturales desde el arte, la ciencia y la filosofía* (UNAM, 2013). She is the head of the interdisciplinary research group Art+Science, based at the UNAM, and the coordinator of the arts collective BIOS Ex machinA (workshop for the fabrication of the human and the non-human). In 2012 she curated the bioart exhibition *Sin origen/Sin semilla* (Without origin/Seedless) at the Museo Universitario de Ciencias y Artes (MUCA) Campus Roma and Museo Universitario Arte Contemporáneo (MUAC).

Bioethics or Ethics of Biotechnology? Reflecting the Limits of Evaluating Biofacts from an Ethics Perspective

Nicole C. Karafyllis (TU Braunschweig, Braunschweig, Germany)

The presentation will emphasize the normative clashes arising in the intersection of application of two forms of "applied ethics": a) bioethics and b) ethics of technology. As will be outlined, both evaluative forms and areas of applied ethics rely on different normative fundaments with regard

to entities and modes of praxis. As a consequence, many products of transgenic Bioart remain in a no-man's land of moral judgement. Whereas the demand for an "ethics of art" has already been announced by ethicists, I will argue for an "ethics of biotechnology", helping to overcome the limits of the above mentioned forms of applied ethics a) and b).

The classical realms of artefacts are technology and the arts, in the last decades challenged by the idea of biofacts: living artefacts. When we look at biotechnologically made entities, we get not inspired to ask "What are they?", but: "What are they good for?" Artefacts in technology have to function according to a specific purpose. "Function" and "purpose" can be seen different in the arts which, per a common definition, do not serve utility. There, the mediality of the artefact shows when the artefact irritates. This special form of drama that the arts have a right to establish will seriously be challenged by classical bioethical approaches. Therefore, we might look at the alternative approach of ethics of technology, as both technology and the arts aim to embody emancipative potential and deal with irritations.

CV:

Nicole Karafyllis is a trained philosopher and biologist, and since 2010 chair of the department of philosophy at Technische Universität Braunschweig (Germany). 2008-2010 she held a full professorship in philosophy at the United Arab Emirates University in Abu Dhabi (UAE), followed by a visiting professorship on Cultural Philosophy of Science 2007 at the University of Vienna (Austria). Her habilitation in 2006 dealt with the phenomenology of growth. Karafyllis main areas of research are: philosophy of science and technology, biotechnologies and the arts, philosophy of culture and intercultural exchange. Selected publications: N. C. Karafyllis: Biologisch, Natürlich, Nachhaltig. Philosophische Aspekte des Naturzugangs im 21. Jahrhundert. Tübingen: Francke 2001 (in German). N. C. Karafyllis/G. Ulshöfer (Ed.): Sexualized Brains. Scientific Modeling of Emotional Intelligence from a Cultural Perspective. Cambridge, MA: MIT Press 2008; Putzen als Passion. Berlin: Kadmos 2013.

Liminal Portraits: The Embodiment of Other Ways of Living

Sebastián Lomelí (National Autonomous University of Mexico, Mexico City, Mexico)

Through the concept of "liminal portraits" I analyze the political and existential possibilities of the work of two artists: Félix González-Torres and Marta de Menezes. Their artworks ask the spectators to recognize themselves in images, which are hardly related to them at all, but in so doing they are questioned in two specific directions. First, the pieces ask about the limits of personal identity and factual existence. Second, the embodiment of those images as (own) possible portraits reveals political programs concerning the definition of the body, health, and death.

CV:

Sebastián Lomelí Bravo is a member of the research group Arte+Ciencia and of the art collective BIOS Ex machinA. He is currently a PhD student at the UNAM (Mexico), and his doctoral work explores the idea of production as taking place in contemporary and high-tech art practices. His general research interests are ontology and aesthetics. He has coordinated two volumes on the philosophy of María Zambrano.

The Freudian Psychic Apparatus: A Lifedeath Bioartifact

Rosaura Martínez (School of Philosophy, National Autonomous University of Mexico, Mexico City, Mexico)

The Freudian psychic apparatus is a bioartifact, that is, a machine that mediates between life as tension and death as the complete discharge of it. This apparatus sets life in motion in a hyperbolic fashion, but as a detour towards death. For Freud, life in historical and evolutionary terms is a burden that has to be lived off. The paradoxical and speculative relation between Eros and Thanatos is seen as the origin of the psyche as a complex mechanism of negotiation between life and death. Thus, the psyche as an apparatus is designed in order to discharge tension (life), but at the same time it also obeys another tendency, which Freud calls the constancy principle. This principle creates a reserve of energy in the form of memory that resists a shortcut, an immediate or suicidal death. Memory is that which saves a deferred discharge and the way through which upcoming tensions discharge. This sort of archive constitutes the protection against death. In this sense, the death drive is, on one hand, that which enlivens the need to create a reserve and, on the other and at the same time, that which is directed at destroying any archive. This means that the channels for tension release can be erotic and life affirmative. The Freudian psychic apparatus turns out to be a lifedeath apparatus or an apparatus of the "good livingdying."

CV:

Rosaura Martínez is a trained philosopher with a focus on Freudian psychoanalysis. She is full time associate professor of philosophy at the School of Philosophy, National Autonomous University of Mexico (UNAM) and head of the research project "Philosophers after Freud" (UNAM, 2013–2016) as well as research collaborator of the project "Manipulation of living organisms. Art limits in the intertwining of sciences and technologies" (UNAM, 2011–2014). In 2012 she was a member of the artist collective BIOS Ex machinA Art exhibition Sin origen/Sin semilla at the MUCA ROMA museum, November 2012. She received her PhD in philosophy from UNAM with the dissertation Freudian Psychoanalysis: A Reading from Derrida's Notion of Writing and an MA in philosophy from The New School University in New York City with the dissertation: The Fragmented Subject of Psychoanalysis, supervised by Richard Bernstein. Selected publications: R. Martínez: Freud y Derrida: escritura y psique (Freud and Derrida: Writing and Psyche), SIGLO XXI, 2013. "The Alterability of the Memory Trace". The Psychoanalytic Review (The Official Journal of the National Psychological Association for Psychoanalysis), vol. 98, no. 4. August, 2011, pp. 531–555. "Freud y Derrida: Escritura en el aparato psíquico". Diánoia. Revista del Instituto de Investigaciones Filosóficas, UNAM y FCE, vol. 58, no. 68. May, 2012, pp. 65–79.

Debating Non-normative Approaches in BioArt Practices against the Prospect of a Bioscience-based Economy

Ingeborg Reichle (Humboldt-University, Berlin, Germany)

In the last twenty years the incorporation of live biological material, like tissue cultures, and scientific technologies, such as plant breeding and genetic engineering, into the arts went hand in hand with debates about the aesthetic value and ethical and ontological consequences of introducing cutting edge science into the arts. With the emergence of BioArt, genetic engineering became part of the art world, raising questions about the aesthetic and ethical status of manipulating living organisms in the age of technoscience. The adoption of bioscience techniques and living materials by the arts has opened up new avenues of artistic expression, and by bringing genetic engineering closer to the public through art has provoked wider reflection about the ethics of turning biology into technology.

In recent years many bioartists have challenged traditional ethics through the non-normative approaches exhibited in their art, and this has thrown open the issues involved for public debate. In my presentation I shall address the issue of whether we need to formulate normative ethical guidelines for BioArt, because BioArt appears to be gaining a voice within the public debate about the transformation of our current economy into a bioscience-based economy — a development which will affect many aspects of our lives in a major way.

CV:

Ingeborg Reichle is an art historian and cultural theorist writing on contemporary art, new technologies, and new media, with a focus on biotechnology and artificial life. 2005–2011 she held a research position at the Berlin-Brandenburg Academy of Sciences and Humanities in Berlin. She currently teaches at the Hermann von Helmholtz Centre for Cultural Techniques at the Humboldt University Berlin. In 2004 she received her Ph.D. from the Humboldt University Berlin with her dissertation Art in the Age of Technoscience: Genetic Engineering, Robotics, and Artificial Life in Contemporary Art, published 2005 in German and 2009 in English, both with Springer publishers, Vienna/New York. She completed her habilitation thesis in 2013 titled Bilderwissen – Wissensbilder. Zur Gegenwart der Epistemologie der Bilder at the Humboldt University Berlin. In 2010 she curated the bioart exhibition Jenseits des Menschen – Beyond Humans at the Berlin Medical History Museum of the Charité Hospital. Since 2000 she has been a guest lecturer at various international institutions including the School of Visual Arts, New York; the Department of Biology, Massachusetts Institute of Technology (MIT), Boston; the Life-Science Lab, German Cancer Research Center, Heidelberg; Timbusu College National University of Singapore; SymbioticA at the School of Anatomy, Physiology and Human Biology, University of Western Australia; School of Creative Media, City University of Hong Kong; Lomonosov Moscow State University.

Abstract number: 35
ID: 501
Symposium

Ética en Investigación: Vulnerabilidad y Protección

Dirce Guilhem, Carla Saenz, Estela Quiroz, Carmen Alicia Cardoso, Dirce Guilhem
Argentina, Universidad de Buenos Aires

La identificación de actores clave, que hayan tenido participación directa en cuestiones relativas a la investigación en seres humanos, permite clarificar los puntos oscuros para así llenar las lagunas que aún persisten.

El simposio constará de diversos "momentos":

- 1) Proyección de Infancia a Prueba (2010, 22 minutos). Dicho cortometraje, documental-testimonial, apela a la reflexión sobre cuáles son los límites de la investigación biomédica a través del relato de Salomón Feldberg, sobreviviente de experimentos llevados a cabo en un campo de concentración nazi.
- 2) Panel de expertas, en cuyo marco Carla Sáenz (Programa Regional de Bioética, OPS /OMS), Estela Quiroz (Profesora de la Universidad Nacional "Federico Villarreal", Lima-Perú) y Carmen Alicia Cardoso (Coordinadora de la Red de Bioética de la Universidad Nacional de Colombia) disertarán sobre el material presentado.
- 3) Discusión y debate entre integrantes del panel y participantes en el Simposio. El intercambio estará coordinada por las realizadoras del video: Patricia Sorokin y Dirce Guilhem, siendo los principales ejes de análisis el consentimiento válido, la necesidad (o no) de investigar en/con niños y niñas, los alcances del concepto "vulnerable", la protección de datos personales y las normativas existentes o ausentes, antes y ahora, aquí y allá, en materia de ética de la investigación con seres humanos.
- 4) Potencialmente (dependiendo de factores imponderables) se hará saber que está presente el Sr. Feldberg, para que quien así lo desee pueda saludarlo y/o tomarse una fotografía con él. No está contemplada la opción de que responda preguntas ya que ello podría provocarle estrés y oportunamente nos comprometimos con "Sali" y con su familia a cuidarlo tanto durante la investigación como una vez que ésta hubiera finalizado.

Mediante este tipo de estrategias se pretende contribuir a que las posturas que se adopten en el contexto de la práctica científica actual y global, garanticen la protección de los y las participantes al promover la reflexión ética y la adherencia a buenas prácticas científicas, enraizadas en el respeto por los derechos humanos.

Abstract number: 36 **PATIENT DEATH SEEN BY THE MEMBERS OF THE COMMITTEE ON BIOETHICS HOSPITALABLE,**
ID: 519 **HOSPITAL OF JUAREZ MEXICO**
Symposium **DOLORES DELGADO OCHOA, HERNÁNDEZ BERNAL CLARA ELENA, GONZÁLEZ RAMÍREZ CECILIA**
 JULIETA, TEJEDA ROMERO MÓNICA, VALLE MOLINA LEOBARDO, Octaviano Humberto Domínguez
 Márquez
 Mexico, HOSPITAL JUÁREZ DE MÉXICO

Participantes:

1. M. en C. Cecilia Julieta González Ramírez,
Profesora de la MACISA*, Vocal
2. Dr. en C. Octaviano Humberto Domínguez Márquez
Profesor de la M en C en Bioética*, Vocal
3. Dra. Mónica Tejeda Romero
Médica adscrita al Servicio de Hematología**
4. Dr. Leobardo Valle Molina**, Vocal
Médico adscrito al Servicio de Cardiología
5. Dra. Clara Elena Hernández Bernal
Médica adscrita al Servicio de Anestesiología**, Vocal
6. M. en C. María de los Dolores Delgado Ochoa
Coordinadora del Laboratorio de Histocompatibilidad**, Presidente

* Instituto Politécnico Nacional

** Hospital Juárez de México, Secretaría de Salud

Todos son integrantes del Comité Hospitalario de Bioética del Hospital Juárez de México

Cada participante contará con 10 minutos para exponer su tema.

Simposium:

Sociedad : Dilemas relacionados el final de la vida

MUERTE DEL PACIENTE VISTA POR LOS INTEGRANTES DEL COMITÉ HOSPITALARIO DE BIOÉTICA DEL HOSPITAL JUÁREZ DE MÉXICO

Para los nahuas la muerte era la degradación y la dispersión de los componentes del cuerpo humano "Onacico in nacian, in nopoliuhyia, in noxamanca, in nopoztequia" ("alcancé mi alcanzadero, mi destrucción, mi ruptura, mi fragmentación"), tanto el inicio como el fin de la vida se ven influenciados por diferentes factores, el objetivo del presente simposium es debatir las diferentes formas de vista de los integrantes del Comité Hospitalario de Bioética del Hospital Juárez de México sobre la muerte del paciente.

La muerte no sólo es un proceso personal, sino social para el hospital; tomando en cuenta que la muerte contradice su finalidad primordial: curar al enfermo, mantener con vida al paciente moribundo, ¿entonces el personal de salud fracasa cuando muere un paciente?, claro que no; también debe de ayudar a morir con dignidad al paciente

La visión de la abogada del hospital es que en México existe un ordenamiento jurídico que regula el Documento de Voluntad Anticipada (DVA), sin embargo no existe una legislación a nivel Federal, solo es aplicable a nivel local. Desde un punto de vista bioético-jurídico es importante respetar el derecho de autonomía del paciente, quien con capacidad jurídica de ejercicio y en pleno uso de sus facultades mentales puede decidir sobre su salud y muerte y esto lo realiza a través del instrumento legal de voluntad anticipada, por escrito el cual manifiesta su deseo sobre los cuidados y tratamientos médicos a seguir, siempre y cuando padezca una enfermedad terminal.

Para la socióloga la creencia de que una persona fallecida volverá a vivir o aparecer con otro cuerpo ha sobrevivido dentro de las religiones, los hindúes aluden la existencia de un alma o espíritu que viaja o aparece por distintos cuerpos, generalmente a fin de aprender en diversas vidas las lecciones que proporciona la tierra. El catolicismo habla del encuentro final con Cristo en su segunda venida; pero asegura la retribución inmediata después de la muerte como consecuencia de sus obras y de su fe. El Corán la muerte trae el alma de su cuerpo material, y luego la transfiere a un nuevo cuerpo que se convertiría en su cuerpo material por su vida en el purgatorio y la vida eterna en el más allá. La Torá habla de "vida y bondad" como una y la misma cosa, las "Aguas Vivientes" son vistas como una fuente de pureza. La muerte es la negación de la realidad Divina en todas sus manifestaciones, mientras el budismo considera un proceso completo desde la muerte hasta el siguiente nacimiento y lo esencial en sí no es la muerte sino cómo se muere, al igual que es importante cómo se vive. Desde la perspectiva bioética la muerte digna es el respeto a la autonomía de paciente conforme a su libre determinación y protege al individuo contra cualquier forma de vulneración de sus derechos. Para el paciente moribundo es importante que los familiares y el equipo tratante lo acompañe en este trance sabiendo que esta acción es desgastante pero enriquecedora, todos somos humanos y moriremos también.

PATIENT DEATH SEEN BY THE MEMBERS OF THE COMMITTEE ON BIOETHICS HOSPITAL, HOSPITAL OF JUAREZ MEXICO

For the Nahuatl death was the degradation and dispersion of the components of the human body "Onacico in nacian, in nopoliuhyia, in noxamanca, in nopoaltequia" ("alcancé mi alcancadero, mi destrucción, mi ruptura, mi fragmentación"), both beginning and the end of life are influenced by different factors , the objective of this symposium is to discuss the different ways to view the members of the Bioethics Committee of the Hospital Juarez Hospital of Mexico on death.

Death is not only a personal process , but social for the hospital , considering that death contradicts its primary purpose : to heal the sick , to keep alive the dying patient , then health personnel fails when a patient dies ? of course not , should also help the patient to die with dignity.

The vision of the hospital 's attorney that there is a law that regulates the Paper Advance Directive (DVA) in Mexico , however there is no legislation at the Federal level , it is only applicable locally. From a bioethical - legal perspective it is important to respect the right of patient autonomy, who exercise legal capacity and in full possession of his mental faculties can decide about your health and death and this is done through the legal instrument will advance , in writing which expresses its desire for the medical care and to continue as long as treatments are terminally ill .

For the sociologist the belief that a dead person live again in another body or appear survived within religions , Hindus refer the existence of a soul or spirit that travels or appears different bodies , usually in order to learn in different life lessons provided by the earth. Catholicism speaks of the final encounter with Christ in his second coming, but ensures immediate retribution after death from his works and faith . The Quran death brings the soul of his material body, and then transferred to a new body that would become his material body for his life in purgatory and eternal life in the hereafter. The Torah speaks of "life and goodness " as one and the same thing, the " Living Waters " are seen as a source of purity. Death is the negation of the Divine reality in all its manifestations, while Buddhism believes a complete process from death to birth and the following essential itself is not death but what dies, just as it is important how you live . From bioethics perspective dignified death is respect for patient autonomy as self-determination and to protect the individual against any form of violation of their rights.

For the dying patient is important that family and the treating team accompanies this trance knowing that this action is exhausting but rewarding , we are all human and we die too.

Abstract number: 37
ID: 542
Symposium

The Islamic Theory And Principles Of Ethics Within The Global Ethical Diversity
Omar Hasan Kasule, Muhammad Zuheir Alkawi
Saudi Arabia, King Fahad Medical City

This paper, using practical case studies, presents a system of ethical theories and ethical principles developed and used in South East Asia and other parts of the Muslim world over the past 17 years. A basic premise of this framework is that ethics is embraced fully within the ambit of the Law since Islamic law contains both positive law and moral law. Under Islamic law the legal and the moral are perfectly equivalent; every moral is legal and vice versa and every immoral is illegal and vice versa. The Islamic ethical theory is based on the 5 higher objectives of Islamic Law, maqasid al shari'at, and its ethical principles are derived from. For an act to be considered ethical, it must conform to or not violate one of the following 5 major purposes of the Law that aim at protecting, preserving, and promoting (i) Morality, hifdh al ddiin; (ii) Life and health, hifdh al nafs; (iii) Progeny, hifdh al nafs; (iv) Intellect, hifdh al 'aql, and (v) Resources, hifdh al maa'l. The 5 ethical principles guide decision making in cases of ethical dilemmas in which the purposes above may be apparently contradictory such as prolongation of life in the intensive care unit that is associated with unreasonable consumption of health care resources. 1. Under the principle of certainty of intention, q'a'idat al qasd, actions are judged by their inner intentions and motivations and not by their external manifestations. Under the principle of certainty, q'a'idat al yaqeen, decisions must be evidence-based. Under the principle of injury, q'a'idat al dharar, the beneficence of an action must out-weight its maleficence and if the two are of equal worth the action is not taken. Under the principle of hardship, q'a'idat al mashaqqat, legal prohibitions are temporarily set aside in order to undertake actions that will preserve life. Under the principle of custom, q'a'idat al 'aadat, existing consensus guidelines and standard operating principles should be followed because they have the force of law. Each of these principles has many sub-principles that cover the whole spectrum of ethical dilemmas. The 4 principles of Beaumont and Childress are subsumed under the Islamic principle of preventing injury. The patient has the right of autonomy because she/he has his best interests at heart and cannot willfully and knowingly take a harmful decision. The principle balances beneficence and maleficence and provides robust decision rules in cases of conflict. Assurance of justice prevents harm due to injustice. The implementation of the purposes and principles above will be illustrated by case studies.

Abstract number: 38
ID: 574
Symposium

Special Session: "El final de la vida and El testamento vital II" organized by Universidad Autonoma del Estado de México
Octavio Marquez Mendoza, Marcela Veytia Lopez, Rosalinda Guadarrama Guadarrama, Sergio Ruiz Peña, Benjamin Herreros Ruiz Valdepeñas, Elba Margarita González Fabián, Gregorio Jesús Palacios García-Cervigón, María Isabel Rivera.
Mexico, CICMED de la UAEMex, Universidad Europea de Madrid y Universidad de Santiago de Chile.

Traditionally the doctor-patient relationship by an authoritarian model that prevailed in the doctor's decision based on the principle of beneficence was governed. This model has been called patronizing. At the end of the twentieth century was changing the clinical setting, increasingly important with patients in decision-making. The ideal of this model is the deliberative relationship, through which professionals and patients are actively involved in decision making, respecting as far as possible the patient's freedom to decide. Respect for patient autonomy has been endorsed with the emergence of regulations and the document is known as a living will or advance directives. Through the figure of living will a citizen can leave writing medical care that he or she wants receive or continue with it or without it (always within of the principles of good clinical practice) when the ability to speak or communicate have been lost.

This commitment is part of the medical quality act that is expressed by means of a document that is integral to the history. As can be seen from two perspectives as a process (medical field) and as a document (legal field).

It is from this that are in place not only for speech but it has been done quite a legal exercise, to establish advance directives, which according to the Law 6 /2005 (Spain) they are defined as "the manifestation written a capable person, acting freely express instructions to be taken into account on the health care you want to receive in situations that prevent personally express their will, or the fate of his body or bodies after the death occurred".

In Mexico the level of knowledge and attitudes of patients regarding advance directives is a little-known both among medical professionals and between patients, since legislation is recent. Sánchez (2011) notes that there is no Federal law on advance directives, only the General Health Law provides this aspect, as well as some local laws (Aguascalientes, Coahuila, Mexico City, Michoacán, San Luis Potosí, State of Mexico), all between 2008-2013. Which results in legal disputes over the gap.

Thus, this symposium aims to bring the current context of advance directives in Mexico, Chile and Spain and from pouring knowledge and dialogue established paradigm to build a fortress to Iberoalatino-america community around this topic.

Key word: Advanced directives, Bioethics, Ibero-america.

Abstract number: 39
ID: 575
Symposium

Special Session: "El final de la vida and El testamento vital II" organized by Universidad Autonoma del Estado de México

Octavio Márquez Mendoza, Benjamin Herreros Ruiz Valdepeñas, Gregorio Jesús Palacios García-Cervigón, María Isabel Rivera.

Mexico, CICMED de la UAEMex, Universidad de Santiago de Chile, Universidad Europea de Madrid.

In bioethical issues, concepts always have anthropological relevance, while their definitions within the framework of knowledge technosciences available. The contributions of this claim in each historical moment be supplemented by other more about the man who articulated a philosophical rationality, but rooted in tradition, in which moral significance change concepts whose definition or redefinition arise.

Only it the reductionist points of view, the extensional definitions are necessary and useful, especially in the field of Bioethics. For that, in this symposium is obligatory take the definition of death. Death, apparently supports a simple and meaningful definition in many contexts, due to the "end of life". However, this definition is not precise enough with the extension of the concept for clinical purposes. The doctor needs many mechanisms to certify the death of a patient.

Before the beginning of the art of transplantation, the clinical definition of death was referred to the stoppage of the heart, after that scientific and technical progress and the realization that it is feasible to make the heart beat again after a cardiac arrest, now no longer speak from the heart but the brain, so that the parameters to determine the end of life change transmuting itself to the concept.

However, the definition is intended to say that what remains intentionally death is the end of life , and she has been fixed which has appealed to the time shifting of borders facilitate expansion in the new instance operational definition . The definition of " death " at the legal level , must be constructed by purely empirical features , and does not have to claim the demise of other more appropriate definitions to ethical discourse .

The essentialist definition that remains is the reference standard for the changes to be given at different levels of discourse (ethical, medical, legal) to question the concept in question. In turn, this is subject to change dependent interpretation of global worldviews and life imposed by cultural and social changes, recalling in this context that feature prominently in the scientific- technical progress and evaluative changes.

The legal standard requires that traits are expressed in operational empirical terms, the extensional definition of an operational nature (traits that refer to specific measures) play an important role at this level.

Justify the appropriateness of these features to the scientific-technical and remain in continuity with the development essentialist definition, is a task of bioethics should articulate the reciprocal influences between medical advances, ethical criteria, changes in the moral conscience and the criteria legal.

1) Speakers:

Benjamín Herreros Ruiz Valdepeñas
Gregorio Jesús Palacios García-Cervigón
María Isabel Rivera Obando
Octavio Márquez Mendoza

2-3) Schedule for the 90 minutes symposium and Topics to be addressed

- Benjamín Herreros Ruiz Valdepeñas.

20 minutes

The end of the life.

- Octavio Márquez Mendoza.

20 minutes

1. Coordinator.

The end of the life

- Gregorio Jesús Palacios García-Cervigón.

20 minutes

The end of the life.

- María Isabel Rivera Ovando.
- 20 minutes
- The end of the life.
- All of them 10 minutes
- 4) Any other details you consider important to share with us:
Octavio Márquez Mendoza will be the coordinator of the symposium: END OF THE LIFE

Abstract number: 40
ID: 637
Symposium

Contemporary Ethical Challenges to Organ Transplantation in Asia

Leonardo de Castro, Daniel Fu-Chang TSAI, Ilhak LEE, Jacqueline CHIN, Hitoshi ARIMA, and Zohar LEDERMAN
Singapore, National University of Singapore

Notwithstanding determined efforts by international agencies and organizations to fight illicit practices and human trafficking related to organ transplantation violations of organ transplant laws and international guidelines abound. These illegal and unethical practices continue to present troubling concerns for Asian countries. New issues or recycled ones emerge after old ones are dealt and essentially remain unresolved.

This Asian Bioethics Review Symposium on Challenges to Organ Transplantation in Asia brings together panel members who have examined practices and related proposals pertaining to their respective countries. Topics covered include the use of organs from executed prisoners, the foreign travel of donor-recipient pairs (many claiming to be related either by consanguinity or emotionally) for organ transplantation, the implementation of presumed consent (or opting out systems) in Japan, Singapore and Israel, the use of minors as organ donors, and the need to regulate cross-border tissue transplantation.

Confirmed speakers are Daniel Fu-Chang Tsai (Taiwan), Ilhak Lee (Korea), Jacqueline Chin (Singapore), Zohar Lederman (Singapore and Israel) and Hitoshi Arima (Japan). The Panel will be chaired by Leonardo de Castro (Singapore and the Philippines), who will introduce the symposium. Questions that the speakers are expected to address include: Are national regulations and international guidelines adequately informed by cultural and economic realities in their implementation? Are current regulations and legislation firmly rooted in sound ethical considerations? How are these ethical considerations facing up to current practical challenges? Is there a need to make policy adjustments on the basis of the challenges to effective implementation?

Contemporary Ethical Challenges to Organ Transplantation in Asia: Experiences and efforts from Taiwan

Daniel Fu-Chang Tsai
National Taiwan University

In this presentation the speaker will address three current ethical challenges and progresses in Taiwan. The using of executed prisoners as organ donors was a criticized and decreased practice in the last 2 decades. In 2012 the Taiwan Transplantation Society re-announced its position of "not encouraging, not supporting and not participating" any transplantation involving executed prisoners. Although 3 death row inmates expressed their wishes for organ donation, none of their organs were accepted for transplantation in April 2013. Transplantation tourism from Taiwan to China has been a controversial and debated practice for more than a decade too. The Medical Ethics Committee of the Ministry of Health has announced an ethical guideline to discourage such practice in 2006 and later requested hospital reporting system on overseas transplantation cases for better monitoring. Efforts to illegalize transplant tourism have been made and are not yet successful. Although an opt-out system was introduced in Singapore, Japan and Israel, according to the author's survey, the general public and medical professionals do not seem to support such policy change so far in Taiwan.

Presumed Consent for Organ Donation: Two Perspectives from Two Corners of Asia

Zohar Lederman
Centre for Biomedical Ethics, Yong Loo Lin School of Medicine, National University of Singapore

Whether to allow a system of presumed consent for organ donation remains a hot topic in the bioethical literature. Current evidence suggests that such a system increases donation rates, even when controlling for other factors such as organizational infrastructure and medical considerations. However, opponents still hold their ground, either challenging the evidence, or doubting the philosophical validity of presuming consent. This presentation aims to critically review the organ donation scheme in two developed countries in Asia that share much in common: Singapore and

Israel. Through the use of case studies, an overview of the current state of affairs in both countries is provided. A comparative analysis offers plausible explanations for the differing schemes. Lastly, the presentation argues that Israel- and other countries which do not implement presumed consent for that matter- should adopt the donation scheme that exists in Singapore.

Emerging international transplant medicine: critical agendas for bioethics

Jacqueline Chin

Centre for Biomedical Ethics, Yong Loo Lin School of Medicine, National University of Singapore

This presentation takes off from a study of cross-border transplant issues (Chin, AJOT, 2012) that highlights the following risks arising from cross-border organ transplantation: (1) inadequate national and global responses to health needs, (2) the market's threat to the integrity of healthcare systems, (3) the negative impact on medical professionalism and social justice, and (4) unchecked expansion of living organ donation at the expense of efforts to rely more on national deceased donor transplant systems. Recommendations suggested for consideration include (1) promo on of standards of practice and governance for international transplant medicine, (2) refinement of regulatory systems targeting coercive practices and regulating medical tourism brokerages, (3) improved training for regulatory gatekeepers (e.g. Transplant Ethics Committees), (4) articulating high standards of medical professionalism in international transplant medicine, and (5) strengthening efforts to encourage deceased donor transplantation globally.

The Japanese organ transplantation law: presumed consent and minor organ donation

Hitoshi Arima

Yokohama City University, Japan

The main focus of the presentation will be the 2009 revision of the country's organ transplantation law, which has led to a large increase of the number of transplantable organs after its implementation. The new law maintains that organs may be procured from brain-dead persons of all ages (including infants and newborns) provided that (i) they had not explicitly refused donation in advance and (ii) their families provide consent. Additionally, the donors can now give priority to their family members for receiving organs. Moral concerns raised over these changes will be examined. The presentation will also touch upon two organ trafficking incidences that recently occurred inside Japan.

Human Tissue Transplantation in Korea: ethical and policy issues

Ilhak Lee, MD, PhD.

Asian Institute for Bioethics and Health Law, College of Medicine, Yonsei University, Seoul, Korea

Increasing demand for transplantable human tissues raises ethical concerns including the possible exploitation of vulnerable social groups and the consequential commodification of human biological materials. This presentation examines Korean legislation on human tissue banks to clarify the nature and legal understanding of human tissue transplantation and identify relevant characteristics that may be important for moral and policy deliberation. Korea's 'Safety, Management, etc. Of Human Tissue Act' (2011) provides standards for human tissue banks and procedures of human tissue donation while recognizing the principle of 'non-commercialization'. Among the questions to be considered are: 'Is the 'dead donor rule' with family consent still legitimately applied to donating human tissue?' and 'Do we need public tissue banks to ensure safety and fair distribution?'

Abstract number: 41

ID: 681

Symposium

Bioethics and Indigenous Peoples: Public Health and Peace

Darryl Macer, Alireza Bagheri, Martha Marcela Rodriguez Alanis

United States, American University of Sovereign Nations (AUSN),

The gap in life expectancy between Indigenous Peoples and general populations ranges from one to three decades, which illustrates the ethical problems in the whole governance systems that most countries have. This symposium argues that there is an overwhelming need to preserve the culture, traditions, health, welfare, and rights of Indigenous Populations throughout the globe. Indeed, health and public health are undisputedly foundational pillars of any sustainable community, society or nation and serve as positive attributes of peace. In order for us to sustain communities and nations, peace, well-being, and maintain respect and understanding for tradition and culture of Indigenous Populations – accordingly we must have a sustainable educational system which promotes education in decision making, medicine and public health.

The panel will compare efforts being made in Asia, the Pacific, and the Americas through efforts of the Fulbright Academy of Law, Peace and Public Health (www.FulbrightAcademyLaw.org; Washington, D.C.). Critical research and analysis was conducted with respect to global public health; the ideals of the Fulbright Program; and the covenants of the Preamble to the Constitution of the World Health Organization, and the UNESCO Declaration on Bioethics and Human Rights.

For instance, striking global public health data concerning the burden of disease and global death rates related to communicable and infectious diseases, cardiovascular diseases, cancer, and diabetes; the health of populations and the increasing of international epidemics; the increasing incidence of natural disasters, complex humanitarian emergencies, refugees and internally displaced persons; the devastating persistence of enormous disparity in healthcare outcomes with respect to global health indicators and basic provisions of and access to medical care between Native American indigenous peoples and non-Native Americans; and the growing disparity in healthcare access and health care, both nationally and internationally, were identified, both over the course of the past decade and as currently exist. The identification and understanding of this global health data formed the foundation of our moral imperative to act and formulate what we believe is a necessary remedy.

Methodology of the Symposium

Following presentations by the speakers there will be invited input from the audience with their experience, and the willingness to consider establishing a network of researchers to further elaborate these issues with concrete case studies in the future. Participants will be urged to comment on actions, whether successes or failures, rather than simply theory or description of the basic facts.

Speakers

Darryl Macer, PhD HonD (and also Chair of the Symposium)

Director, Institute for Indigenous Peoples and Global Studies; Provost, American University of Sovereign Nations, 8800 East Chaparral Road, Suite 250, Scottsdale, Arizona, 85250 USA;

Secretary, Asian Bioethics Association; Director, Eubios Ethics Institute, Thailand

Thomas A. Gionis, MD JD MPH MBA MHA LLM FICS FCLM

President & Chairman of the Board, Fulbright Academy of Law, Peace and Public Health; President, American University of Sovereign Nations, 8800 East Chaparral Road, Suite 250, Scottsdale, Arizona, 85250 USA

Jasdev Rai, MD

Chair, Sikh Human Rights Group, Southall, UK

Abstract number: 42
ID: 703
Symposium

Analysis of the Inter-American Court of Human Rights ruling on the case of Artavia Murillo et al. ("In Vitro Fertilization") vs. Costa Rica
Manuel Ramos-Kuri, Dr. José Antonio Sánchez Barroso, Martha Tarasco.
Mexico, Centro de Investigación Social Avanzada

Summary: The rulings made by international human rights courts are key elements on the protection and advancement of human rights in a globalized world. The decisions made by the Inter-American Court of Human Rights (IACtHR) are valid throughout the Americas, but only for those countries that have signed and ratified the American Convention on Human Rights.

On November 28th 2012, the IACtHR issued a controversial resolution against Costa Rica in the case Artavia Murillo et al. ("In vitro fertilization") v. Costa Rica. The IACtHR resolution obliged the Costa Rica government to lift the ban on the in vitro fertilization (IVF) technique that had been established in the year 2000 for all private and public clinics. Furthermore, it established that the government should implement the IVF technique within its Social Security System and pay a 25,000 dollars compensation to each injured couple.

The Court's decision has been questioned, among other reasons, because of the lack of scientific basis in the field of embryology.

Since it is a judicial last resort for the parties involved, the Court's decision admits no appeal, and it is now being used as a relevant argument in the discussion of legislative problems related to the topic of the beginning of life throughout Latin America.

This panel will debate the scope of the decision, its legal and scientific mistakes and the possible lack of impartiality on behalf of the Court.

In order to reach a broad vision of the topic, the members of the panel will include a researcher that supports the decision, one that will conduct an analysis from the perspective of human embryology, and one that challenges it from a legal point of view.

The schedule is as follow:

Titer:

Analysis of the case: In Vitro Fertilization vs. Costa Rica by the Inter-American Court of Human Rights

Speakers:

Dr. José Antonio Sánchez Barroso,(2)

Martha Tarasco (3).

Dr. Manuel Ramos-Kuri,

Methodology of the panel:

25 minutes for each individual presentation, and

15 minutes at the end of presentations for questions-answers.

Subtopics (if needed):

José A. Sánchez Barroso. Human Rights and the Decision of the Court

Héctor A. Mendoza. Juridical Analysis of the Case

Manuel Ramos-Kuri: Embriological Defects

Abstract number: 43 Construction of knowledge in Bioethics

ID: 748 J. Alberto Campos.

Symposium Mexico, UNAM

I PRIMERA PARTE. MODERADOR: Carlos Viesca T.

I 1

León Olivé Morett.

México.

Instituto de Investigaciones Filosóficas, UNAM, México.

* Title of the presentation:

Bioethics and epistemology.

Bioética y epistemología.

* Name of the author: LEÓN

* Last name: OLIVÉ

* Institution: Instituto de Investigaciones Filosóficas, UNAM.

* Full Address: Circuito Mario de la Cueva s/n ciudad universitaria. MÉXICO, D.F.

* Country: MEXICO

* Telephone 55 56227200

Country-State code: 52

* E-mail: olive@unam.mx

Type of participation: Symposium

* Key Word 1: bioethics

* Key Word 2: epistemology

* Key Word 3: social practices

Mini Abstract:

Bioethics is conceived, against many conceptions, as the analysis of the social practices that are relevant for the phenomenon of life in our planet. This includes not only biomedical practices, but all concerned with the preservation of life: agricultural practices, environmental ones. etc. Therefore the concept of social practice is elucidated.

I 2

Fernando Lolas Stepke.

Chile.

Centro Interdisciplinario de Estudios en Bioética, Universidad de Chile. * Title of the presentation: Epistemic levels and interstitial knowledge: bioethics and its vicissitudes.

Niveles epistemológicos y conocimiento intersticial: de la bioética y sus avatares.

Name of the author: Fernando

* Last name: Lolas Stepke

* Institution: Centro Interdisciplinario de Estudios en Bioética, Universidad de Chile

* Full Address: Diagonal Paraguay 265 - Oficina 806

Santiago de Chile

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* Telephone: 229 78 22 74 / 229 7825 39

Country-State code: 56

* E-mail: flolas@u.uchile.cl

Type of participation: Symposium

* Key Word 1:

* Key Word 2:

* Key Word 3:

Mini Abstract:

After defining epistemological levels such as data, information, knowledge, wisdom, and stressing their place in established disciplines such as speech or professions, bioethical knowledge is proposed as "interstitial", "between" discourses bound by social practices. This laxity of bioethical discourse should be analyzed to consolidate the discipline and to establish bioethics as a social practice.

I 3

J. Alberto Campos.
México.

Programa de Maestría y Doctorado en Ciencias Médicas, Odontológicas y de la Salud, Facultad de Medicina, UNAM, México. * Title of the presentation:

Models as knowledge construction tools in bioethics.

Modelos como herramientas de construcción de conocimiento en Bioética.

* Name of the author: J. Alberto

* Last name: Campos

* Institution: Programa de Maestría y Doctorado en Ciencias Médicas, Odontológicas y de la Salud, UNAM, México.

* Full Address: Unidad de Posgrado, Edificio A Primer piso.

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Country-State code: 52

* E-mail: alberto_campos@hotmail.com

Type of participation: Symposium

* Key Word 1: models

* Key Word 2: bioethics

* Key Word 3: epistemology

Mini Abstract:

In spite of their explanatory power, the laws of science do not describe reality but idealized objects in models that allow us to make inferences. Close ethical systems establish general laws; they are thus incomplete and inadequate for specific situations. It might be possible to model flexible strategies for assessing phenomena in bioethics.

II SEGUNDA PARTE. MODERADOR: J. Alberto Campos, Javier Luna Orosco, Javier Sábada, Carlos Viesca Treviño

II 1

Javier Luna Orosco.
Bolivia.

Academia Boliviana de Historia de la Medicina. * Title of the presentation:

Rescue of Latin American thought in the interest of building a bioethics of its own.

Rescate del pensamiento latinoamericano en aras de la construcción de una bioética propia.

* Name of the author: Javier

* Last name: Luna Orosco

* Institution: Academia Boliviana de Historia de la Medicina.

* Full Address:

* Country: Bolivia

* Telephone:

Country-State code:

* E-mail:

Type of participation: Symposium

* Key Word 1: bioethics

* Key Word 2: social determinants

* Key Word 3 Latin America

Mini Abstract:

Being bioethics an applied ethics, its fields of action and relationship to other disciplines are beyond biology, with philosophical, doctrinal, cultural, social, political, and economic determinants. The challenge remains to recognize Latin American bioethics in the international context, through its intellectuals, Alberdi, Bunge, Freire, Henríquez Ureña, Vasconcelos, Zea, Uslar Prieto and others.

II 2

Carlos Viesca T.
México.

Programa de Maestría y Doctorado en Ciencias Médicas, Odontológicas y de la Salud, UNAM, México. * Title of the presentation:

Bioethical knowledge and cultural plurality.

Conocimiento bioético y pluralidad cultural.

* Name of the author: Carlos

* Last name: Viesca T.

* Institution: Programa de Maestría y Doctorado en Ciencias Médicas, Odontológicas y de la Salud, UNAM, México.

* Full Address: Unidad de Posgrado, Edificio A Primer piso.

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* Telephone: 55 5623 3153
Country-State code: 52
* E-mail: carlosviesca@yahoo.com
Type of participation: Symposium
* Key Word 1: bioethical systems
* Key Word 2: historical traditions
* Key Word 3: plurality

Mini Abstract:

The questioning of right and wrong of health care generates tensions derived from the power to do and what should not be done. From a phenomenological record a critical analytical corpus is constructed to establish criteria of applicability. Historical and current cultural traditions compel us to think a plurality of bioethical systems.

II 3

Ambrosio Velasco.

México.

Instituto de Investigaciones Filosóficas, UNAM, México. * Title of the presentation:
Equidad ética y epistémica.

Ethical and epistemic equity.

* Name of the author: Ambrosio

* Last name: Velasco

* Institution: Instituto de Investigaciones Filosóficas, UNAM.

* Full Address: Circuito Mario de la Cueva s/n ciudad universitaria. MÉXICO, D.F.

* Country: MEXICO

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Type of participation: Symposium

* Key Word 1: Equity

* Key Word 2: Diversity

* Key Word 3: Culture

Mini Abstract:

The purpose of the paper is to defend epistemic and ethical equity in the context of cultural diversity. Equity is not arithmetic equivalence, but positive consideration of all voices and opinions concerning a particular issue or problem. The kind of rational argument that is appropriate for epistemic and ethical equity is rhetoric and dialectics and the resolution of disputes is more akin to phronesis or practical reason.

Abstract number: 43

ID: 758

Symposium

Bioethics and Security of the Patient Wellbeing and Human Rights

Enrique Mendoza Carrera,

Mexico, Mexican Academy of Surgery

Patient safety is the basis of the quality of care in hospitals. Responsibilities include medical and structural problems of the system, such as hand washing, medication administration i. v., properly applied drugs, appropriate surgical procedures, care and protection of patients, recording of adverse events-planning, coordination of hospital events and development of medical guidelines, medical equipment supply, education, research etc..

From this perspective we see many relationships in which patient safety is to bioethics and clinical ethics and can be seen remarkably, still scarce mention of these disciplines in the literature, despite the fact that patient safety has been seen as an essential element in the international and national policy there we took the opportunity to pose in this work again and depth of ethical and bioethical elements of patient safety situation of interest, both because of its complexity in the intention of give original ideas, as challenging in its conceptualization and feasibility.

With this in mind, knowing human behavior in which the errors are frequent, it seems obvious that we should learn from mistakes, so we must learn and understand these situations that give rise to these errors. These results should give a collective understanding where problems could be avoided and not do so, the thought of actually located "not just for the provision of health care institutions." Bioethics is precisely one of the most obvious areas today due to criticism of the protest rationalities of ethics in the light of developments and dilemmas in scientific knowledge and technology, but mostly represents an alternative policy, social-educational, which requires a continuous response to critical reason, vital essence in modern and post-modern in the times we live. With this view, we can argue that bioethics is a new discipline and a true emblem of our era. No other discipline that reflects more accurately our contemporary time, involving many dilemmas generated by research and medical applications, which involves basic problems of life and death involving questions and answers because the arguments of the bioethical currents current.

Given the above reasons, this symposium to patient safety, is the pursuit of human rights and welfare in health fair in which bioethics of care applies, the precautionary principle of risk-benefit trying to

prevent medical errors pandemic, considering the autonomy, integrity, vulnerability and dignity of the patient, to be essential factors in the bioethical thought, considering ethics in the practice of medicine today can become an ethic of responsibility, highlighting the medical humanism that many doctors do not know.

Patient safety requires daily monitoring multiple processes to correct health and needs, therefore, a huge teamwork within health institutions and a correspondence between health personnel, both individually and in groups, in the development of institutional ethics as clinical decisions corresponding to a more committed and specialized patient safety, medical care which requires more communication and clearly defined responsibilities and oriented realistic understanding of modern medicine requires professionals cooperation, take responsibility includes respect and dialogue with patients, respecting their needs, expectations, fears and hopes.

Participants are:

1. Dra. Cristina Caballero Velarde: President of the Mexican National Academy of Bioethics A.C. Medical specialties in Pediatrics and Pediatric Intensive Care. Master of Bioethics. Member of the Mexican Academy of Pediatrics AC Miembro founder of the Mexican Association of Pediatric Intensive Care and corresponding Certification Council. Graduate Professor at UNAM. Associate Professor of the Master of Bioethics at the University Panamericana. Presidente Hospital Bioethics Committees and Research Ethics Angeles Metropolitan Hospital. Scientific production in Pediatrics, Intensive Care and Bioethics. Four awards for clinical research.

2. Dr. Jorge Alfonso Pérez Castro y Vázquez: Coordinator Patient Safety Committee of the Mexican Academy of Surgery, AC Member of the Mexican Academy of Surgery, Medical AC specializing in General Surgery. Member of American College of Surgeons and the Mexican Association of General Surgery, Endoscopic Mexicana Mexicana Surgery and Gastroenterology. Certified by the Mexican Board of General Surgery and Gastroenterology. The Diploma Course in Teaching, (UNAM) and Senior Management of Health Services (ITAM). Medical Assistant Commissioner of the National Medical Arbitration Commission. Compiler of "Patient Safety to all" (2013). Editorial Bishop. Mexico.

3. Dr. Enrique Mendoza Carrera: Biochemist, with specialties in hematology, immunohematology, higher education, psychoanalysis and MA and Ph.D. in Philosophy. Member of the Commission on Patient Safety of the Mexican Academy of Surgery , Fellow of the Mexican Academy of Bioethics at the University La Salle Member; cash and the board of the Mexican National Academy of Bioethics, AC Member. Author of books: " Bioethics: Look at your standard medical humanities " (2007), edited by Editors Mexicanos Texts. Mexico and "Bioethics, Humanism and Psychiatric Clinic" (2011) edited by Bioquimed Laboratories. Mexico. Author of Chapter 31: " Bioethics and Patient Safety: Human Welfare Rights "of" Patient Safety to all " (2013) whose compiler is Dr. Jorge A. Pérez and Vázquez Castro. Editorial Bishop. Mexico. Member of the Bioethics Committee of the New Sanatorium Hospital Durango. Chair in Bioethics Advisory, Education and Health, S.C. (ABES, SC) and Chairman of the Ethics Committee in Research Ambulatory Surgery Center Medisur.

4. Probably more to confirm two participants, one from Mexico and one from Borja Institute of Bioethics
Barcelona.

Methodology:

Each participant will present his paper for 20 minutes and finally a series of questions and answers between panelists and audience will be established.

Abstract number: 44

ID: 763

Symposium

Social Determinants of Health and Research Ethics:

Challenges of an International EU-funded Research (SDH-Net)

Astrid Stuckelberger, Manuel Urbina, Lucinda Cash-Gibson, Masuma Mamdani, Elis Borde Switzerland, Institute of Global Health, Faculty of Medicine, University of Geneva

EU- FP7 Funded Collaborative Project (2011-2015)

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Masuma Mamdani, Ifakara Health Institute, P.O. Box 78373, Plot 463, Kiko Ave., Mikocheni, Dar-es-Salaam. Tanzania. Tel: +255 686 997 015, email: mmamdani@ihi.or.tz

Elis Borde, Centro de Estudos, Políticas e Informação sobre Determinantes Sociais da Saúde (CEPI-DSS), Escola Nacional de Saúde Pública (ENSP) (FIOCRUZ), Rua Leopoldo Bulhões, 1480 - Manguinhos, Rio de Janeiro. CEP: 21041-210, Tel.: (21) 2598 2492, email: borde.elis@gmail.com

Keywords: social determinants of health, research capacity building, international research ethics
Health research is carried out in increasingly complex and challenging environments with collaborations between researchers and research institutions in low, middle and high income countries (LMIC). Consequently, health research carried out without a common understanding and ethical principles may result in failing to conduct the research, mistrust, invalid data and potentially even do harm to the studied population (e.g. provoked by conflicts in the community, violations of human rights and other unintended deleterious situations).

International research has an ethical responsibility at many levels: to uphold principles of equity, to contribute to research capacity building, to strengthen health systems research in LMIC and to address relevant policies to reduce health disparities, not only through the study of the thematic itself but also through the application of ethical criteria to health research in general and to social determinants of health (SDH) research in particular. This is even more crucial if the research is carried out in LMIC by international or multi-centric teams requiring that the research be sensitive to the social, cultural, political and economic context of the country or specific communities in which the research will take place. The design of these studies should avoid any harm to the participants or any exploitation of big data and biobanks without consent of the population involved in the study. However, despite the fact that SDH is one of the six priorities of the WHO agenda for 2014-2019, no specific research ethic guidelines for research involving SDH currently exist. The current guidelines used in international health research have set ethical norms to govern research with human subjects, based mainly on the Revisions of CIOMS International Guidelines (2002) and the Revisions of Declaration of Helsinki (2000). Although the WHO systematically conducts ethical reviews for all its global research proposals, there are no specific SDH ethics guidelines, protocols or section mentioned in international research documents, management or training.

This panel will present an EU-funded SDH research project, where one of the objectives is not only to build research capacity in LMIC on SDH but to build ethics in SDH research, through the production of useful material such as guidelines, protocols and tools to implementation. Policy implications of introducing an ethical perspective in SDH in general and in research in particular will also be discussed.

The participants to this symposium will be invited to share their views and expertise and actively collaborate in elaborating the ethics dimension in SDH research.

Abstract number: 45
ID: 766

Symposium

Control: duty and virtue, nightmare and fear; security and the role of the ethics committees. A Latin-American- EU

Jim Dratwa, Inez de Beaufort, Jaime Burrows, Siobhan O'Sullivan
Bureau of European Policy Advisers

To be confirmed.

Abstract number: 46
ID: 746.

Network Iberoamerican
Symposium

Drogas de uso ritual, recreativo y de abuso I

Francisco Pellicer Graham Jorge Enrique Linares Salgado, Oscar Prospero, Bia Labate
Mexico, UNAM

To be confirmed.

Abstract number: 47
ID: 746.

Network Iberoamerican
Symposium

Drogas de uso ritual, recreativo y de abuso I

Francisco Pellicer Graham Jorge Enrique Linares Salgado, Oscar Prospero, Bia Labate
Mexico, UNAM

To be confirmed.

Oral Presentation

Oral Presentation

Abstract number: 1 Allocating limited humanitarian resources fairly: an ethical framework to assist humanitarian
ID: 2 actors in their decision-making process
oral Caroline Clarinval, Nikola Biller-Andorno
Switzerland, Institute of Biomedical Ethics

Humanitarian actors respond to natural and man-made disasters to address the needs of affected populations. Assuming we bear a moral obligation to assist the distant from death, lack of food, water, shelter and disease it is still unclear as to how the limited humanitarian aid is to be allocated fairly. International human rights laws provide a legal framework, however, the assistance humanitarian actors intend to provide may not only do good or prevent additional suffering, aid programs may very well contribute to cause unexpected harm. Parallel to the legal frameworks, humanitarian actors can eventually refer to their professional codes of conduct or to other ethical principles such as neutrality, impartiality, independence, charity and solidarity. Yet, these humanitarian principles fall short in telling humanitarian aid workers how they ought to allocate the limited humanitarian resources fairly. Furthermore, it may occur that instead of articulating the decision-making rationale of humanitarian aid responses in a structured and transparent manner, operational decisions are waved through on political grounds thereby disregarding the common ethical principles for the sake of vague political reasoning.

Hence, an ethical framework to assist humanitarian actors in their decision-making process is required, which will increase the transparency of the process. An increased transparency of the decision-making process is expected to contribute to improving the monitoring and evaluation of the impact of the action and to ultimately improve future humanitarian aid programs.

First, selected cases will illustrate the ethical challenges humanitarian actors may encounter in specific contexts. Secondly, an ethical framework will be proposed to assist humanitarian actors in their decision-making process to contribute that the distribution of limited humanitarian resources is just.

Abstract number: 2 On the Necessity of Universals in Bioethics
ID: 3 Mary C. Rawlinson,
oral United States, Stony Brook University

Frequently, criticism by Western feminist scholars of the subjugation of women in other cultures elicits charges of paternalism, imperialism, even racism. Uma Narayan reports being "lashed" as "Westernized" for her criticism of the treatment of women in India. Political leaders in other Asian or Arab countries reject criticism of limits on liberty for women or racial and ethnic minorities as an imposition of "Western" values.

In development and global health projects, a distinction between universal and local values is often invoked to justify the complicity of the project team with local structures of subjugation. For example, doctors working in rural areas frequently inform and negotiate consent only with men, though their subjects are women and children, justifying this as 'respecting local values.'

Martha Nussbaum remarks, "An international feminism that is going to have any bite quickly gets involved in making normative recommendations that cross boundaries of culture, nation, religion, race, and class." I argue that recognition of universals in bioethics is a precondition for securing in any culture and globally both individual bodily sovereignty and the solidarities necessary to health and happiness.

While Nussbaum attempts to generate a list of universal values, I argue from two universal conditions that determine human life: everyone is born of a woman and everyone must eat. The former implies an ethics of generativity requiring specific individual and collective actions and investments, in e.g. health care and education. The latter implies an ethics of interdependency, respect, and collaboration requiring specific ways of comporting ourselves in nature, with other animals, and toward those whose labor feeds us. Thinking from these universals shifts ethics and politics away from the effort to produce universal rules or figures of the human toward the universal project of remaking the material infrastructures of life to promote generativity and solidarity globally.

Abstract number: 3 ID: 9 oral	<p>Attitudes of Healthcare Providers Towards Family Presence during Resuscitation: A Cross-Cultural Comparison.</p> <p><u>Zohar Lederman,</u> Singapore, Centre for Biomedical Ethics, National University of Singapore</p>
	<p>Introduction: Various organizations have advocated for the practice of allowing family members to be present during their loved one's cardiopulmonary resuscitation (CPR). Since 1982, numerous anecdotal reports and retrospective and prospective studies have examined the risks and benefits of family presence during resuscitation (FPDR) and the attitudes of healthcare professionals towards it; the majority of these studies were conducted in the United States and published in American journals. Recently, studies have been conducted in other countries such as Israel, Italy, Singapore, etc. Some studies have compared staff's attitudes among different hospitals in the same country, but to date, no published study has used the same questionnaire to compare the attitudes of healthcare professionals in different countries.</p> <p>Objective: To offer a cross-cultural analysis of attitudes of healthcare professionals towards FPDR by comparing data from emergency departments in the U.S.A, Singapore, and Israel.</p> <p>Method: Computer based survey, translated into English and Hebrew accordingly. The survey consisted of both open and multiple-choice questions and inquired about socio-demographic data, attitudes towards FPDR and personal experience with FPDR.</p> <p>Results: Preliminary data show that healthcare professionals in the U.S.A were most tolerant towards FPDR, followed by Israel and lastly Singapore. In all countries, physicians demonstrated more negative attitudes than nurses and other members of the medical staff.</p> <p>Conclusion: Different cultures might view FPDR differently, making it more difficult to draft and implement relevant universal guidelines in hospitals worldwide. Therefore, it is recommended: first, to take into account cultural values while drafting guidelines to allow FPDR, and second, to conduct similar studies among healthcare providers, patients and families, in order to deepen our understanding of personal and cultural values which influence medical policy and practice, specifically relating to FPDR.</p>
Abstract number: 4 ID: 12 oral	<p>DESCRIPTIVE STUDY ON THE OPINION OF MEMBERS OF THE NATIONAL CRIMINAL AND CIVIL (FAMILY) COURTS IN CASES OF WITHHOLDING OR WITHDRAWING LIFE SUSTAINING TREATMENT I</p> <p><u>Maria Susana Ciruzzi, Jorge Oscar Selandari, Fernanda Ledesma, Céllica Menéndez, Hernán García Argentina, Hospital de Pediatría SAMIC Prof. Dr. Juan P. Garrahan - Observatorio de Salud Facultad de Derecho UBA</u></p>
	<p>Introduction: The technological development of the medical sciences has stated the appearance of different techniques that allow to keep biological life far beyond experience. The need to establish boundaries to protect certain rights (autonomy, dignity, quality of life), the duty to avoid bad consequences (therapeutic obstination or disianthanasia, abandonment of a person near death), and the active role that the patient and/or his/her family has in the medical relation nowadays, has made us questioned the way to deal with those conflicts in order to protect the patient. There's a ditto in Bioethics that assured that not all that is technological possible is ethical permissible, but decision making in this field has been challenging the best patient interest principle. Among those challenges, we can mention the ones related to liability, which has been intensify by the lack of legal precisions, a fact that has been very important in this subject. <i>¿At what point those fears are grounded?</i> Material and methods: Aim to this general goal, we have proposed to explore the opinion on this subject, through a semiorganized survey to judicial personnel who belong to the criminal and civil (family) competency and medical forensic members, in three particular medical situations ("no chance", "unbearable suffering" and "permanent vegetative state").Results: 28 professionals (55%) found no crime in neither of the 3 cases. 13 (25%) found the 3 cases to be a crime. 6 (12%) found one of the cases to be a crime and 4 (8%) found 2 of the 3 cases to be a crime. Conclusions: we think that fear of liability for the medical professionals at end-of-life issues is confirmed by the results of this study.</p>
Abstract number: 5 ID: 13 oral	<p>Justice and Scarcity: the Bioethical Problem of the Distribution of Health Resources</p> <p><u>María Elizabeth De los Ríos,</u> Mexico, Universidad Anáhuac México Norte</p>

There are multiple factors affecting the health of individuals and populations, health should not therefore be understood simplistically. Money is one of the factors determining people's health status, and poverty is a determining factor in the maintenance, improvement or deterioration of health. This presentation discusses the importance of creating transverse strategies that tackle the parallel causes of poverty and encourage the promotion of individual and community health.

Abstract number: 6	Bioethics Against the Current
ID: 19	<u>Daniel Piedra-Herrera,</u>
oral	Cuba, Comité Nacional Cubano de Bioética

The starting point is a review of the inconvenience, inappropriateness and unfairness of considering bioethics as a conventional discipline. A detailed account is given of the incorrectness of enclosing it within the limits of any philosophical system, isolating it from the contributions made to it by experimental science. Relevance is given to aspects of the historical context in which bioethics emerged and the fate that befell it, together with the ostracism imposed on its founder, V.R. Potter. In this regard note is taken of the linkages between genetics and thinking on complexity. This brings to light two of Potter's barely known and very rarely cited publications on the topic of cybernetics. A completely exhaustive attempt is made to explain the nexus between the recent contributions of cognitive science and a theory founded in human moral behavior that gives support to science, including neuroscience and cybernetics, without excluding the social sciences. Thus the author aims to contribute to a debate that should yield considerably valuable results.

Abstract number: 7	Quality of life related to Health: equivocal concept in a globalized world
ID: 20	<u>Gilberto Alfonso Gamboa-Bernal,</u>
oral	Colombia, Universidad de La Sabana

In life as in clinical practice, there are several ways in which it is frequent to come across the "quality of life" (QL) concept. It is important to remember how its origin is not precisely linked to healthcare sciences and that it has only been adopted and adapted for them with some consequences, not entirely harmless.

The ambiguity of the QL concept comes out of the shadows, in which it has almost always remained, when healthcare professionals have to face the problems that some of their patients have: the chronic ones or with a terminal illness, those who need palliative care, or, in the early stages of life, during the perinatal period, when there are congenital or emerging pathologies. Its effects are also seen on the changes of those that make the binomial welfare-consumption, one of their golden rules. They change not only themselves, but also their traditions, their life habits, the laws they make, their children's education, their requirements and demands that are made, etc.

This approach will attempt to remove misunderstandings of the improper use of the QL concept and to recognize life and human being's dignity, regardless of the accidents or modifiers of life itself, showing how the reality of being a person is well above the fact of being subjected to more or less relevant constraints.

In a globalized world, it is essential to remove the ambiguity of some terms so that their use promotes personal and social development and they don't become the whitened grave of the human condition, Human Rights and the humanization process to which we all will incline to.

This paper aims to provide elements to understand how it is used and how far we can arrive with an inadequate concept of HRQL; which are their limitations as well as their possibilities, and thus, to offer some alternatives that, - from Bioethics-, tend to make more applicable its use, without the danger of harming the dignity neither of those who receive healthcare services nor of those who administer them.

Abstract number: 8	Public Health and Implementation Research in latin America
ID: 35	<u>CLAUDE VERGES</u> , Florencia Luna, María Angélica Sotomayor, Irene Melamed, Liliana Siede, Nilza Diniz
oral	Panama, Latin American Network of Research Ethics Committees

Latin American research ethics has traditionally focused on classic problems and debates involved in biomedical –clinical and pharmacological research such as informed consent, double standards and obligation during and post research. However, in the last years, an increasing awareness regarding the importance of implementation and public health research for the development of feasible, cost-effective, and culturally adequate solutions to the region's most pressing health problems, has given a new impulse to this research in Latin America. Implementation research may involve clusters; informed consent may be difficult to obtain risk- benefits analyses may differ from "traditional" clinical research. Moreover, such research may be affected by the inaccuracy of data; another problem could be the internal laws in some countries because of the implementation of public insurance systems with specific required treatments. As FLACEIS is a Latin American network of research ethics committees and one of its goals is to develop capacity building in research ethics evaluation, the failures and challenges regarding implementation research are considered. This symposium proposes an analysis of the ethical problems of evaluating implementation and public health research and will consider the specific problems that its design and evaluation presents to research ethics committees in Latin America.

Main questions to be shared with the public:

1. How is implementation and public health research defined and which are the factors inhibiting its development in Latin America?
 2. Are there specific ethical concerns with health and implementation research in Latin America?
 3. What is the role of FLACEIS for research ethics committees regarding public health operational or implementation research?
 4. Since health systems are the focus of implementation research, what actions educational and research institutions need to take to build capacities in this area of research?
- Methodology: expositions, study cases and debate with the public.

Abstract number: 9 **Shared roots of oppression between species and gender**

ID: 37 Fabio Oliveira,

oral Brazil, Federal University of Rio de Janeiro

Women and animals share—to different degrees-- analogous situations of oppression. They suffer through incarceration in households controlled by masculinity which imposes itself through aggression and predatory behavior; they suffer from the systematic imposition of the logic of the hunt, in which the strongest is granted a "natural right" to oppress the weaker; and they suffer through essentialism, which holds that the physiological differences between individuals define them hierarchically and ascribe to them positions in the world as either dominant and dominated. All these elements undoubtedly contribute to the social oppression of both gender and species and, and as such may suggest a new discursive lens for gender theories. One of the major developments of in human thought is the discovery that differences in race and gender are not the result of essential biological features, but rather that identities are complex, psycho-social, relational expressions constructed through the interactions between individuals. In this paper I assert that feminist theory can question the essentialized notion of "the species," and may thereby better understand—from a more empathic posture—the relational cruelty between humans and animals.

Abstract number: 10 **Voluntariness is not a component of valid consent**

ID: 54 Michael Dunn, Dr Mark Sheehan

oral United Kingdom, University of Oxford

There is now a significant amount of empirical evidence that threats and inducements are used across clinical practice and medical research settings. The standard view presented within the field of bioethics is that these threats and inducements are ethically problematic because such external pressures can undermine the voluntariness of a person's consent under certain conditions. Our argument in this paper is different and more radical: the act of giving or withholding consent is, by definition, voluntary. Drawing on methods of philosophical analysis, we begin by observing that bioethical analysis has, to this point, equivocated on two accounts of the concept of 'voluntary': the first that stands in opposition to 'involuntary', and the second that stands in opposition to 'compulsory'. By expanding on both, we go on to argue that there are good reasons to endorse the first account, which closely connects the giving of consent to discussions of intentional agency in the philosophy of action. Accepting this account leads us to conclude that the ethical analysis of threats and inducements is distinct from the question of whether an agent is able to make a choice. Importantly, our analysis is not simply an exercise in conceptual clarification. Once it is recognised that voluntariness is not a component of valid consent, bioethicists are far better placed to correctly diagnose and explain the ethical concerns associated with the threats and inducements that researchers and clinicians apply in their practices.

Abstract number: 11 **CONSCIENTIOUS OBJECTION IN LATINAMERICA. COMPARATIVE RESEARCH**

ID: 55 Maria de la Luz Casas Martinez,

oral Mexico, Panamerican University

Freedom of conscience has been considered a human right. In the field of health its observance is recent, but increasingly is recognized in various global ethical codes. Legislation sometimes has supported these assumptions, giving a mandatory character and promoting respect to these concepts. Documentary research was conducted between the years 2000-2009 on the laws and codes that supported various fields of conscientious objection in Latin America in the area of health. We conducted a reflection on the multiple displays, scopes, foundations and implications of this concept coverage in Latin American countries. The study demonstrated the variety of interpretations as well as the multiplicity of coverage, moral and legislative regulations developed in most of the Latin American countries.

This study is relevant to understand the needs of Latin-American promote a comparative analysis with alien countries and consider the political repercussion and the impact in population who ask for the objected services.

Knowledge of reality allows more sensitive approach and possible understanding of the problems, in this case, the recognition and demand of respect of the multiplicity of ethical approaches, moral and belief systems. In the case of medical conscientious objection the analysis also reflects the possible impact of these measures on the health system in the user population.

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- Abstract number: 12 Ethical and Bioethical Issues Perceived by Health Sciences Students, from the Classroom to Hospital Practice
ID: 58
oral Eduardo García-Urrutia Alcántara, Dra. Mirtha Flor Cervera Vallejos
Peru, UNIVERSIDAD CATOLICA SANTO TORIBIO DE MOGROVEJO

The research used qualitative and descriptive methods. Its objectives were to describe and analyze health science students' perceptions of ethical and bioethical issues, from the classroom to practical work, at the university hospital department in Lambayeque. Thirteen university students took part and were chosen by saturation technique. A questionnaire with open-ended questions was used for data collection and the data was processed using content analysis. Ethical principles and scientific rigor were observed throughout the research process. Three categories were obtained as a result of the analysis. The first, a deterioration of respect as a fundamental ethical attitude had two subcategories: a lack of respect in the teaching-clinical setting and loosely related selfish tendencies. The second category, ethical malpractice in teaching practice, with three subcategories: allegations of wrongdoing by teachers, discouraging the application of values and the improvisation of teaching. The final category is the alteration of ethical and bioethical issues in clinical practice. Finally consideration is given to the perception of university students of ethical and bioethical issues emerging from the free and voluntary behavior of teachers and students, and their behavior is self-regulated through the government of their actions.

Keywords: ethics, bioethics, perception

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- Abstract number: 13 TEACHERS OF RELIGIOUS EDUCATION AND PRACTICE OF HUMAN VALUES
ID: 60
oral ROSA ELVIRA BAZALAR-WHU, CERVERA VALLEJOS, MIRTHA FLOR
Peru, UNIVERSIDAD CATÓLICA SANTO TORIBIO DE MOGROVEJO

The descriptive qualitative research aimed to: describe and analyze the practice of human values by teachers of religious education - CARABAYLLO ODEC, Lima - Peru 2012 and a conceptual outline of the practice of human values. Seven teachers participated, saturation and redundancy obtained with informed consent, who were given an in-depth semi-structured interview, the data were analyzed by thematic analysis. The research used the ethical requirements of Presidential Decree No. 011-2011 - JUS - Peru, and also took into account the principles of Elliot Sgreccia, protected by the criteria of scientific rigor . We obtained three categories: First, members values and convictions behavior on teachers. The second category: Ways teachers convey values : With the habit of good judgment, through religious education with experiential requirement and achievable model for students, with closeness to Christ, saints and reflection own life. Finally the third category: Limitations and weaknesses in the expression of values, with the subcategories: negative external influences in the achievement of values, wrong actions and distortion of values. Among the final considerations of religious education teachers believe that the practice of repeating values requires slow, gradual and steady virtue with articulation between bioethics and education throughout the educational process, achieving experience the structured value ethics rules, virtues and property.

Keywords: values, teacher, education.

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- Abstract number: 14 Why Privacy is or not so important in Human Subject Protection: A comparative study between Chinese and American Patient Subjects
ID: 72
oral Haihong Zhang, Airong Luo
China, Peking University Health Science Center

People could not build a one-site-fit-for-all Human subject protection system regards to the concrete culture background and research context, though understanding such factors are crucial for a better practice. In one of our empirical research aimed to explore the perceptions and concerns of patient subject why they participated in clinical research, 44 patient subjects (half in Michigan, U.S and half in Beijing, China) with different age, social economic status and education background were chosen to join intensive interview and discuss the factors affect their decision-making and their concerns of protection during the research. Two investigators coded all the transcriptions to ensure the inter-personal validity and found something interesting besides the common problems (e.g. therapeutic misconception, paternalism and so on). When it came to the protection of privacy, all Chinese interviewees said they did not concern it, because they "do not have any secret" from their doctors, they told investigators that "to strangers who do not know me, it does not matter whether or not they know any information about my (illness), I do not care. My only concern is about those acquaintances who know me but do not

know me well". Such phenomenon could be interpreted from the cultural understanding of "privacy" in China. Privacy is some kind of stigma or discrimination; it is "Something bad" that needs to be "hide from others". Knowing this would contribute a lot to understand why protect privacy is not so important in China from the subject perspective, while investigator should not stop here, on the contrary, they should be more active and bare more burden to respect and protect the privacy of subject as their basic human right.

Abstract number: 15 The good death
ID: 74 Suzanne van de Vathorst,
oral Netherlands, AMC

There have been publications, based on empirical research, on what western people consider a good death. Important elements include being surrounded by family at time of death, being at home, being at peace, and being aware of the fact death is imminent. The WHO definition of palliative care also underwrites some of these elements.

However not all people in the western world, and certainly not all in other cultures will share this ideal. There is a danger that these descriptions of what many people view as an ideal, becomes a normative, prescriptive view on what a good death is. Similar transitions from descriptive to normative have happened regarding the phases of grief, where the steps described as commonly occurring (denial, anger, bargaining, depression and acceptance), are used by some as a proscribed and necessary phases. In my paper I want to address the danger of defining a good death for other people. I will argue that in many programs of palliative care the danger of imposing an ideal of a good death on unwilling patients is real and present.

Abstract number: 16 Compensation for research-related injuries: whither Africa? A collaborative responsibility approach
ID: 78 Patrick Kamalo, Prof Stuart Rennie and Dr Lucinda Manda-Taylor
oral Malawi, College of Medicine, University of Malawi

The subject of compensation for research-related injuries (RRIs) has dominated ethics discourse in the recent past due to several developments in global collaborative research. These developments have included: an increasing consensus that participants with RRIs should not be left uncompensated[6]; the increasing realisation that the United States of America (USA) lacks a comprehensive system for managing RRIs as reported by the US Presidential Commission for the Study of Bioethics and the effect of such deficiency on global research; and the introduction of new regulations for clinical trial-related injury and deaths in India, currently a major player in global research. Surprisingly, there is lack of agreement on the subject of compensation for RRIs despite the clear moral arguments in support of compensation, but also the numerous international and local guidelines advocating for such compensation. The need exists for consensus on compensation for RRIs especially for low and middle income countries (LMICs) who are increasingly participating in research originating from high income countries (HICs) and limited options exist for participants who suffer RRIs. In this paper we discuss existing guidelines on compensation for RRIs, then models of compensation available in HICs; we then discuss experiences on LMICs with RRIs and attempts which have been made to resolve such issues. Lastly we introduce the concept of compensation and morality in Africa – the collaborative responsibility approach - which supports no fault insurance for RRIs but puts responsibility of funding that insurance system on all parties benefiting from the insured research activities, including the host governments and institutions. We finally motivate how this model guide compensation in Africa.

Abstract number: 17 Estimating the Social Priority of Addressing Violence Against Women
ID: 80 Randall Waechter,
oral Grenada, St. George's University

Gender-based violence remains one of the most prevalent social problems on earth. It is estimated that 25 to 50% of women will be sexually assaulted at some point in their lives, with 7% of women in the United States experiencing the most severe form of violence – rape, over their lifespan (CDC). Many of these assaults will occur prior to age 18, with lifetime female child sexual abuse prevalence rates estimated at 20%. The implications of this violence for female health across the lifespan are profound. Women who experience child sexual abuse and/or sexual assault as adults report higher rates of gynecological problems, gastrointestinal problems, sexually transmitted diseases, depression, posttraumatic stress disorder, drug and alcohol abuse, use of healthcare services, and lowered educational attainment / socioeconomic achievement across the lifespan. In 2008, researchers estimated that each rape in the United States was associated with \$32,000 in direct victim and justice system costs. Given the prevalence rates, poor health outcomes, and societal cost associated with gender-based violence, it is reasonable to hypothesize that government and healthcare systems are taking significant steps to address this

problem. In this study, we analyze healthcare and health research expenditures across major healthcare areas such as cancer, cardiovascular disease, infectious disease, neuropsychiatric conditions, injuries, and violence against women. We then compare these expenditures against disease burden to gain a rough estimate of the "social priority" of addressing violence against women.

Abstract number: 18 **Ethics of Standardization of Traditional Medicine is Better Understanding of its Underneath Philosophy**
ID: 81 **Subhas Dutta,**
oral **India, J B Roy State Ayurvedic Medical College & Hospital**

Introduction: Ayurveda, the Indian traditional medicine is based on a strong philosophy especially its drug and their mode of use and action. Hundreds of herbs, minerals – their probable mode of actions had been categorized and summarized through the unique philosophical hypothesis of Ayurveda or otherwise it had been developed from the categorized understanding of actions of different herb and minerals. So it is the primary step to understand the philosophy of Ayurveda for its scientific standardization.

Materials and Methods: It is easier to assess the mode of action of a new herb/ drug through the philosophical hypothesis of Ayurveda. According to Ayurveda, all the herbs bitter in taste will have anti-pyretic, analgesic, anti-inflammatory properties. If we think of a modern drug like Paracetamol which is anti-pyretic, analgesic & anti-inflammatory agent is bitter in taste. So a new herb, bitter in taste may be taken to find out its anti-pyretic, analgesic, anti-inflammatory properties. As well as a drug already in use for other purposes may be taken to find out its anti-pyretic, analgesic, anti-inflammatory properties. Adding to it, we may find out the chemical structure of the active principle, responsible for bitterness and may modify its structure for better efficacy and acceptance through QSAR technology.

Expected Outcome: Proper understanding of philosophy will be helpful to specify research question easily and thus minimize initial expenditure of research and rapid scientific standardization of Ayurveda which will be helpful a lot to minimize health burden worldwide.

Keywords: Ayurveda- The Indian Traditional Medicine, Philosophy, Standardization, QSAR- Quantitative Structural Analysis Relationship

Abstract number: 19 **ARE ETHICS LOCAL OR UNIVERSAL? THE CASE OF HOMOSEXUALITY IN AFRICA AND ELSEWHERE**
ID: 84 **Godfrey Banyuy TANGWA,**
oral **Cameroon, Cameroon Bioethics Initiative (CMBIN) / University of Yaounde 1**

Ethics are partly local and partly universal or, to put it another way, ethical values necessarily have universal outreach but the application of such values in concrete contextual situations is necessarily constrained, shaped and coloured by local realities and conditions. How does this square out with a practice like homosexuality, severely condemned by some in some contexts, tolerated by some in others and approved by some to the extent of legalizing homosexual marriage in others? In this paper, focusing mainly on Africa, where all three attitudes to homosexuality are manifest, I discuss the ethics of homosexuality in relation to the question as to whether ethics are local or universal. In recent years some African countries have come under considerable diplomatic pressure from countries and agencies of the Western world to legalize or decriminalize homosexuality as a human rights issue. The main thrust of my argument is that, while homosexuality between fully competent consenting individuals is ethically unobjectionable as an act that causes no harm and does no wrong to any putative third party, the legal approbation or proscription of homosexuality is ethically highly prejudicial and inadvisable. What may ethically be wrong in homosexuality is no different from what may ethically be wrong in heterosexuality, such as rape, sex with minors or incompetent adults, exploitative sex, non-consensual sex, etc. The law should be directed at what ethically may be wrong or harmful in sexuality, not at what may rightly be claimed to be a sexual orientation, a state of being beyond freedom and choice.

Abstract number: 20 **Best Interests in Pediatrics**
ID: 93 **Fernanda María Ledesma, Menéndez C, Barraza N, Ciruzzi S, Ferreria JC, Garcia H, Iervolino MA, Mazzuchelli T, Marin D, Novali L, Ortega L, Ponce C., Rodriguez E, Schejter V, Scigni A, Selandari J**
oral **Argentina, Hospital Nacional de Pediatría J.P. Garrahan**

We report on the care issues presented by a female child with an oncological disease responding poorly to conventional treatment. Her parents decided to withdraw her from this treatment in favor of treating her by orthomolecular therapy.

Clinical Case

Five year old girl, from the province of Neuquén, referred for treatment suffering from a left suprarenal neuroblastoma with multiple bone metastases. She began chemotherapy with a good clinical response, but after the fourth cycle of induction the disease was still present in the bone marrow. A change to the chemotherapy medication using an alternative scheme was suggested to the parents in order to achieve remission in the disease.

Against this background and because of their convictions borne from experience of conventional medicine and its approach to care, the girl's parents decided to stop her hospital treatment and to continue her care in a "Center for Orthomolecular Medicine." Here her treatment was based on micronutrients and high doses of intravenous ascorbic acid. These treatments were associated with home sessions of physically induced hyperthermia.

The parents believed in naturopathic and homeopathic medicine, and not in the conventional medicine on which the team's medical treatment was based. They therefore argued that the child could be cured of the underlying disease by means of unconventional alternative medicine.

The team presented the case to the ethics committee.

Abstract number: 21

ID: 96

oral

Clinical photography and social media

César Palacios González,

United Kingdom, The University of Manchester (Institute for Science Ethics and Innovation)

Clinical photography is an important tool for medical practice, training and research. While in the past clinical pictures were confined to the stringent controls of surgeries and hospitals the technological advances have made possible to take pictures and share them through the internet with only a few clicks. Confronted with this possibility I explore if a case could be made in favour of using clinical photography in tandem with social media. In order to do this I explore i) if the patient's informed consent is required for the publication of any clinical images that depict her, irrespective of whether the patient can be identified from the image or not; ii) if social media is an adequate place for clinical images to be displayed; and finally iii) if there are special considerations that should be taken into account when publishing clinical images on social media.

Abstract number: 22

ID: 99

oral

SENIORS, VULNERABILITY AND POWER RELATIONS: Bioethical conflicts when giving up treatment.

Carolina Consejo y Chapela, Carlos Alfonso Viesca Treviño

Mexico, Universidad Nacional Autónoma de México/ IMSS

OBJECTIVE: In this paper we analyze the vulnerability in elderly hospitalized patients, who asked to give up medical treatment in the context of severe chronic or terminal illness. We analyze the role of power relations existing between physicians, families and patients, in decision-making and its link to conflicts when the possibility of giving up treatment is present. We analyze the latter from an ethic of responsibility.

METHODOLOGY: We made a Bioethical analysis from a case constructed with qualitative methodology in a public general hospital in Mexico's City. We used participative observation, semi-structured and open interview's. The bioethical analysis was centered in vulnerability. We used Diego Gracia's case approach. We used Heidegger's, Paul Ricoeur's and Diego Gracia's Hermeneutics, as theoretical tools. Eduardo Menendez as well as Kleinmann and Hellman's Medical Anthropology were used. Michel Foucault's concept of "power" was used to analyze power components in the doctor-patient relationship.

RESULTS: We report the case of a 78 year old woman diagnosed with advanced lung adenocarcinoma and pneumonia, discharged from the hospital by refusing treatment. Power relations, dominating moral values related to practices and representations of disease, were fundamental to decision making. Patient treatment refusal was held in a context of health personnel coercion, family abuse and negligence that lead to a diminished autonomy.

CONCLUSIONS: Vulnerability is largely determined by power relations and the configuration in which they are present. But the economic, sociocultural and anthropological context, are essential to understand vulnerability from an hermeneutical approach as part of its multi-dimensional nature. We propose a theoretical tool intended to allow hospital ethics committee's to understand vulnerability as a multidimensional phenomenon and recommend actions to protect and empower the vulnerable patient.

Abstract number: 23	Banking (On) The Brain: From Consent to Authorisation and the Transformative Potential of Solidarity
ID: 101	<u>Shawn Harmon, Aisling McMahon</u>
oral	United Kingdom, University of Edinburgh

Modern technologies and ambitions for biomedicine have resulted in the rise of new models of medical research, including population biobanking. One example of biobanking is brain banking, which refers to the collection and storage of brain and spinal cord samples for research into neurological diseases intended to benefit individuals and society more broadly. Obviously, brain banking involves taking brains and tissue from deceased people, a fact which complicates the task of recruiters and which makes consent a relatively poor tool for stakeholders. This paper will contextualise brain banking, considering the public health issues at stake. It will then explore the legal definitions and demands of, and actual processes around, 'consent' in England/Wales/Northern Ireland and 'authorisation' in Scotland, articulating and evaluating their conceptual and practical differences. It then argues for an expanded but improved operation of 'authorisation' in the brain banking (and broader biobanking) setting, adopting the socio-moral value of 'solidarity' as our foundation and the improvement of the 'public good' as our legitimate objective.

Abstract number: 24	An Assessment of the Knowledge, Attitude and Practice of Research Ethics Amongst the Postgraduate Students of the Faculty of Clinical Sciences, Obafemi Awolowo
ID: 107	
oral	Cornelius Ewuoso, Nigeria, University of Ibadan/West African Bioethics Center

Research is a systematic investigation designed to contribute to development of health or generalizable knowledge. The goal of research is to seek out ways to improve the quality of human life, human knowledge of the environment and human society. Maintaining ethical standards in research is, therefore, imperative. Non-adherence to ethical standards or ethical misconduct such as fabrication, plagiarism and falsification, can easily cause profound harm to individuals and societies, who ought to be beneficiaries of research. Given this potentials for harm, ethical misconduct should have no place in research. Sadly, this is not the case. Ethical misconduct continues to take place in research, and it is highest amongst graduate and postgraduate students, especially in developing countries.

Our review of existing studies shows that no one has satisfactorily answered the question why research misconduct is prevalent amongst graduate and postgraduate students in developing countries. Are the reasons for this prevalence due to insufficient knowledge of research ethics? This study would attempt to answer this question, and thus fill the existing gap. Since, it would be impossible to assess the knowledge of 'all' postgraduate students in all the developing countries, this study would focus principally on the postgraduate students of the clinical faculty of Obafemi Awolowo University, Ile-Ife, Osun State, Nigeria.

100 postgraduate students from the clinical faculty of university would be recruited and given questionnaires to fill. Information from the filled questionnaire would be collected and entered into STATA (Statacorp Inc.). Describe command would be used to find differences in knowledge, attitudes towards and practices of research ethics. Variables would be compared using the t test, Fisher exact test, Mann-Whitney test ($p < 0.05$ would be considered significant). The result of this study would be shared with the academic community, through publication of the same.

Abstract number: 25	Ethical Double Standards: What are they? What can be done about them?
ID: 108	<u>David Wendler,</u>
oral	United States, Department of Bioethics, US NIH Clinical Center

Research in developing countries raises a number of important ethical issues. These include: What is an acceptable standard of care? To what extent and in what ways should host populations benefit? There is now a wide literature defending a range of positions on these questions. In contrast, there has been significantly less discussion of the ethical concerns that often inform these positions. The present paper focuses on one of these, the issue of ethical double standards. To cite one instance of the role of this issue, revisions to the Declaration of Helsinki included significant debate over whether placebos should sometimes be allowed for research in developing countries. Following the consultation meeting in Sao Paulo, the draft document proposed to allow such trials in some cases. However, following further consultation, this provision was dropped. While this issue has received a great deal of attention, little attention has focused on the fact that much of the debate revolves around ethical double standards. Typically, it is unethical to conduct research in the developed world using less than the best methods. Hence, some commentators conclude that allowing such trials in the developing world relies on an ethical double standard. Others implicitly reject this view on the ground that allowing a trial design in one place, but not another, does not necessarily constitute an ethical double standard: it can be acceptable to conduct research using bovine-derived drugs in the United States, but not in India. This analysis suggests that one way to possibly make progress on what

have become intractable debates is to consider more carefully the underlying concern regarding ethical double standards. The present paper uses conceptual analysis to evaluate what constitutes an ethical double standard and how they should be handled.

Abstract number: 26 **POPULATION EXPLOSION, DISTRIBUTIVE JUSTICE AND ENVIRONMENTAL SUSTAINABILITY.**
ID: 112 Peter Osimiri,
oral Nigeria, University of Lagos

The global society more than at any other time in history is at a critical crossroad. Confronted with the imminent collapse of its biological support system and an impending ecological catastrophe, we must decisively deal with the challenge of burgeoning populations which threatens to exacerbate the already existing myriads of environmental problems. If there is a measure of consensus on the need to curb global population growth, opinions are however divergent about specific policy directions. While some advocate population control programmes backed by state coercion where necessary, others contend that the population explosion is a function of a pervasive social injustice occasioned by uneven distribution of wealth and power between the affluent few and the numerous poor, and instead recommend redistributive policies aimed at eradicating absolute poverty. In the light of the imperative of environmental sustainability, this paper critically examines the debate over the two policy alternatives that has been put forward from an ethical perspective, and argues that while there is some merit to the contending policy prescriptions, they are not necessarily mutually exclusive: a combination of indirect state's population control which do not necessarily infringe on couple's reproductive freedom with promotion of social justice and poverty reduction strategies is indeed the necessary ethically commendable precondition for stabilizing global population growth and ensuring environmental sustainability. A further critical component of an integrated strategy for achieving the latter, the paper adds, is the replacement of the resource-expensive lifestyle characteristic of affluent western societies with a more eco-friendly one.

Abstract number: 27 **The Globalisation of Clinical Trials: How the Market Shapes Law and Bioethical Discourse**
ID: 114 Gerard Porter,
oral United Kingdom, University of Edinburgh
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In recent years, there has been a dramatic rise in the numbers of foreign-sponsored clinical trials conducted in low-to-middle income countries. Many of these countries have weak regulatory systems for the governance of medical research. When examples of dubious practices have occurred, commentators have often framed the central problem as being 'an absence of law and bioethics'; with the obvious solution being the strengthening of regulatory regimes and better enforcement of ethical standards. This understanding reflects the idea - prevalent since the post-war era - that law and bioethics act as a 'restraint' on power; whether that power is embodied in the form of the state or private corporations. This paper seeks to problematize this assumption.

Whilst accepting that law and bioethics are necessary and important, it will be argued that their relationship with 'the market' is more complex than is generally thought. Drawing theoretical insights from the literature on 'global production networks', the paper examines the shaping effects that commercial interests can have over the development and stabilisation of legal and bioethical norms. The central claim is that the emergence of a thin, market-friendly form of law and bioethics (dubbed here as 'neo-liberal bioethics') demonstrates that in certain situations, far from acting as a 'restraint' on power, law and bioethics can become the very media through which power operates and is legitimated. As a case study, the paper focuses on the US Food and Drug Administration's 2008 decision to abandon the Declaration of Helsinki as the relevant ethical standard for the conduct of clinical trials outside the United States.

Abstract number: 28 **Reading Caplan in Karachi**
ID: 118 Farhat Moazam, None
oral Pakistan, Center of Biomedical Ethics and Culture, SIUT

In developing countries, medical ethics is being introduced through a feat of transplantation instead of as a thoughtful movement guided by understanding local realities and value systems. This transplanted version is modeled on the dominant paradigm which construes bioethics as a secular discipline grounded in Anglo-European philosophical thought capable of providing a universal, globally applicable "common morality" that transcends cultural norms and values.

This paper is based on eight year experience with the only public center in Pakistan that focuses on bioethics education and research targeting healthcare professionals. It demonstrates that in countries that are hierarchical, deeply religious and family centered, adopting this paradigm uncritically while remaining inattentive to indigenous value systems and local socio-economic realities that shape

professional and public moral spheres, risks reducing the discipline to an abstract, academic exercise. The presentation focuses on issues discussed by students enrolled in the center's graduate programs during class, and on the student blog which is part of distance learning assignments. It reveals that discussions frequently involve ethical dilemmas faced in daily clinical practice rather than esoteric topics dominating international conferences, and how to negotiate between rational arguments and positions of Muslim scholars pertaining to novel advances in biomedical science. Ethical discussions generated by two articles of American bioethicist, Art Caplan – female insemination with dead husband's/partner's harvested sperm, and Pakistani militants preventing polio vaccinations in children - will be employed to illustrate how Pakistani students used ethical analyses and priorities that differ from those of the author. In the first, while Caplan focuses on explicit consents and advance directives, students prioritized family, socio-economic realities, and the position of Muslim scholars. In the case of harm to non-vaccinated Pakistani children, discussants expanded the ethical discourse to their deaths from American drone attacks within their territory.

Abstract number: 29 **Bioethicist's Proactive Engagement In Clinical Rounds And Consultations, Hospital Risk Management And Quality Programs: Experiences Of The King Fahad Medical Ci**
ID: 121 **Omar Hasan Kasule, N/A**
oral **Saudi Arabia, King Fahad Medical City**

This paper describes the author's experiences of proactive engagement of the ethicists in hospital procedures that represents a paradigm shift from waiting to be called to solve ethical problems to being there when problems occur. The paper describes experiences of the involvement of the bioethicist in clinical ward rounds, clinical ethics consultations, clinical ethics committees, risk management programs, and quality assurance programs. The ethicist attending ward rounds in departments most vulnerable to ethical dilemmas to observe and resolve ethical problems as they arise. The 24-hour ethics consultation service enables bioethicist on duty to attend ethical dilemmas as they occur and writes observations in patient charts. Complicated cases encountered during ward rounds and consultations are referred to the clinical ethics committee that recommends long-term policy-related solutions. The bioethicist receives, investigates, and resolves incident reports from the risk management system with ethical implications. The bioethicist as a member of various quality committees is exposed to reports of adverse and sentinel events several of which involve ethical violations. The ethicists in all these scenarios plays multi-faceted roles plays roles of a patient advocate, a mediator between practitioners and patients, a problem solver, and an educator. The paper will present and analyze case reports and statistical data for a period of 12 months starting in June 2013 and use starting June 2013 and use the derived lessons as a basis for formulating a proactive role for the bioethicist in the hospital setting. It will also propose specific training needed for the hospital bioethicist as well as for the practitioner to enable them understand the roles of the consultants.

Abstract number: 30 **Ethics of Non-communicable Diseases: A Perspective from India**
ID: 122 **Chhanda Chakraborti, Rhyddhi Chakraborty**
oral **India, Indian Institute of Technology Kharagpur, Kharagpur**

This paper argues that there are major ethical issues ingrained in the way some preventable non-communicable diseases (NCDs) are addressed; however, these are not given adequate attention in the national health policies and public health programs in certain developing countries. The special ethical issues discussed in the paper are: (a) Affordability of preventive measures and treatments, (b) accessibility of screening, treatment and counseling facilities, (c) the oversight of the causal role of the social determinants, and (d) a systematic lack of adequate public spending in the health sector. The paper utilizes as an example the case of India, which is facing an epidemic of NCDs in both urban and rural areas and across the genders. It keeps its arguments confined to some of the non-communicable diseases (NCDs) that are major but preventable, such as, cardiovascular diseases, breast cancer, type 2 Diabetes. The recommendations include an application of the ethical framework of social justice, and the concepts of collective obligation, and cost-sharing, and are guided by the vision of protection of all from the premature morbidity and mortality from the preventable, high-cost diseases.

Abstract number: 31	Actors and arguments against surrogacy in Swedish public debate
ID: 125	<u>Kjell Asplund</u> , Karin Wilbe Ramsay, Lotta Eriksson
oral	Sweden, Swedish National Council on Medical Ethics

Background. The Swedish National Council on Medical Ethics (Smer) is an advisory body to the government and the parliament and includes politicians and experts.

In early 2013, Smer released a major report on assisted reproduction. Although the report covered several controversial topics (upper age limits for assisted reproduction, donation of fertilized eggs, etc.), the vivid discussion in mass media and social media stirred by the report very much focused on surrogacy. The Council recommended that altruistic surrogacy should be permitted under several specified restrictions but rejected commercial surrogacy.

Observations. Major actors in the public debate against any form of surrogacy included Christian thinktanks (and other religious institutions) and several women groups. In social media, there was also an element of homophobia (the Council proposed that also homosexuals should be eligible as parents). Pro-surrogacy actors were mainly parents who had children after surrogacy abroad and infertile people. Politically, Christian Democrats and the left-most party were opposed to surrogacy, whereas five other parties wanted to explore a law permitting altruistic surrogacy.

Arguments used by opponents to altruistic surrogacy included (i) it is not a human right to have children, (ii) surrogacy is unnatural, (iii) the delineation between and altruistic and commercial surrogacy cannot be maintained, (iv) women are exploited, (v) pregnancy involves medical risks, (vi) maternal-fetal emotional attachment is lost, and (vi) legal problems. All these arguments were discussed in detail in the Smer report. The Council had not addressed the argument that permission of altruistic surrogacy promotes rather than prevents commercial surrogacy.

Conclusions. Even in a highly secularized country like Sweden, religious groups are strong contributors to the public debate on surrogacy. Feministic arguments (both pro and con surrogacy) are also prominent. Few entirely new arguments, not considered in the Smer report, appeared during the public debate.

Abstract number: 32	Legal and ethical issues around human-animal chimera research
ID: 126	<u>Laura Cabrera</u> , Dr. Sabrina Engel
oral	Switzerland, Institute for Biomedical Ethics

Currently, different approaches for the treatment of a variety of neurological diseases are under investigation. One approach that has gained increased attention in recent years, particularly in relation to Parkinson's disease, is stem cell therapy. In order to test new therapeutic approaches with stem cells, researchers urge to move to non-human primates (NHP) as animal models. According to the scientists, NHPs better mimic human physiology than all current animal models. However, the transplantation of human neural stem cells into the brains of NHPs raises a number of ethical concerns. Besides animal welfare concerns and ethical issues associated with the use of embryos, the research is also regarded as controversial from the standpoint of NHPs developing cognitive or behavioral capabilities "unique" to humans. Our paper summarizes the various ethical issues raised by research with human-animal brain chimera. It compares the relevant regulatory instruments and different recommendations addressing chimera research issued in national reports from three important European research nations: Germany, Switzerland and the United Kingdom (UK). Finally, we discuss whether and how such research may be performed balancing freedom of research with benefits and costs for humans and animals within the European context.

Abstract number: 33	Consensus conferences on gestational surrogacy: autonomy, procreative rights and gender
ID: 130	<u>Yun-Hsien Diana Lin</u> ,
oral	Taiwan (Republic of China), National Tsing Hua University

Law and policies on assisted reproductive technologies in Taiwan has been directed by professionals in the fields of law, medicine and bioethics, policies on gestational surrogacy is no exception. Therefore, the 2004 and 2012 consensus conferences on gestational surrogacy held by the Taiwan ROC Bureau of Health and the Department of Sociology of National Taiwan University, which were designed as a "bottom-up" communicative mechanism; provide the unique lens to observe policy debates among lay persons.

This paper will examine the minute and conclusion reports of the two consensus conferences for the following purposes. First, by investigating what the professionals and lay persons said during the conferences, their arguments will be categorized into three types: the State, the society or the individual level. Next, through analyzing the language of the discourse, this paper will focus on whether arguments at individual level, especially those based upon women's procreative rights and autonomy, actually increased in the 2012 consensus conference. Finally, to have a more profound understanding of the potential gender implications, this paper will explore the key issues in the 2012

and why? should the gestational mother be paid and to what extent? and how to better protect the gestational mother's autonomy during the pregnancy?

Keywords: consensus conference, gestational surrogacy, autonomy, procreative rights, gender implications

Abstract number: 34
ID: 132
oral

Direct to the consumer nocebo effects - the ethics of pharma advertising.
David Hunter,
Australia, Flinders University

While banned in many countries the direct advertising of medicinal products to consumers does still occur in some countries such as New Zealand, Canada and the US. And even where direct to consumer advertising is banned, in some jurisdictions such as Australia, pharmaceutical companies are allowed to fund and organise health information campaigns as long as they aren't associated to specific products. Direct to consumer advertising has been criticised both because it encourages medicalisation (hot flushes associated with menopause become a medical problem for example instead of part of a natural transition) and because it rarely does a good job of educating consumers. In this paper I will suggest a further problem that direct to consumer advertising is likely to cause - nocebo effects. These effects are the converse of the placebo effect - negative health effects that don't occur from an external physiological cause but instead arise from the care environment and the beliefs of the person. It is probable that the significance of the effect is dependent on the condition being induced, with certain medical conditions (those with high social/psychological components) being more sensitive to nocebo effects than others the prevalence varies from study to study but it is not unheard of for approximately 30% of participants/patients to suffer from nocebo effects.

If this is correct then this casts doubt on the neutrality of even public health information campaigns since these won't merely inform the public, to some degree they will contribute to the existence of the disorder and hence the market for it.

Abstract number: 35
ID: 134
oral

Cultivating integrity: some experiences and obstacles in ethics teaching
Medard Hilhorst, Suzanne van de Vathorst
Netherlands, Erasmus University Medical Center Rotterdam

Integrity in medical research is a growing concern in many countries. Reports of unethical conduct point to a great variety of misbehavior and bad practices, ranging from fraud and plagiarism, to misleading authorships, improper interests, data massage and biased research outcomes. In many institutions like ours there is a tendency to respond to new cases of misconduct by new regulations, stricter codes of conduct, training requirements and assessments. The message is: 'be decent, be honest'. The notion that someone can be honest to a certain degree, or relative to particular circumstances is out of the question: no one can be sort of pregnant.

We will argue and show, however, how findings from psychology and the behavioral sciences offer a more firm and realistic basis for integrity debates and teaching activities. Only by understanding the causes, motives and circumstances of misconduct, the challenges for policies, regulation and teaching become clear.

We conclude that from an ethical perspective integrity can best be seen as an ideal that can be realized to a certain extend, but is never fully achieved. This challenges all involved in research to improve practices piecemeal and on a day by day basis.

Abstract number: 36
ID: 140
oral

The Child's right to autonomy: dilemmas arising in a multicultural society
Adalberto De Hoyos, Nelly Altamirano-Bustamante & Myriam Altamirano-Bustamante
Mexico, FES Acatlán, Universidad Nacional Autónoma de México

Decision making in the face of strong ethical dilemmas is a complex and multidimensional task when dealing with a pediatric patient because this doctor-patient relationship has some special features concerning the autonomy of the patient. The principle of autonomy in the child can normally be represented by the will of his parents or guardians, because to the eyes of the law a minor is considered incompetent to make these decisions. Here, we present an analysis of the recent modifications to Mexican law, and how and to what extent minors should be considered in their own treatment. Special emphasis is made in those cases where there are differences between the parties; consideration is given to the dilemmas that arise due to cultural, linguistic or religious differences. In those cases where medical staff and parents are not of the same opinion, special ethical consideration has to be given to protect the minor's "higher interest", but it is not a simple task to point-out someone's higher interest without reference to their own viewpoint. Considering constitutional reforms and international conventions signed by Mexico, we study the impact of the obligations to provide information and respect the opinion of children, through the concept of a progressive autonomy, which allows him

to have a say in his own treatment, in accordance with his own understanding and capacities. We also consider the consequences of these changes, in the form of the pediatric practice, as well as in the relationship between the parents (or the guardian) and the minor in these specific cases. It is also established how respect along with ethical considerations for the patient's dignity together may provide answers to some difficult cases.

Abstract number: 37 Bioethical dilemmas and possible solutions in Pediatric Intensive Care in the Federal District of Mexico
ID: 142 Maria Cristina Caballero, Dra. María de la Luz Casas
oral Mexico, Academia Nacional Mexicana de Bioética A.C.

In Making decisions in Pediatric Intensive Care Units (PICU) a scientific, legal and ethical process is done including parents and tutors which therefore will be done seriously, calmly and methodological rigor. A survey was designed by experts with anonymous and voluntary, non-institutional form in which issues were raised relating to bioethical dilemmas generated in the PICU services and procedures for resolution. The application of the instrument was the Delphi method, in two rounds. The main results were to recognize that all of the physicians surveyed, face ethical dilemmas in their unit, being the most frequent therapeutic futility by 32%, linked to the difficulty of establishing the diagnosis of terminal patient in a 13% result. The decision of placement of children with oncological diseases and Multiple Organ Dysfunction with recoverability uncertain prognosis, 23% of physicians responded affirmatively. The scope of autonomy in the pediatric patient and his family said in doubt 16%. The doctor-patient-family relationship has been affected by the decisions taken in context, 32.5% answered affirmatively. Of the participants of the study 37.5% complained, some noted they had only been questioned once. Regarding the involvement of the interpersonal relationship with the rest of the team, prevailed with 75% negative response. The relationship between the presence of bioethical dilemmas, as causal factor of increased burn-out syndrome in medical personnel, yes 75% are evident. The participants expressed response to the question whether there is fear of possible legal claims in the affirmative was 93.7%.

One should include the study of bioethics and decision making moral content in the training of these professionals, as well as implement assertive communication in the team health / family and promote the proper functioning of Bioethics Committees, with emergency consultations are proposals raised by the findings of this study .

Abstract number: 38 Is biomedical enhancement a disenchantment of the world?
ID: 144 Anton van Niekerk,
oral South Africa, Stellenbosch University

This paper examines whether biomedical human enhancement is necessarily the ultimate culmination of the alleged post-enlightenment disenchantment of the world, as identified by Weber. This disenchantment may be viewed as the process whereby mystical or supernatural causes and solutions to practical, everyday problems came to be replaced with rational and scientific explanations and technological solutions, with the concomitant alleged loss of humanity's sense of wonder, mystery and dependence on factors and forces that are not self-created.

A favourite argument against enhancement within the ambit of these considerations, is that of Michael Sandel, who regards the aim to enhance as characterised by a desire for perfection and control over the world, a denial of the "giftedness of life". This argument is inconsistent. Sandel appears to have no objection to the non-genetic modes of influence and manipulation that we exert upon our offspring in an attempt to shape them to our perceived desires.

Humanity has always tried to improve itself, thus to oppose enhancement is in a sense to oppose the inevitable. This inevitability suggests that we should focus upon specific projects of enhancement that may be more problematic than others, rather than rejecting enhancement outright. Our guiding principles for adjudicating such projects ought to be whether or not they are to our benefit or disadvantage as a species.

Rather than viewing biomedical enhancement as a blunting of our sense of mystery and awe, we should allow the possibilities opened up by modern science to stimulate our sense of wonder. A sense of awe need not be limited solely in response to the unknown but may also arise from a disclosure of the unknown. An enchantment with the world need not be the outcome of darkness but rather an anticipation and result of discovery.

Abstract number: 39 ID: 149 oral	"I don't need my patients' opinion to withdraw treatment": Patient preferences at the end-of-life and physician attitudes towards advance directives in England Ruth Horn, United Kingdom, The Ethox Centre, University of Oxford
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This paper presents the results of 28 qualitative interviews on physicians' views on advance directives (ADs), and on their experience in making end-of-life (EOL) decisions for incompetent patients. The paper aims to examine problems physicians from different contexts evoke with regard to EOL decision-making and shows how the place accorded to patient preferences influences the potential role of ADs in ethics guidance and policies in England and France.

The interviews focus on (1) problems that emerge when deciding to withdraw/-hold life-sustaining treatment from both conscious and unconscious patients; (2) decision-making procedures and the participation of proxies; (3) previous experience with ADs and views on their usefulness; and (4) perspectives on ways in which EOL decisions might be improved.

The analysis reveals differences in the way patient preferences are taken into consideration and shows how this influences physicians' attitudes towards ADs. Respect for individual wishes and beliefs plays an important role for English physicians. Hence, ADs are considered important means to enhance patient autonomy. Yet, at the same time, the understanding of autonomy as an ideal according to which a person's wish is authentic and free of influences makes English physicians reluctant towards ADs. French physicians by contrast focus on collective, social aspects rather than individual preferences. The physicians' role is to protect the vulnerable person and, where necessary, to make decisions on behalf of the latter. Hence, ADs are perceived as a foreign "Anglo-Saxon" concept that does not match with the respective medical attitudes.

Understanding the differences between the physician-patient relationship in both countries helps to inform the kind of policy and ethical guidance that should be developed. It follows that a comparative approach of these countries is an important first step in developing comprehensive recommendations for the use of ADs.

Abstract number: 40 ID: 150 oral	Separate Goals, Converging Priorities: On the Ethics of HIV Treatment as Prevention <u>Carla Saenz</u> , Florian Ostmann (University College London) United States, Pan American Health Organization / World Health Organization
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Recent evidence confirming that the administration of antiretroviral drugs (ARVs) to HIV-infected persons may effectively reduce their risk of transmission has revived the discussion about priority setting in the fight against HIV/AIDS. The fact that the very same drugs can be used both for treatment purposes and for preventive purposes (Treatment as Prevention) has been seen as paradigm-shifting and taken to spark a new controversy: In a context of scarce resources, should the allocation of ARVs to HIV-infected persons be prioritized based on the goal of providing treatment to persons in medical need, or on the goal of preventing the spread of the HIV epidemic?

Contributions to this discussion tend to assume that the goal of treatment and the goal of prevention entail conflicting priorities. We challenge this assumption on the basis of both conceptual and empirical examination. We argue that, as far as the provision of ARVs to HIV-infected persons is concerned, the goals of treatment and prevention do not entail conflicting priorities; instead, they suggest converging strategies for the optimal allocation of ARVs. As a consequence, the concept of Treatment as Prevention can indeed be seen as paradigm-shifting, yet in a novel way: Rather than extending the tension between the goals of treatment and prevention to the level of drug-allocation, it dissolves this tension by providing a rationale for a unified strategy for allocating ARVs. At the same time, this should not obscure the independent ethical significance of the principles that support each of these two goals.

Abstract number: 41 ID: 152 oral	Genetics, Identity and Tri-parenting <u>Anthony Wrigley</u> , United Kingdom, Keele University
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In this paper, I discuss the extent to which techniques offering mitochondrial replacement therapies can pose ethical problems concerning harm and identity of the individual child created.

New reproductive technologies that allow mitochondria carrying harmful DNA mutations to be replaced by using healthy mitochondria from donated eggs can potentially allow parents to avoid the transmission of inherited mitochondrial disorders to their children. Such techniques appear extremely appealing to prospective parents as they would allow both parents to be genetically related to their child whilst preventing the serious or life-threatening mitochondrial disorders; options which are unavailable using existing reproductive technologies such as PGD and embryo selection.

What singles this area out as different from previous questions in reproductive ethics about genetic selection techniques are the additional questions of genetic relatedness and hereditability. A person

created using mitochondrial replacement techniques will have three rather than two immediate genetic origins. This tri-parent origin will also be passed on to all future descendants of that individual. These raise ethical concerns as to the extent to which having three genetically related parents can affect an individual's identity and to what extent mitochondrial genes contribute to the 'essential characteristics' of a person. Moreover, as the genetic modifications are passed on through the germ line, there is additional scope for intergenerational risks and harm to future persons. As mitochondrial replacement techniques differ in their approach to when and how the genes are replaced, there is scope to apply Parfitian-style arguments about harms and non-identity. Accordingly, I will argue that those techniques that manipulate the maternal gamete after fertilization might be conceived as benefitting an individual child whereas those that transplant DNA before fertilization cannot be deemed to have benefitted (or harmed) the individual child so created.

Abstract number: 42 Valuing Stillbirths
ID: 153 Joseph Millum, John Phillips
oral United States, National Institutes of Health

Estimates of the burden of disease assess the mortality and morbidity that affect a population by producing summary measures of health such as quality-adjusted life years (QALYs) and disability-adjusted life years (DALYs). These measures typically do not include stillbirths (fetal deaths occurring during the later stages of pregnancy or during labor) among the negative health outcomes they count. Priority setting decisions that rely on these measures are therefore likely to place little value on preventing the more than three million stillbirths that occur annually. In contrast, neonatal deaths, which occur in comparable numbers, have a substantial impact on burden of disease estimates and are commonly seen as a pressing health concern. In this presentation we argue in favor of incorporating fetal deaths that occur late in wanted pregnancies into estimates of the burden of disease. Our argument is based on the similarity between late-term fetuses and newborn infants and the assumption that protecting newborns is important. We respond to four objections to counting stillbirths: (1) that fetuses are not yet part of the population and so their deaths should not be included in measures of population health; (2) that valuing the prevention of stillbirths will undermine women's reproductive rights; (3) that including stillbirths implies that miscarriages (fetal deaths early in pregnancy) should also be included; and (4) that birth itself is in fact ethically significant. We conclude that our proposal is ethically preferable to current practice and, if adopted, is likely to lead to improved decisions about health spending.

Abstract number: 43 Ethical Issues in Patients with Breast Cancer
ID: 160 Roberto Contreras, Juan Manuel Granillo
oral Mexico, Facultad de Medicina Universidad Autónoma de Chihuahua

Keywords: breast cancer, privacy, spirituality.

There is an ethical aspect to every medical act. Nevertheless, where the diagnosis of cancer is concerned, the ethical dilemmas over any patient's care are intensified, especially when treatment includes the removal of a breast, as this implies the mutilation of part of a woman's body that symbolizes self-identity, femininity, privacy, sensuality, sexuality, motherhood, and even spirituality. When treating patients with malignant breast disease, the physician must fulfill several criteria that can be summarized in terms of the application of science and awareness.

General aspects. Respect for women's privacy of women should be a priority, including medical confidentiality.

Self-image. The new image combines embarrassment with natural shyness.

Truthfulness. The communication of the diagnosis puts the character of the doctor on display; he/she should be authentic, truthful, without giving false hope, giving explanations with compassion, humility, prudence, diligence, and empathy.

Informed consent. Not only must there be respect for the decision and how it is handled but the possibility of a second opinion should also be respected.

Spiritual meaning. For women the mammary gland has an important spiritual significance which must be taken into account.

Researching breast cancer patients. Breast cancer research should always be supported by research ethics committee certifications at national and international levels.

Abstract number: 44 **Exploitation in International Surrogacy Arrangements**
ID: 167 Stephen Wilkinson,
oral United Kingdom, Lancaster University

International commercial surrogacy arrangements (e.g. those that have resulted in the growth of so-called 'surrogacy hostels' in India) have recently attracted considerable attention from the media and from academic researchers.

One of the most important ethical arguments against such arrangements is that surrogates are exploited, or at risk of exploitation.

This objection is best understood as an amalgam of concerns about (a) the quality of their consent, and (b) their pay and conditions. Both concerns are entirely proper. However, they are not unique to, nor are they essential or unavoidable aspects of, international surrogacy. Also, it should be noted that commissioning couples may themselves be the victims of exploitation in such arrangements.

This paper argues that, rather than taking a wholly negative or prohibitive approach to international commercial surrogacy, we should focus instead on improving and regulating surrogates' pay and conditions and on ensuring that participation in surrogacy arrangements is truly consensual and voluntary.

This may be hard to achieve in practice but, if it can be achieved even partially, then we would have solved, or at least reduced, the exploitation problem, whilst still allowing both surrogates and 'commissioning' parents to access the considerable benefits that they seek to derive from international surrogacy arrangements.

Abstract number: 45 **Informed Consent previous to Assisted Reproduction: A National Inquiry**
ID: 168 Antonio Cabrera Cabrera,
oral Mexico, Universidad Anáhuac México Norte

The problem of infertility has widened as time passes by. It is a vital issue for women alone, but also for the couples. One of the possible ways to face the problem are the Reproductive Technologies (RT). In Mexico regulation is quite poor, but there are clear directives on the compulsory informed consent in: The General Health Law, its Regulation Acts, the Official Mexican Standards, as well as Declaration of the Rights of Patients (CONAMED), among others, that can be applied to this case. Informed consent is the tangible and concrete expression of autonomy, which includes the right to a clear, truthful, timely, and objective information, on the total process of medical care, specially diagnosis, treatment and prognosis. An adequate consent promotes freedom of election: after being adequately informed. In order to know the status of informed consent for RT in Mexico, a mixed, descriptive, observational and correlational inquiry was applied to 566 persons that were submitted to RT, of which 90% came from private clinics. The sample was non probabilistic, with chain technique, and the inquiry was auto administrated. The statistical analysis was performed with square chi, t.student and ANOVA in SPSS program, with a very high Cronbach coefficient.

The results of the study show that less than 20% of the patients received complete information on the risks for the mother and the child, such as malformations, possible destinations of surplus embryos, multiple gestation risk, effectiveness and alternatives. On behalf of cost, procedures, and ovarian hyper stimulation risks, the percentage of information was higher.

Remark: There is an urgent need that the obligation of the informed consent be accomplished under the ethical and legal ordinations of our country. Lack of consent implies manipulation and abuse situations, that must be avoided, and accomplish the justice that all patient needs.

Abstract number: 46 **BETWEEN THE BIOETHICAL IMPERATIVE AND LAND ETHICS: THE CONTRIBUTIONS OF FRITZ JAHR AND ALDO LEOPOLD FOR THE CONSOLIDATION OF BIOETHICAL THOUGHT**
ID: 171 Jailson José Gomes da Rocha,
oral Brazil, Universidade Federal da Paraíba

Bioethics, as scientific knowledge, has its birthplace - at least in its hegemonic-north american discourse – in the theories and institutional implementations carried out in the 70s of the previous century. With a divided paternity between biochemist Van Rensselaer Potter and gynecologist and obstetrician André Hellegers, Bioethics presented itself as a source of moral conflict mediator relating to the life – beginning, continuous and end – and the moral issues of the Health Sciences.

However ethical concern and semantic stretch of Bioethics has previously been ventilated by German author Fritz Jahr with his bioethical imperative and forester Aldo Leopold proposed an ethical reflection biocentric-oriented with his Land ethics.

Through exposure of the thoughts of Fritz Jahr and Aldo Leopold this essay will propose a counter-hegemonic genealogy of Bioethics. It intends to expose the field of Bioethics in a larger and deeper way, that put into account subjects such as the relations established between human kind and the environment, the links between non-human animals and human animals, a concern with a sustainable biotic community, et coetera.

Thru a documental analysis methodology we could restructure the genealogy of bioethical thought and, as a consequence, enlarge its field of work. This could resonate in social actions and practices in a way to promote a biocentric-oriented social emancipation.

Abstract number: 47	Medically Assisted Death. National Realities/ International Topics
ID: 172	<u>Edith González Moreno,</u>
oral	Mexico, Universidad Michoacana de San Nicolás de Hidalgo

The next test is to place the issue of medically assisted death in the context of some national indicators taking into consideration the arguments that have arisen around the issue in other countries. The first section defines some of the concepts that help us understand what we are referring to euthanasia and medically assisted suicide. In the second section the issue of medical and legal paternalism in Mexico is addressed considering that there are two elements that must be taken into consideration to fully understand the limits and possibilities of the options at the end of life and finally in the third paragraph is some arguments used in other countries considering what can be taken up to the Mexican case considering some particular characteristics of the country.

Abstract number: 48	The responsiveness requirement revisited: global attention for global health needs and priorities
ID: 173	<u>Rieke van der Graaf, A. Algra, D.E. Grobbee, J.J.M. van Delden</u>
oral	Netherlands, University Medical Center Utrecht

Background

Since the early 2000s various international ethical guidelines for human subjects research require that research with people in low- and middle income countries (LMICs) can only be conducted if the research is 'responsive to the health needs and priorities' of the population in which the research is conducted. The moral status of the requirement is intensively discussed. In order to clarify the responsiveness discussion the requirement will be analysed and evaluated in this presentation.

Analysis

Responsiveness appears to be multifaceted. It is interpreted as a local negative obligation that aims to avoid 1. exploitation of people in resource poor settings, or 2. displacement of local clinical care, as a local positive obligation that aims to 3. raise the standard of living by means of research or 4. strengthen the priorities of those living in LMICs in externally sponsored research, as a global negative obligation that tries 5. to avoid exploitation of disadvantaged groups in both resource poor and resource rich settings, and as a global positive obligation that aims to 6. strengthen the priorities of global minorities in global research.

Evaluation

The responsiveness debate has been restricted to the negative obligations of external sponsors in LMICs. This orientation has neglected moral obligations of internal sponsors in LMICs. Furthermore, empirical data show that the interests of several disadvantaged populations in high-income countries are also underrepresented in research. Furthermore, according to several theories of global justice we have positive duties to assist the globally disadvantaged, starting with accountability.

Conclusion

Responsiveness is not only relevant in externally sponsored research. For any proposed research project we may ask to what extent it addresses the needs and priorities of globally disadvantaged groups. As a first step towards global responsiveness, we may require accountability for responsiveness in protocols, journal papers and international trial registries.

Abstract number: 49	The ethics of priority setting for health systems research in developing countries: Should global priorities drive national priorities?
ID: 177	<u>Bridget Pratt, Adnan A. Hyder</u>
oral	United States, Johns Hopkins Berman Institute of Bioethics

Recent scholarship has applied theories of justice to consider what, if anything, rich people owe to poor people to achieve justice in global health and the implications of this for international research. Yet this work has primarily focused on international clinical research. Health systems research (HSR) is increasingly being performed in low and middle-income countries (LMICs) and is essential to reducing global health disparities. This paper focuses on identifying global actors' obligations of justice with respect to priority setting for HSR in LMICs. It, first, describes a concern raised in the literature on HSR in LMICs that priority setting for HSR at the global level drives or replaces national HSR priority setting processes. The result is the conduct of HSR in LMICs that aligns with global priorities imposed by donors such as HSR to advance the Millennium Development Goals.

The paper then considers whether this state of affairs is consistent with global justice, relying on a particular theory (the health capability paradigm) to assess this. It argues that, since state actors are in the best position to set their country's priorities for HSR, they have the primary obligation to do so under the health capability paradigm. Where states are unable to set their own priorities, global actors acquire secondary obligations to assist them that are consistent with their functions. Accordingly, entities that have expertise in research priority setting like the Alliance for Health Policy and Systems Research and COHRED must help LMICs to set HSR priorities at the national level (and build their capacity to do so). A number of requirements for this process of global actor-facilitated priority setting are identified and described. HSR funders have an obligation to fund projects and programs in LMICs that are consistent with the resultant national priorities, rather than global priorities.

Abstract number: 50 **Fit for the future: misdiagnosing the need for moral enhancement**
ID: 179 Felice Marshall, none
oral New Zealand, Victoria University of Wellington

Moral bioenhancement – the enhancement of moral dispositions through biomedical means – aims to improve moral capacities for the greater social good. One of the most discussed recent proposals for such bioenhancement comes from Ingmar Persson and Julian Savulescu. In *Unfit for the Future: The Need for Moral Enhancement*, they argue that human moral capacities have not kept pace with scientific and technological advances so we are now faced with a world in which our moral capacities lag behind the means we have to act immorally. They label the threat humanity faces due to this disparity as 'ultimate harm'. Ultimate harm includes disastrous climate change and the risk of nuclear annihilation. Persson and Savulescu argue that to avoid ultimate harm we must move beyond traditional means of moral enhancement and pursue moral bioenhancement through genetic and pharmacological interventions. I present two arguments against moral bioenhancement. First, I argue that moral bioenhancement will be ineffective in preventing ultimate harm. Moral bioenhancement is best understood as targeting moral motivation. I claim that merely enhancing people's motivation is unlikely to improve moral performance in a way conducive to preventing ultimate harm. In order for moral bioenhancement to be effective against ultimate harm it must promote structural reform. I claim moral bioenhancement would not accomplish this reform and hence would not be effective against ultimate harm. Second, I argue that moral bioenhancement may not just be ineffective but may actually be counter-productive towards preventing ultimate harm. This is because of the tendency of people to display single action bias. The prevalence of this psychological bias could hinder moral progress by misdirecting people's motivation towards ineffective moral bioenhancement instead of taking effective action to prevent ultimate harm.

Abstract number: 51 **Are parents ethically entitled to refuse fertility preservation procedures for their child with cancer?**
ID: 180 Rosalind McDougall,
oral Australia, Melbourne School of Population and Global Health, University of Melbourne

Cancer treatments are known to significantly compromise fertility. Procedures aimed at preserving fertility are thus routinely offered as part of cancer treatment in the paediatric hospital setting. Some parents refuse fertility preservation procedures for their children. In this paper, I consider whether parents are ethically entitled to refuse these procedures. I argue that future fertility is a compelling element of a child's wellbeing and thus that parents are generally not entitled to refuse fertility preservation. I suggest two exceptions: when the fertility preservation procedure is experimental (as is currently the case for pre-pubertal children) and when the procedure inhibits effective treatment of the cancer. Using Gillam's theory of the "zone of parental discretion", I claim that fertility preservation should be presented by health professionals as an assumed element of a child or young person's care. I also argue that hospitals and the state have associated obligations to provide structures and resources conducive to protecting children's future fertility.

Abstract number: 52 **OBSTETRICS AND GYNAECOLOGY RESIDENTS' KNOWLEDGE OF THE INFORMED CONSENT PROCESS AND IT'S PRACTICE IN THEIR TRAINING INSTITUTIONS**
ID: 184 Patrick Okonta, Nil
oral Nigeria, Delta State University Teaching Hospital

Introduction: The ethical principle of autonomy as expressed in the practice of informed consent is a core tenet of clinical practice and good patient physician relationship.
Aim: To identify specific gaps in the knowledge of trainee Obstetricians and Gynaecologists about the informed consent process and its content. It also sought to describe the practice of informed consent in their respective institutions.
Materials and Methods: A survey of Residents in Obstetric and Gynaecology attending the revision

course of the Faculty of Obstetrics and Gynaecology of the National Postgraduate Medical College was done to determine their knowledge of the informed consent process and its practice in their institutions.

Results: None of the residents was able to give responses that contained all five conditions for an informed consent to be valid. Furthermore, only 3 (2.22%) Residents mentioned that the name of the surgeon to perform the surgery should be part of the information provided to patients during the informed consent process. Similarly only 8 (5.93%) mentioned that consequences of not having the surgery should be part of the informed consent process. The concept of the 'emancipated minor' being competent to give consent was known by 38% of the residents.

Conclusion: Although Residents in Obstetrics and Gynaecology in Nigeria have some knowledge of the informed consent process, this knowledge is deficient in certain areas such as competency to give consent, content and scope of information to be disclosed to patients for surgery. There is a need to teach residents the rudiments of informed consent and bioethics in general.

Abstract number: 53 **BIOÉTICA Y ASEDIO GRUPAL (MOBBING) EN EL TRABAJO**
ID: 185 ROCÍO FUENTES VALDIVIESO,
oral Mexico, INSTITUTO POLITÉCNICO NACIONAL

This work shows the importance of the study and application of bioethics as a scientific, holistic and interdisciplinary discipline. The analysis of concrete social phenomena such as group harassment at work needs to be considered from a bioethical perspective to understand the emotions that humans develop in the workplace and its social consequences.

First I will try to explain what is meant by harassment at work group and its relationship to bioethics and then I will show why it is necessary to promote bioethics in the study of this phenomenon.

The methodology for conducting this study is qualitative. Its objective was directed to the study of suffering at work and seeking explanations on why it develops. The research is supported by interviews with closed and open-ended questions and follow-up of cases that have been collecting from various research projects on the subject, hence the analysis presented so far, is an exploration of the material observed in different institutions and work environments, in order to illustrate certain characteristics about the language used in the labor group siege and the effects it has on the lives of those who have suffered.

Abstract number: 54 **When eating and drinking may be harmful: Perspectives of patients and speech pathologists**
ID: 186 Belinda Kenny, N/A
oral Australia, University of Sydney

When healthcare professionals manage ethical dilemmas, there may be no absolute right or wrong solutions. Whilst Codes of Ethics provide a foundation for ethical decision making, each ethical dilemma includes unique features and requires sensitive consideration of patients' information, needs and consequences. This study explores speech pathologists' experiences with dysphagia management; an ethically complex area of professional practise. Speech pathologists, who shared their experiences of dysphagia management, were drawn from a broader qualitative study of ethics in the speech pathology profession. Participants were requested to describe the nature of ethical dilemmas they experienced in professional practice during individual work place interviews. Interviews were transcribed and narrative analysis generated ethical reasoning stories. Four cases demonstrate speech pathologists' approaches to managing ethical issues that may occur when managing adults who present with severe dysphagia. Their ethical reasoning stories demonstrate how experienced health professionals provide opportunities for patients to express their values regarding eating and drinking. The four cases illustrate how speech pathologists may adopt an important role within interdisciplinary teams when patients need to make informed choices regarding the nature and consequences of health care choices. The cases further show the application of principles and values espoused in professional codes of ethics during complex professional practice scenarios.

Abstract number: 55 **Biological Motherhood: What is it and why does it matter?**
ID: 192 Lindsey Porter,
oral United Kingdom, Lancaster University

In our everyday speech we use the term 'biological mother' (or sometimes, 'birth mother') to pick out the woman who is appropriately biologically, but not necessarily socially or interpersonally related to a given child. But this term is ambiguous, in both its extension and its import, particularly in an age of fast-advancing technology and techniques for assisting reproduction. It is unclear, for example, whether egg donors are biological mothers; whether donor-egg recipients are; whether there are multiple biological mothers in cases of mitochondrial transfer; and so on.

In this paper, I will ask, 'who is a biological mother?' What acts or features qualify one as a biological mother? Then I will address the ethical significance of being a biological mother: do biological mothers have duties towards their offspring in virtue of this biological relationship? Do they have rights over them? Is gestation morally transformative? Are merely biological mothers mothers, morally speaking? I will argue first, that on the most successful account of parental obligation, both genetic and gestational 'mothers' are appropriately causally (and thus morally) related to the child, such that we ought to consider them biological mothers. Second, that merely biological mothers are not mothers. But third, that biological mothers stand in a special moral relation to their biological offspring, and have duties towards their offspring in virtue of this moral relationship, even though they fail to meet the criteria for motherhood.

Several things follow from this conceptualisation of biological motherhood. First, it means that a given child can have (at least) two biological mothers. Second, it means that gestation is morally transformative. Finally, it means that non-parents have duties towards children similar to those which we would normally attribute only to parents.

Abstract number: 56 **The yardstick of the pharmaceutical regulation: which GCP issues may also be ethical issues?**
ID: 193 Rosemarie Bernabe,
oral Netherlands, University Medical Center Utrecht

Within the area of regulation of clinical trials, ethics has always been in the picture. However, which regulatory issues may also be considered of ethical interest has not been specified. This specification is necessary not only for ethicists who are interested in clinical trial regulation, but also for regulators evaluate these issues either for a new marketing authorization application or for post-marketing purposes.

To address this issue, we wish to identify which of the articles in the ICH Guideline for Good Clinical Practice (E6) may also be considered as being ethically relevant. To identify the relevant articles, we needed an ethical framework. Given that the goal is to identify regulatory issues that may also be of some ethical relevance, we thought it necessary to use a broad ethical framework. Hence, we put together five international ethical guidelines on research with human beings (i.e., Nuremberg, Helsinki, Belmont Report, Oviedo Convention, and CIOMS) and clustered their articles to formulate an inclusive ethical framework. We used this framework to identify the GCP articles that may be ethically relevant as well.

We wish to present our findings in the conference, along with an elaboration of how such issues may figure in actual regulatory work.

Abstract number: 57 **A lens on current documentation of Research Ethics Committees in South Africa which guide ethics review of research involving children as participants: a document**
ID: 195 Blanche Pretorius, S Kling & T Mayekiso,
oral South Africa, Nelson Mandela Metropolitan University

Background

Ethics review of research involving child participants continues to engender considerable debate for review committees. Central to the debate appears to be the tension that arises from epistemological and ontological perspectives between regulatory frameworks/instruments that exist and the evolution of the representations or constructions of children over time. This paper explores how child participants and their interests are represented in the content of documentation provided to researchers by Research Ethics Committees in South Africa.

Methods

The documentation of 21 committees currently registered with the National Health Research Ethics Council in South Africa was reviewed using the method of qualitative document analysis.

Results

Generally documentation reviewed showed a blending of compliance with regulatory and ethics frameworks and a pragmatic yet sensitive engagement with the 'real world' contextual realities of child participants.

Informed consent was reinforced as underpinning respect for autonomy and self-determination rights. While documentation was clear around parental consent, less clarity was evident around assent by child participants. Furthermore, examples of "best practice" emerged where innovative methods were suggested for engagement with children, as well as pragmatic guidelines for enrolling children in the absence of parental figures. Gaps were identified in the availability of samples of age-appropriate assent forms and information letters, and also with regard to compensation of child participants and their parents. Documentation reviewed was mainly silent around managing deeper complexities of assent such as dissent by children and how to deal with situations between dissenting child participants when there is parental consent.

Conclusions

The complexities in ethical research with children necessitate consideration of separate or specific ethics documentation. A need for clearer guidelines and the necessity for formative research data in order to strengthen a focus on children's participatory rights are highlighted.

Abstract number: 58
ID: 196
oral

Patent on genetic information – discoveries, inventions, processes and products
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For a technological product or method, in general, to be eligible for patent it needs to represent an invention, as distinctive from a mere discovery. According to Westerlund (2002), we witness "[t]he gradual expansion of the concept of an invention at the expense of discovery" in the biotech area. DNA technology presents hard cases for establishing a sharp line as its products, like a cDNA, might be understood as copies of substances that freely occur in nature per se, the only addition being purity and stability. Even though the copy itself is removed from the natural DNA's environment, the isolated substance essentially needs to carry over the informational content of the natural DNA, at least enough of it to be useful for diagnostic tests for example. An apparent reversal of the expansion of invention was witnessed in the recent US Supreme Court ruling in the case of Myriad Genetics' patented BRCA1 & 2 tests. The court ruled that naturally occurring DNA was not patentable, unlike complementary DNA sequences, the synthetically produced near-copy of a gene sequence. However, the ruling does not provide clearer and much needed criteria for deciding patentability of DNA, with the risk of biotech companies choosing secrecy rather than disclosure through patent (Ledford 2013). In this presentation, we discuss the distinction between invention and discovery from an ethical and political perspective, asking whether the distinction between product and process patents can be useful in clarifying the distinction between discovery and invention in cases like the Myriad patents. We will argue that developments in biotechnology threatens to render the traditional distinction between invention and discovery useless and that connecting biotechnological patents to processes instead of things is one way to reestablish ethical tools for determining patentability.

Abstract number: 59
ID: 198
oral

Strengths and weaknesses of guideline approaches to safeguard voluntary informed consent of patients within a dependent relationship
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Background

It is thought that a dependent relationship between patients and physicians who enroll their own patients in research could compromise voluntary informed consent. Therefore, several ethical guidelines for human subjects research provide strategies to mitigate the impact of a dependent relationship on voluntary informed consent. No systematic evaluation exists considering the effectiveness of these guideline strategies. Given that voluntariness of consent for research is considered absolutely essential, alleviations of threats to voluntary informed consent deserve examination. In this presentation, we analyze the strategies of ethical guidelines and discuss their strengths and weaknesses.

Results

Ethical guidelines use two different approaches to manage the impact of a dependent relationship on voluntary informed consent, some focus on the process, some on content. Both approaches could be of value to patients, when the influence of the dependent relationship is diminished or when providing information empowers patients to make voluntary decisions. However, both approaches also face several challenges: Physician-investigators will eventually be informed about decisions of their patients; research nurses are not as independent of patients' treatment as suggested; the right to withdraw cannot sufficiently be protected by simply pointing at this right; and this right may be difficult to act upon in a dependent relationship.

Discussion

Despite some potential value, the guideline approaches appear suboptimal safeguards for voluntary informed consent of patients within a dependent relationship. In order to provide additional protection for patients who are recruited by their own physicians, we propose a supporting role for physicians based on theories of shared decision making. Physicians should be aware of their own influence and communicate their conflicts of interest. Patient interests should never be made subordinate to research interests.

Conclusion

In order to appropriately protect patients within a dependent relationship a form of shared decision making should complement strategies of ethical guidelines.

Abstract number: 60
ID: 199
Oral

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México, Hospital General Dr Manuel Gea Gonzalez Secretaria Salud Mexico

The relevance of youth (10-24 years) in the national Mexican context lies not only in their numbers, but mainly by the challenge posed to society ensure the satisfaction of their needs and demands , as well as the full development of their individual capacities and potentialities. The proportion of adolescents in Mexico in relation to the rest of the population by the year 2010 we have about 30 million, 70 % adolescents and 30 % young people .There are few papers to discuss it bioethical issues related to health care for pregnant adolescents, considering the agreement and / or informed consent including ability to provide legal and medical autonomy to adolescents. These issues become more relevant if we consider that the pregnant teenager is at a vulnerable life situation.

The study was retrospective for data collection of informed consent and informed assent or agreement as well as demographic data of 887 cases of pregnant adolescent patients the informed assent is an agreement to participate in research or medical act by a person who has the legal or cognitive capacity to give regular informed consent

Results : in 43.17 % of the records was present the informed consent , in only 29.6 % had filled in full , in 57% of cases do not have a seated profit risk , nor is it mentioned what medical act was performed. In 61 % exist absence of their name and signature of the attending physician, in 58.9 % do not have the name and signature of the adolescent patient, in 68.3% exist deviation of informed consent in the absence of the name and signature of the parent or guardian.

Abstract number: 61
ID: 200
oral

Best interests in paediatric intensive care decisions - what can practical understandings tell us?
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Where children are unable to contribute to healthcare decisions, clinicians may share healthcare decision making with the child's family. The shared decision must be made with reference to the child's best interests, a standard that some suggest should take account of the wider interests of the child's family. Others counter that the child is the weakest party and the subject of the decision, so their interests should be given special priority. Little investigation has taken place of the understandings of best interests that operate in practice. This paper presents results from an empirical ethics investigation into understandings of best interests in life or death decisions in paediatric intensive care.

In a three year project funded by the Wellcome Trust, empirical and theoretical work is used to determine a concept of best interests that is both philosophically robust and practically useful in the treatment of infants without antecedent wishes in paediatric intensive care. The empirical investigation consists of 39 in-depth interviews with doctors, nurses, ethics committee members and parents in three UK hospitals. While further interpretation is currently being conducted, emergent themes include differences in the degree to which the child's interests are considered paramount or subservient to the family by different decision making groups, the way the physical appearance of the child is used in bargaining, methods by which decisions are shared in practice and the degree of independence of nurses and clinical ethics advisors within the decision making process. These early findings offer a platform from which to enrich current thinking about the validity of the best interests test and its practical implementation. Such understanding will help meet the challenge of making robust decisions that take account of the complex web of interests that surround children, without losing sight of the child themselves.

Abstract number: 62
ID: 201
oral

BIOÉTICA MULTICULTURALIDAD Y CÁNCER EN MUJERES ZAPOTECAS DEL ISTMO DE TEHUANTEPEC
ALMA ROSA FUENTES VALDIVIESO, ROCÍO FUENTES VALDIVIESO
Mexico, CENTRO DE ESTUDIOS DE PREVENCIÓN DEL CÁNCER A.C.

Este trabajo trata sobre una reflexión en torno a la multiculturalidad y las relaciones de género en el istmo de Tehuantepec Oaxaca, México. Interesa resaltar el aspecto emic, es decir, qué opinan las mujeres habitantes del istmo de Tehuantepec con respecto a las maneras de enfermarse de cáncer como resultado de un sufrimiento como por ejemplo, la violencia intrafamiliar, la vergüenza y la tristeza. La pregunta que rige nuestra investigación es ¿cuál es el posible papel de la bioética y el entendimiento de la cultura para tratar problemas de mujeres con cáncer? La bioética la consideramos como una de las disciplinas que pueden ayudar a mediar entre la cultura y los tratamientos médicos. Este trabajo de investigación es parte de un proyecto que iniciamos en el istmo de Tehuantepec con mujeres con cáncer y que nos interesa conocer sobre su sufrimiento y su enfermedad. La metodología es de corte cualitativa y se han aplicado entrevistas en profundidad a más de cincuenta mujeres, así mismo, se han reconstruido sus trayectorias de vida. Así proponemos que una aproximación desde la bioética holística dará cuenta de la relación entre cáncer y cultura en una sociedad indígena zapoteca debido a que estamos abordando la valoración de la vida de un grupo social y los avances de la medicina.

Keywords: salud, género, cultura

Abstract number: 63 **Ethics and climate change**
ID: 203 Santiago Outon G.
oral Mexico, UNAM

In recent years a certain agreement regarding climate change and its consequences for human and non-human life has emerged. However, the general population remains in the dark and knows very little about the situation or the strategies that may reduce the damage. Science has shown us the current state of the world as well as the probable scenarios we may face in the future should we fail to implement efficient measures, but this is not enough to make a real change in the perception of governments and people. If we are to face the environmental challenges we must take into consideration moral aspects, such as justice, equality and responsibility.

Abstract number: 64 **Ethical and political aspects of climate change**
ID: 204 Ma. Teresa de la Garza,
oral Mexico, UNAM

Undoubtedly, climate change is one of the most menacing problems that humanity faces. In order to face it, it is necessary to investigate its causes in an interdisciplinary way. Philosophy has to play a part in this important task, and I believe it is that of analyzing the ethical and political aspects of the problem, so we can better understand how is it that we found ourselves in this situation and how a change in the way we behave towards nature could help to face it.

Abstract number: 65 **How to promote integrity in research through bioethics committees at university level**
ID: 205 Itziar De Lecuona Ramírez,
oral Spain, University of Barcelona - Bioethics Commission

The European Union is now focused on how to promote integrity in research. As a part of the European League of Research Universities special group on "how to promote integrity in research". I will explore the contributions of bioethics committees at university level to promote integrity in research, prevent misconduct practices and capacity building for researchers in ethics, bioethics and scientific conduct. In this context some initiatives will be presented for networking and generating good practices in research, based on sharing knowledge on a virtual platform and ways of debating case analysis. An international trend of doing bioethics backed up by organizations with a leading role in bioethics such as UNESCO or the COUNCIL of EUROPE. It is time to apply the theoretical framework develop since the so called beginning of bioethics in the aftermath of the second world war to move to a more practical approach based on procedures how to do what principles and human rights establishes in international declarations, ethical codes, etc. In this sense the presentation will focus on protocols and statements that bioethics commission at university level have developed to deal with problems of authorship, thesis dissertations and publishing results of research, information and informed consent templates and uses of human biological samples in research and its results, data protection and data sharing, conflicts of interests, participation of students in research- including ways of coercion and undue influence-, and some initiatives to establish a common ethical and legal framework on research in social sciences. Moreover, initiatives such as MOOCs or capacity building and specific training in research will be explored. The intention is to show through the work of a special group of the LERU ways of promoting integrity in research taking advantage of the already bioethics infrastructure created at university level.

Abstract number: 66 **Just what is just in public health emergency preparedness and response? Preliminary findings from a qualitative study of public health policy-maker perspectives**
ID: 209 Maxwell Smith,
oral Canada, University of Toronto

A scan of the public health literature illustrates the centrality of 'justice' to the vocabulary of public health. Yet, the term 'justice' is often not defined in this literature, nor is it acknowledged that 'justice' has multiple meanings. This is problematic, as different theories of justice will ostensibly diverge in terms of what should be preferred in the organization and practice of public health. The use of the term 'justice' by public health actors and scholars might therefore represent distinct, if not conflicting, normative beliefs about the ethical goals and obligations of public health. Moreover, different beliefs about what constitutes 'justice' may exist in different public health contexts. There is some indication in the public health ethics literature that a distinct conception of justice obtains during public health emergencies. For instance, some argue that thinking about justice in public health emergency preparedness and response is 'pointless' because emergencies tend to

overwhelm society's capacity for rational thought. Others ask whether we should retreat to the utilitarian ethic during public health emergencies, making an exception to the ethic of justice that generally prevails. While an emerging body of philosophical work has begun to explore the concept of justice in public health, this work has not been sensitive to the notion that different norms of justice might exist, and perhaps should exist, in public health emergency preparedness and response, nor has it solicited the views of public health policy-makers and practitioners in order to understand what norms of justice might be operating in different public health contexts. This presentation explores this question by reporting preliminary findings from a qualitative study that explored the views of public health policy-makers about the meaning and role of justice in the contexts of public health emergency preparedness and response and chronic disease prevention.

Abstract number: 67
ID: 210
oral

Is there such a thing as personal utility in genomic testing?

Eline Bunnik,
Netherlands, Erasmus MC

In ethical and regulatory discussions on new applications of genomic testing technologies, the notion of 'personal utility' has been proposed repeatedly as an alternative to the traditional criterion of clinical utility. Whereas clinical utility refers to the ability of a genomic test to improve health outcomes, personal utility generally refers to the non-medical value of a genomic test and covers, *inter alia*, psychological and social effects of testing. The notion of personal utility has been used not only to describe wider rationales for testing, but also in justificatory ways: to justify direct access to commercially offered genomic testing, or feedback of individual research results to research participants. Sometimes research participants claim a right to genomic information with an appeal to personal utility. Participants usually prefer to be reported back as many individual genomic test results as possible, including test results of unclear clinical significance, for, they feel, these results may be personally meaningful. This presentation addresses two questions: 1) Is there such a thing as personal utility in genomic testing?, and 2) Does personal utility justify (direct) access to genomic testing? I will argue that perceived utility does not equal personal utility. When individual consumers or research participants claim that - for them - genomic testing has personal utility, they may be mistaken. I will outline a set of preconditions to personal utility, notably 'information' and 'reasonable potential use'. Although personal utility does highlight important values such as self-determination, access and wider notions of wellbeing, and may rightfully be considered in the evaluation of a genomic test, its role is not unlimited. Personal utility cannot replace clinical utility as a moral justification of the provision of testing, neither within healthcare systems nor on the direct-to-consumer market.

Abstract number: 68
ID: 212
oral

Bioethics, Law and Judicial Impartiality. Critical Analysis of the Artavia Murillo et al. v. Costa Rica Judgment

Hugo Ramírez,

The Inter-American Court of Human Rights (CrIDH is its Spanish language acronym) gave its judgment on the case of Artavia Murillo et al. v. Costa Rica on November 28, 2012. It stated that Costa Rica was responsible for breaching the human rights of many infertile couples, as recognized by the American Convention on Human Rights, which is also known as the Pact of San José (PSJ), including the right to private and family life and the right to enjoy the benefits of scientific and technological progress. One of the key points of the CrIDH interpretation, which underpinned its judgment, is directly concerned with the range of meanings of the term "conception," which appears in the wording of Article 4.1 of the PSJ.

The beginning of protection of the right to life depends precisely on the phenomenon to which the term "conception" refers. When it decided that conception meant the "implantation of the fertilized egg in the mother's womb" the CrIDH was choosing between two possibilities. What was the reasoning behind its decision? And can the justification be considered sufficient, given the importance of the decision and the precedent it sets? If not, the CrIDH was placing the principles of judicial independence and impartiality at risk, and undermining its mandate to interpret the content and scope of human rights.

Abstract number: 69
ID: 213
oral

Climate Change, health problems and anthropocentrism that overpopulates

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Keywords: Climate change, health problems, overpopulation.

Climate change is a pressing problem that deprives of a habitable planet to thousands of species that are in extinction and aggravates epidemics, causing new health issues and even death to some humans. The proposal of the IPCC and Earth summits about reduction of emissions are significant.

But the problem goes beyond the use of life-friendly technologies and the deceleration of capitalism. Although both aspects are indispensable, there is one that it has not been seen: overpopulation, which comes -as Lynn White pointed out years ago and Levi Strauss- from our cultural roots: Judeo-Christian anthropocentrism, anti-ethical by essence, marked us with arrogance, dominance, violence, possession, the dualistic cut with nature, thus, the narcissist enclosure unable to see the needs of other live beings. This anthropocentrism has declared us "owners of the planet" and gave a privileged way of such appropriation to "grow and multiply."

Population growth generates key factors of global warming: the increment in the use of energy and the expulsion of greenhouse gases; more inorganic rubbish (reducible) and organic (non-reducible) and the urban growth that produces heat and harasses endemic species. Furthermore overpopulation provokes the depletion of basic resources, all of them becoming not renewable: fertile soil, clean air, drinking water; is mining the capacity of renewal of Earth. More humans, more devastation - as John Sulston (Nobel Prize) and David Attenborough among others have seen it. I propose then a "non-anthropocentric" eco-ethics, capable of thinking about public and educational policies for reduction of new births -for love to Life and quality of human life.

Abstract number: 70

ID: 215

oral

Accounting for illness in the medical encounter - a tailored account of autonomy

Rebacca Tock,

Australia, Macquarie University

Being sick is common to the human experience; whether it is a runny nose, having a broken bone, or a more serious chronic disease, we can all sympathise with the feeling of being ill. It hinders our normal functioning and can severely compromise our ability to behave 'normally' and rationally. In medical ethics, patients are viewed as having autonomy in spite of their runny noses and broken bones. Theoretical accounts of autonomy discount the embodied nature of illness and its potential effect on the rational decision maker. Due to the particular and contingent history of medicine and a view of external influence as inappropriate for independent agents, influences on autonomy (both external and internal) have been viewed as the kind of thing we need to negate. However, in the case of illness and the medical encounter, it is surely counter productive to negate the significance of being ill when we consider patient autonomy in the clinic.

In this paper I will argue that the traditional, procedural model of autonomy used in medical ethics misses some important features of the experience of being ill and therefore fails to give an adequate account of autonomy in the context of illness. This model assumes that healthcare is centred on discreet, rational decisions that do not require context to be given normative value. I suggest that the clinical model of autonomy needs to incorporate the effect of illness on the patient in order to be coherent. Rather than adopting a conception borrowed from philosophy for the purposes of justifying decision making, medicine needs an understanding of autonomy that is tailored to the context of the medical encounter.

Abstract number: 71

ID: 218

oral

Against Pedigree: The Ethics of Artificial Selection in Dogs

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In this paper we want to argue that artificial selection in dogs is harmful to the individuals and is morally condemnable. Artificial selection is understood as the intentional breeding that aims at certain desirable traits to be expressed in successive generations. The term was introduced by Charles Darwin to distinguish it from natural selection, in which the differentiated reproduction of individuals leads their progeny to a better survival and inclusive fitness, being the environment a selective factor of the adaptive variations that remain.

Dogs and humans coevolved throughout history. Dogs, as we know them today, appeared around 14,000 years ago in Eurasia through a gradual process of domestication in which certain traits were selected. Some 6,500 years ago, there were only around five different types of dogs. As the selection practices became more common and specific, more breeds were developed. Even though many breeds are still used for work, looks became more important and, in many cases, functionality was surpassed by it. Today, there are 400-500 breeds of dogs, and most of them were developed in the last 150 years.

Artificial selection, however, does not improve survival-, functionality-, and health-characteristics in dogs: more than 400 diseases are recognized in purebred dogs caused by these means. Some of the selected traits per se are disadvantageous for the organism, for instance, strains in biomechanics due to alteration of the size and angles of bones and joints; loose skin, which predisposes different health conditions, and so on. The physiology of the organisms may be compromised to meet the breed standards, for example, very big or very small sizes.

To obtain the desired traits, endogamy has to be induced, and this is made mainly by inbreeding, in which the probability of expression of recessive genes increase, which may be detrimental both at the

individual and at the population levels. While selecting for desired traits, unknowingly, a selection for undesired traits may happen through different genetic mechanisms, such as deleterious conditions, modifications in behavior, and some characteristics that may not be desired by the breeder or are rejected by the breed standard. This may end up with the culling of the animal, either by killing it or just by throwing it away.

Who gains with artificial selection? Humans, not dogs. Dogs do not gain anything, but health problems and reduced survival capacity. Although the people involved know this, they maintain these practices and sacrifice dogs' quality of life, by using them as objects of profit in an enormous business, and to satisfy aesthetic and status ideals.

Abstract number: 72 Will neuroscience become an apology for violence? Disability, law and the aggressive legal subject
ID: 222 Karen O'Connell,
oral Australia, University of Technology, Sydney

As neuroscience evidence is increasingly used to explain complex human behaviours, including aggression and violence, bioethicists and legal scholars need to decide how such explanations will impact on legal responsibility. Much has been written about the idea that neuroscience will erode the concept of free will that seems an essential component of moral and legal responsibility. Should a person be responsible for behavior over which they do not have control? And if so, should they still be held to account in law?

To date, this scholarship has focused on criminal law and violent offenders. Yet law treats aggression as both a social threat and an individual vulnerability. In the criminal law, aggression is a form of anti-social behaviour that is highly regulated. Yet where there are biological explanations for such behaviour, it may be viewed as a disability, for which law is supposed to offer certain protections and mitigations.

As neuroscience increasingly ascribes biological causes to challenging or aggressive behaviours, these categories of disability are expanding in unexpected ways. If aggression is biologically caused, is it ethically and legally right to consider aggression a disability? And if so, what are the implications for law?

What too are the implications for gendered violence? There is a submerged theme of gender in the case law, where aggressive behaviour is more likely to manifest in men and boys with behavioural disabilities, without the implications of this for women being acknowledged or addressed.

Looking at cases from Australia, Canada and the United States where neuroscience and other brain-based sciences have been used to mitigate against legal responsibility for violence, or to protect legal subjects with disabilities that manifest as aggression, this paper examines a relationship that is growing more complex: that between the brain-based sciences, disability, aggressive behaviour and law.

Abstract number: 73 Editorial police what say you? Analysis of duplicate publications in PubMed.
ID: 233 Mario Malicki, Ana Utrobiticic, Ana Marusic
oral Croatia, University of Split School of Medicine, Split, Croatia

Background: Committee on Publication Ethics states that journal editors have a responsibility for pursuing suspected misconduct even in submissions they do not intend to publish, and provides guidance on how to publish expressions of concern, corrections and notices of retraction.

Aim: To determine how transparent are journal editors in their handling of duplicate publications.

Methods: We analysed 1011 articles listed as "duplicate publication" under publication type in PubMed on 16 January 2013, checked their titles, time from the duplicate article publication to the notice of duplication/retraction and analyzed their content, including reasons for the notice and duplication, and methods of resolving them.

Results: 680 (67.3%) duplicate publications identified in PubMed lacked any notice in their respective journals. 175 notices of 331 duplicate publications were marked as either Comments or Errata, however 97 (55.4%) of these were not linked to the articles at their respective journals' websites. Of the 175 notices, 112 (64%) reported author's error as the reason of duplication and 63 (36%) the publisher's error, yet only 23 (13.1%) were retracted. Of notices reporting author's error 45 (40%) do not mention contacting the author or the authors response. In 2 (2%) of notices, both published in the same journal, editors have decided to ban authors from further publication in that journal.

Conclusions: More than half of duplicate publications in PubMed have not been corrected by journal editors, and half of those that were not visible on journals websites. Furthermore, almost half of notices do not provide information on contacting the authors, and only 13% are followed by retractions. Journal editors seem to be unwilling to take actions in cases of article duplications. In order to preserve the integrity of the published record a more active role of all stakeholders is needed.

Abstract number: 74	Bioethics and Health in the Changing Caribbean Environment
ID: 235	<u>Cheryl Macpherson</u> , Muge Akpinar-Elci
oral	Grenada, St George's University School of Medicine (SGU) and Windward Islands Research and Education Foundation (WINDREF)

Globally, climate change is harming health, reducing food security, and generating civil unrest and national security concerns. The diverse but related harms have unique manifestations in different geographic, cultural, and socioeconomic settings. Given the resulting challenges for nations, institutions, and individuals, it is perhaps unsurprising that there is renewed interest in Van Rensselaer Potter's concept of global bioethics. Potter's global bioethics called for multidisciplinary work aimed at deepening our understanding of, and ability to sustain, the environment and natural resources that are essential for health and wellbeing. This conception of global bioethics grounds our cross-disciplinary bioethics and public health study of Caribbean health impacts of climate change. We conducted focus groups of health professionals in Grenada and Trinidad, among the nations most threatened by rising sea level and temperatures. Trinidad and Grenada are middle income nations with differing geographies; population sizes; levels of industrial development; and significantly different per capita CO₂ emissions. Participants were asked their perceptions of how climate change affects health in their nations. In both nations climate change was perceived as contributing to increasingly frequent and severe droughts, floods, and hurricanes, and as having increased hospital admissions for heat-related and vector-borne diseases therein. This presentation summarizes the perceived harmful health impacts in both nations, and frames these with recent and related bioethics and environmental ethics literature. Our study models a cross-disciplinary collaboration with both global and regional relevance in bioethics, public health, and other disciplines. Our findings highlight the urgent need to reduce global and regional carbon emissions, and reinforces the views that climate change is the biggest health threat of the 21st century and that no issue demands greater care in balancing benefits and risks.

Abstract number: 75	Acces to legal-bioethics data in networks
ID: 239	<u>Ma. Sílvia Navarro</u>
Oral	Spain, Biblioteca del Congreso Nacional de Chile

The progress made in Information Technology and Communications (ITC) has provided access to a vast wealth of information. However, this does not always lead to this information being verified and updated. This is particularly relevant in regard to tackling legal norms and deficiencies since the flaws are noticeable in the way analyses of legal text with bio-ethical implications are presented - whether verified or not- by not considering the social context and institutional space in which they have been drafted.

Regarding the reliability of the sources and the content used, it is often seen that access to the material does not occur directly through primary or official sources but through intermediaries; for example, websites that are not necessarily updates which provide links to other sites or do not certify the authenticity of the information they contain.

As regard the implementation of regulatory frameworks, bioethics papers often contain flaws in the handling and use of the information on which it rest. The shortcomings in this regard -committed by both lawyers and laymen- often cause to types of problems concerning the reliability and contextualization of such.

Unreliability and de-contextualization can lead both authors and readers to reach wrong opinions and approaches that are detrimental to a dialogue based on sound science. This can have a negative effect and can trigger the wrong decisions in public policy and new regulations.

Abstract number: 77	The Ethical Dilemmas of Assisted Reproduction and New Parenthood
ID: 243	<u>Jorge Carreño Meléndez</u> , M. Consuelo Henales Almaraz
oral	Mexico, Instituto Nacional de Perinatología

The assisted birth of Louise Brown in the late seventies heralded a new era in biotechnology. It offered the first indication that it is feasible to manipulate genetic material, making it one of the fundamental technological advances of the previous century. Today it places a cutting edge technological resource at the service of the vast majority of infertile couples. Cytoplasmic injection techniques have recently raised couples' expectations of having a biological child. Such rapid advances in biotechnology have left discussion of the emerging ethical dilemmas behind. New questions arise over when couples should use resources such as artificial insemination with donated sperm or eggs, surrogacy or cloning. One of the basic technological circumstances of this globalized world is the speed of communication via the Internet. It is possible to find auctions on the Internet for the sperm or eggs of fashionable actors or actresses, as well as uteruses for gestation, on offer to the highest bidder. This has turned reproduction into a service with a market-driven logic. We are at a new ethical crossroads with the

dilemma of whether to be guided by strictly biological or social criteria.

The fundamental goal of reproduction is for genetic continuity and consanguinity to create a bloodline and parenthood, and new forms of reproduction will bring new types of family bonds to Latin America. The breaking of the bonds of bloodline and parenthood recognized up until now will bring new freedoms, but also new responsibilities.

Abstract number: 78

ID: 244

oral

My brain made me not do it: Neurodeterminism and the negative sense of free will

Daniel Pallarés Domínguez,

Spain, Universitat Jaume I de Castellón (Spain)

Current neuroscientific results and techniques have reinforced the need for a deeper discussion of neurodeterminism vs free will. This presentation identify some problems that both positions face in the core of the neuroethics field, trying to establish a possible link between them.

Taking in account that human freedom is not absolute, but determined by diverse possibilities between which the subject must choose, I try to establish a correlation between free will and the term "conscious veto", introduced by Libet, and previously by Kornhuber and Deecke, in their study of the readiness potential a change in the electrical activity of the brain that happens before the subject's decision. The ability to inhibit a voluntary action that Libet identified might be interpreted as a possibility of free human action within the deterministic position. Assuming this common point between neurodeterminism and free will means that our ability to act notably moral action would be formulated in a negative sense. That is, humans do not possess a capacity for free will to perform an action chosen from all available, but to choose not to perform a certain action.

The confirmation of this hypothesis would have consequences for applied ethics especially for bioethics and neuroethics and introduce a new way of thinking about human action that might influence justice and education. It could change our vision of the authorship of a certain action, because the reason of doing an action will not be just in the brain or just in our volition, the cause will be shared by our anticipatory decision of our brain and our volitional control for not doing that. Moral education would not focus on giving reasons for some actions, but on justifying why to refrain from some actions.

Abstract number: 79

ID: 245

oral

A shared understanding? Attitudes of stakeholders to newborn screening consent practices

Stuart G. Nicholls, Brenda J. Wilson, Jamie C. Brehaut, Holly Etchegary, Beth K. Potter, Robin Z. Hayeems, Daryl Pullman, Jennifer Milburn, Pranesh Chakraborty, Monica Hernandez, Janet Marcadier, Laure Tessier, Charlene Simmonds, Lesley Turner

Canada, University of Ottawa

Background: Newborn bloodspot screening is routinely offered to all newborn babies in Canada. As with many procedures for children this requires proxy decision-making on the part of the parents. Moreover, technical advances have led to a situation where the information generated by screening can exceed providers' capacity to intervene therapeutically. Despite an abundance of data indicating parents' support for mandated screening in the case of treatable conditions, and a need for consent for those that are not treatable, these studies foster an implicit assumption that parents, healthcare professionals, and policy decision-makers have a shared understanding as to what terms such as informed consent imply, but also the requirements that the different approaches create.

Central research question: How are current consent practices to newborn bloodspot screening described by key stakeholders, what are the attitudes towards these different approaches, and how are attitudes associated with descriptions of different approaches?

Methods: Qualitative interviews with key stakeholders in Ontario and Newfoundland & Labrador, Canada.

Content of the presentation: We will present the results of semi-structured interviews with parents, healthcare professionals, and policy decision-makers regarding consent practices for newborn bloodspot screening. Specifically, we will present results of thematic analyses focussing on stakeholder interpretations of key terms such as informed consent and implied consent, together with evaluations of necessary requirements for different approaches within the newborn screening context. In particular we report perceived differences between these approaches, the principles invoked, and practicalities required by the differing approaches to consent. Finally, we will present analyses of the components of each approach, as described by participants, which appear to be determining stakeholder's assessments of ethical best practice

Abstract number: 80	Perceived benefits and barriers of telemedicine in Botswana: A preliminary study of two referral hospitals in Botswana
ID: 246	REKHA KUMAR,
oral	Botswana, UNIVERSITY OF BOTSWANA

World Health Association (WHA 58.28) clearly noted the potential impact that health advances in information and communication technologies (ICTs) could have on health care delivery and research on health. Currently, the telemedicine initiatives in Africa are operational (although, in piecemeal) in countries, such as, Sudan, Kenya, Burkina Faso, Tanzania, South Africa and Botswana. Most of initiatives lack mechanism of accountability, transparency, and evaluation in the way they operate in the countries. Small steps are being made in this direction in telemedicine/health in Botswana and they need to be examined critically. The paper focuses on the use of ICTs for health service delivery- via telemedicine in Botswana. A preliminary survey of 140 stakeholders was carried to find about the future prospectus /barriers in its growth and expansion in Botswana as perceived by health care providers including main two referral hospitals in the country. The research in its outcome attempts to draw attention to the fact that if the prospects are very high, so is the magnitude of the requirements with diversities in this region. The paper also bring forth an examination of the complex ethical challenges relating to privacy, confidentiality; data transfer, autonomy, decision making issues among others, yet remain unsettled in the region. The challenge is inextricably linked to the subject of regulatory issues, require further attention, and appear to be insufficiently appreciated in the African countries including Botswana.

The paper delve into some of the crucial issues in telemedicine, such as policies, access, equity, quality, and cost-effectiveness, facing health care in low resources settings like Botswana. It appears that understanding of meaningful participation in telemedicine operations in theory and practice is vital to explore specially the oversight of incompatible cultural subsystems that prevent the transfer of knowledge from one cultural context to another.

Abstract number: 81	Does migration lead to unjustified disparities in health care? A factorial survey among physicians in Switzerland
ID: 247	Daniel Drewniak, Tanja Krones; Verina Wild
oral	Switzerland, Institute of Biomedical Ethics, University of Zurich

The equal treatment of patients is one of the core values in professional medical ethics. The Geneva Convention calls for treatment without any "adverse distinction founded on sex, race, nationality, religion, political opinions, or any other similar criteria". There is a substantial body of empirical literature showing that race and ethnicity have an influence on medical decision making. Recent studies indicate that physicians' implicit attitudes related to ethnicity are associated with different treatment recommendations or that patients' ethnicity influence the patient-provider communication. However, little is known whether and how (irregular or regular) migration status influences decision-making in the clinical setting. Even though questions about migration overlap with questions about ethnicity and race, we claim that migration brings with it specific potential barriers (e.g. related to legal requirements or language issues) and requires specific areas of health care professionals' education (e.g. not only cultural competency but also knowledge about legal and human rights). In order to find out more about which factors actually influence medical decision-making and to which degree we conducted a factorial survey among 1180 physicians in Switzerland. One of the methodological advantages of factorial surveys is that it is possible to investigate the influences that are responsible for the constitution of a judgment. The method is especially suitable for research questions that evaluate topics of high complexity. Among the factors surveyed were insurance status, citizenship, ethnicity, language, severity of disease, educational background and others. In our presentation we will 1) describe the study method, including our experiences with its practicability in empirical bioethics. We will 2) present the findings and show which relevance migration status, citizenship and insurance status have in the context of clinical care. Finally we will 3) discuss our results in the larger context of migration and healthcare disparities.

Abstract number: 82	The ethics of sham interventions in an era of emerging biotechnology
ID: 248	Sophie Niemansburg, Johannes J.M. van Delden, Wouter J.A. Dhert, and Annelien L. Bredenoord
oral	Netherlands, Department of Medical Humanities, Julius Center, University Medical Center Utrecht, The Netherlands

An important ethical challenge in the design of clinical trials is the choice of the comparator. Especially the use of surgical (invasive) placebos, also called sham interventions, is ethically challenging. It is time to reconsider the ethical debate about sham, especially in response to two developments. First, an increased number of clinical trials investigating Regenerative Medicine (RM) interventions is expected, in which the choice for a placebo requires a sham procedure. Second, there is an increased

awareness of the lack of systematic research in surgery, raising debate about the acceptability of sham-controlled clinical trials.

Aim and method

To discuss the ethical acceptability of sham interventions by means of literature review and ethical analysis, to facilitate the debate about sham procedures in emerging fields like RM.

Results

Review of the literature shows agreement that insufficient compelling reasons exist to consider sham-controlled trials unacceptable a priori. Sham interventions are considered ethically acceptable provided the conditions of social value, scientific necessity, reasonable risks, and valid informed consent are fulfilled. The main dispute in the literature focuses on when sham is scientific necessary, and when the risks of sham are reasonable.

Discussion

When sham is scientifically necessary should be addressed by clear methodological criteria concerning, for example, the outcome measures and the goal of the study. Reasonableness of risks should be determined by the criterion of risk-benefit proportionality. Similar to clinical research such as phase I trials, justification of risks to participants might be sought in the social value of the study, instead of individual benefits.

Conclusion

Although sham procedures are morally salient, mainly due to its risks, trade-offs between individual risks and social value are inherent to clinical research. Sham-controlled trials should not be treated as categorically different types of clinical research and are conditionally acceptable.

Abstract number: 83 **LTE in Psychotherapy**

ID: 254 Gabriel Mercado Velázquez,

oral Mexico, Sanatorio San Francisco de Asís S.A. de C.V.

The limitation of therapeutic effort (LTE) has important ramifications for how information is handled in psychotherapy and the extent to which it must be integrated and resolved by both the therapist and the patient in the sessions. To what extent should the patient expect the therapist to reveal their situation to them, and through it construct new integrative processes? How far should the therapist go in bearing the soul of the patient in order to ensure their wellbeing after the therapy session, without jeopardizing the patient's dignity and security in the process? How should the therapist retain and manipulate information in line with the own code of ethics or the patient's rights? The goal is to identify models in which patients are the sole owner of their data and who will dispense it according to their ability and the potential for integration.

Abstract number: 84 **Physician acquiescence, medical virtue, and evaluative conditioning in direct-to-consumer pharmaceutical advertising**

ID: 255 Justin Oakley,

oral Australia, Monash University

Some ethical analyses of Direct to Consumer Advertising (DTCA) of prescription pharmaceuticals suggest that physician acquiescence to patients' DTCA-based drug requests undermines the therapeutic orientation of physician-patient relationships and medical virtues. However, some empirical studies of such physician behaviour suggest that physician acquiescence to such requests can in certain cases be in their patients' best interests. Ethical discussions of such issues rarely investigate how patients' drug preferences can be influenced by evaluative conditioning in DTCA. In this paper I present the results of several original empirical studies of evaluative conditioning in pharmaceutical DTCA, as a basis for examining whether physician acquiescence to patients' drug requests can be in their patients' best interests, in cases where the preferences underlying such requests seem to result from evaluative conditioning. In doing so, I also consider whether or not evidence of the intractability of such conditioned preferences supports claims that physician acquiescence in this context can sometimes be in their patients' best interests, and so could be consistent with both medical virtue and the therapeutic orientation of good physician-patient relationships.

Abstract number: 85 **Evaluation of the End-of-Life Clinic**

ID: 256 Marianne Snijdewind, Dick Willems, Luc Deliens, Bregje Onwuteaka-Philipsen, Kenneth Champaere

oral Netherlands, Academic Medical Center Amsterdam, University of Amsterdam

Context: Since 2012, an End-of-Life Clinic (ELC) has become active in the Netherlands. Patients whose request for euthanasia or physician-assisted suicide (EAS) is refused by their attending physician can register at this clinic. If the case meets the Dutch due care criteria, physicians working for the ELC are willing to perform EAS. Public ethical concern is that it will be practically impossible for the ELC to reject requests.

Objectives: To evaluate the ELC after one year of practice with focus on patient characteristics and accepted and refused requests.

Design: Data was used from all registration forms the ELC received in the first year of existence and supplemented by patient files, to include the request's outcome.

Results: The ELC received 709 unique registrations during their first year. 47% of these cases patients suffered from a somatic illness, 27% suffered from psychiatric illness, 10% suffered from both a somatic and a psychiatric illness, 8% suffered from dementia and 8% were tired of living. The ELC performed EAS in 14% of the cases and 47% of the cases were refused by the ELC. Of the remaining 39%, the patient died naturally or by unassisted suicide (19%), the request was granted by the attending physician (11%) or the patient withdrew his request (9%).

Conclusion: The ELC rejected a great number of cases; this could indicate a thorough assessment, or either question the justification of the ELC's existence, since the attending physician correctly assessed the case by rejecting it. Cases in which the patient died before the ELC could assess the request and cases in which the patient withdrew his request, show the complex balance of making a quick decision to grant the patient's wish and waiting long enough to give the patient the possibility to reconsider his decision.

Abstract number: 86

ID: 258
oral

Incidental Findings through Imaging in Population-based Research: Participant Perspectives

Lisa van Bodegom, Prof. dr. I.D. de Beaufort, Dr. W.L.A. Pinxten, Drs. E. Bunnik
Netherlands, Erasmus MC, Medical Ethics and Philosophy of Medicine

The Rotterdam Study is a large population-based cohort study (\pm 15.000 subjects) that focuses on causes and consequences of age-related diseases. Brain MRI scans, an important component of this study, sometimes show unexpected asymptomatic brain abnormalities, which are designated as incidental findings (IF). IF are findings of potential health relevance unexpectedly discovered within research beyond the aims of the study. IF can have a profound impact on the lives of research participants in both beneficial and harmful ways. Because of this twofold character IF raise ethical problems.

In a research climate where the use and quality of imaging is growing exponentially an increase of IF is expected. It is, thus, important to further develop guidelines for a morally responsible management of IF. Existing guidelines require that research should anticipate and articulate IF in the study design and establish a protocol for handling them. Also, the possibility of discovering IF should be included in the informed consent process. Furthermore, most guidelines presume a responsibility to report certain IF based on researchers obligation to respect subjects' autonomy and interests.

Existing guidelines on IF, however, are mostly based on expert opinion. Stakeholder perspectives are largely missing in the development of these guidelines. Very few empirical data on the concerns, motivations and interests of research participants in population studies exist. It is important to fill this knowledge gap to be able to take participant views into account. Our research project 'Previously Healthy? An ethical approach of incidental findings through imaging in research', sheds light on Rotterdam Study participants' preferences, expectations and values through case descriptions and interviews. We will present the results of a series of interviews of participants who were confronted with IF and discuss a set of challenging cases.

Abstract number: 87

ID: 265
oral

Population studies and the ethics of representativeness

Hallvard Fossheim,
Norway, The Norwegian National Research Ethics Committees

Population genetics studies are of great interest not only for their potential to disclose shared features for a certain group and thus facilitate better health care for the population in question, but also for the way in which these studies can help us realize past migrations and patterns of interaction. In contemporary studies, populations are normally defined by the researcher at the outset, and the data is gathered on the basis of this definition. This state of affairs in some cases raises two ethical conundrums which should be faced by the investigator before launching such a study.

(1) If the group is in any way racially/ethnically determined, the researcher has a responsibility to acknowledge the fact that the relevant group identity is not simply the aggregate identity of the individuals involved, but is something which ought to be respected in its own right.

(2) If the ethnic group in question is not on beforehand unproblematically defined in a way about which there is broad consensus within as well as outside the group, the researcher has a *prima facie* responsibility to ensure that alternative understandings are appropriately acknowledged.

I will argue that the common denominator in both issues is the question of representativeness, and that a solution in terms of representativeness will provide viable replies to each of them. As part of the argument, I will suggest a general solution to the challenges relating to determining a reasonable and required division of labour between researchers and participant groups in ensuring a responsible consent process.

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- Abstract number: 88** "Understanding decision-making in the setting of Mexican adolescents who died of cancer: preliminary results of a qualitative research study"
ID: 268
oral Carlo Egysto Cicero-Oneto, Valdez-Martinez Edith, M.D., M.Sc., PhD.
Mexico, Hospital Infantil de México, \Federico Gómez\"
- Background:** Cancer is the second cause of death in Mexican children, only behind accidents. Little is known about the decision-making processes in this specific context, and what is known comes from high-income countries. This is the first study that emerges from a population sample that represents middle-income and developing countries.
- Objective:** To examine parent and paediatric oncologist decision-making when cancer therapy is no longer curative. Specifically, we were interested on three essential areas: (1) how agreement is reached, (2) perspectives of the different actors, (3) characteristics of child death and care delivery.
- Methodology:** Using grounded theory methods we interviewed parents of five adolescents who died of cancer and five primary paediatrics oncologists at a tertiary paediatric hospital in Mexico City. Face-to-face in-depth interviews were carried out from July to October 2013. Patient charts were reviewed for demographic data, time from terminal-stage-medical-decision to death, age at death and type of palliative care. This study was approved by the research ethics committee.
- Results:** The present data demonstrated that the way information about futility and palliative care was given, directly influenced the decision made by the parent. Oncologists' perspective was strictly biological, while parents accepted the therapy proposed without question, because of the authority doctors represent to them. Most of the adolescents received basic support and palliative chemotherapy. Three out of five died at the hospital; parents and oncologists would have preferred that the adolescent had died at home.
- Conclusion:** This study is part of a larger, current ongoing, research work on decision-making process in this specific context.
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- Abstract number: 89** Dialling international for consent to deceased donation – ethical hazards in family consultation
ID: 277
oral Dominique Martin, Dr Riadh Fadhil
Australia, The University of Melbourne
- Consultation of families of potential deceased organ donors is routine practice in countries with opt-in, or even opt-out consent systems. Families play a vital role in the decision making process for donation, and routine consultation fosters trust in the donation process at the personal and public levels. In some countries, families may be unable to attend the potential deceased donor and participate in on-site discussions about donation with healthcare professionals, due to economic or geographical factors that impede timely travel to tertiary healthcare services where potential donors are customarily located.
- In Qatar, a country in the Gulf peninsula where expatriate workers comprise the majority of potential donors, consultation with family members primarily occurs through telephone contact, although provision may be made to assist family members in traveling to Qatar to attend their relatives at times of life threatening illness. Establishment of telephone contact may be difficult, and where established, discussion of donation may be hampered by familial distress and lack of familiarity or understanding of deceased donation.
- In this paper, we discuss the ethical dilemmas surrounding family consultation in this setting; in particular, whether families should be consulted in the case of individuals who have previously registered their informed consent to donation in Qatar. The risks of exacerbating familial distress and undermining the autonomy of registered donors are weighed against the importance of promoting trust in the integrity of the donation program among expatriate communities, and a set of proposed strategies are briefly reviewed which aim to optimise public trust within and beyond Qatar and to minimise familial distress with minimal loss of deceased donors through familial override of registered consent to donation.
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- Abstract number: 90** Bioethics Education for Ecological Researchers
ID: 282
oral Gillian Crozier, Albrecht Schulte-Hostedde, Dylan Gault
Canada, Laurentian University
- Despite growing recognition that ecological research has important ethical implications, this field has not yet created 'cultural space' for the discussion of the ethical dimensions of field research methodologies. Ecological researchers rarely received any training in the ethical dimensions of their work, in graduate school or otherwise, and ethically salient dimensions of methodological decisions

are not discussed at conferences or in publications.

To illustrate, consider a case wherein a group of ecological researchers have long studied a particular population of organisms that have recently fallen prey to a voracious predator; the researchers must choose between, on the one hand, safeguarding future research projects by protecting this study population on which so much longitudinal data has been collected, and, on the other hand, hunting the predating animal or animals, possibly even leading to the disrupting of the natural cycles of the local ecosystem. Dilemmas like these are why it is critical that ecological researchers be given the opportunity and the conceptual tools to discuss the ethically salient dimensions of their work, and this is where the introduction of ethics education for ecological researchers would help.

We identify two elements that should be central in the development of an ethics curriculum for ecological researchers: a set of ethical principles that can apply to both the human and non-human entities that are impacted by field research design, and instruction in various kinds of uncertainty as they pertain to ecological research. By introducing these bioethical and epistemological tools into the graduate school curricula for ecological researchers, and by offering similar bioethics training courses for professional field ecologists, a 'cultural space' can be opened up for the discussion and debate of the ethical implications of ecological research.

Abstract number: 91 **Pertinencia de los componentes éticos de la ciencia biomédica para la investigación social en salud mental**
ID: 283 **oral**
 Dr. Liliana Mondragón
 Mexico, Instituto Nacional de Psiquiatría Ramón de la Fuente

ANTECEDENTES. La investigación social en salud mental presenta desafíos éticos propios del estudio de fenómenos como la violencia, las adicciones, el suicidio, entre otros. Una de las razones es que en esta área se trabaja con poblaciones denominadas "vulnerables". Se trabaja, también, con datos sensibles de los sujetos de investigación, riesgos "indirectos" o menos tangibles, lo que conlleva a la posibilidad de suscitar, ya sea por omisión, inopia o propensión, el estigma, la discriminación, la violación a los derechos de los participantes o, bien, el atropello de su dignidad. **INTRODUCCIÓN.** Los requisitos éticos que han guiado los estudios sociales en salud son los postulados para la investigación biomédica. Sin duda, es de gran relevancia lo expuesto en códigos y declaraciones internacionales sobre ética. Pese a ello, conocemos muy poco sobre cuál es la congruencia de aplicar algunos elementos éticos de la ciencia biomédica en la investigación social sobre salud mental. **OBJETIVO.** Este trabajo tiene como propósito analizar la pertinencia del consentimiento informado y proporción favorable de riesgo/beneficio para la investigación social en salud mental. **MÉTODO.** Estudio descriptivo en el que se llevó a cabo una encuesta piloto, a través de un cuestionario en formato electrónico, con un grupo de científicos sociales, hombres y mujeres, que trabajan líneas de investigación en salud mental (violencia, adicciones o suicidio), previo consentimiento informado. **RESULTADOS.** Los hallazgos indican que la mayoría de los investigadores estiman procedente la aplicación del consentimiento informado y la proporción favorable de riesgo/beneficio en la investigación social. Sin embargo, existen particularidades de los estudios sociales que podrían cuestionar la aplicación de ambos componentes éticos, por tal razón, es necesario considerar el entramado de relaciones que se dan en un contexto social estudiado para dilucidar una pertinente aplicación de consentimiento informado y la proporción favorable de riesgo/beneficio.

Abstract number: 92 **Towards an Epistemology of Bioethics**
ID: 286 **oral**
 José Antonio Sánchez Barroso,
 Mexico, Universidad Panamericana

Acknowledging that "using criteria to judge a work" is not the same as "knowing the criteria on which a work is judged," this paper applies the principles of the theory of knowledge to bioethics. It therefore sets out an epistemology of bioethics, with guidance on: i) how and where to find out about the ethical criteria for human action in relation to the possibilities of life and development arising from technological-scientific progress, ii) the value or certainty that we should place on ethical knowledge and iii) the place of the latter in relation to truth.

It is assumed that the purpose of all thinking and theorizing is always oriented to the truth. According to this principle, the epistemology of bioethics can be characterized in two ways: 1) beginning with the first absolutely certain truth that is existence itself, man's aspiration to acquire universal knowledge to help understand the world around us, and to understand ourselves better for the sake of greater self-realization, and 2) that the essence of truth is indifferent to the vicissitudes of universal suffrage, since the unanimous agreement of all people makes not an ounce of difference to the truth. When talking about the concept of truth in bioethics we should be aware that we cannot criticize the work of fellow humans, in other words, we cannot pass judgment on the morality of individual acts such as euthanasia, abortion, assisted reproduction, environmental protection and so forth, without first formulating studies into the foundations of moral behavior, i.e. on how man may discover or learn

the ideals or criteria for his actions or the foundations on which he builds his moral life. This study is inextricably bound by the level of bioethics today, drawing on the "epistemology of bioethics." It is proposed that: i) all logical and rational explanation of a thing always points to the truth, ii) to the extent to which it is achievable, it is human nature to want to seek and know the truth, iii) man is able, to some extent, to distinguish truth from falsehood, which means, in turn, having some notion of truth with which to judge the value of knowledge, iv) it is human nature to let actions and moral decisions be guided by a notion of what is right, whether they are one's own, another's, or a combination of the two, v) the moral life of man requires a certain degree of certainty, and vi) all actions and all moral decisions must be supported or upheld by reasons.

Abstract number: 93

ID: 287

oral

Rocky Mountain spotted fever in Sonora: an epidemiological problem or an ethical neglect?

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Mexico, Universidad de Sonora

Rocky Mountain spotted fever (RMSF) is a life-threatening disease having an epidemic pattern in Sonora since a decade. RMSF affects people of any age, but is particularly serious in certain vulnerable individuals such as children, causing a high mortality and other severe medical complications, if not promptly diagnosed and properly treated. In Sonora, RMSF has had a higher burden of morbidity and mortality in people living in poverty and social deprivation, such as migrant populations and children with diminished social cohesion and limited educational and financial resources. The substrate of these adverse conditions is the social injustice that denies equality of opportunities to people to meet their basic needs. It is also the basis of unfairness in the distribution of resources, which creates barriers to effectively deal with health-related problems, such as RMSF.

It is known that the effectiveness of medical interventions to face RMSF is based on the quality and timeliness of diagnosis and treatment. Additionally, we propose that to succeed in their public control and to reduce its impact in Sonora, a bioethical approach is required. This paper discusses ethical issues related to the efforts done in Sonora to address the epidemic of RMSF. Moreover, examines the level of participation and responsibility of stakeholders involved in technical and political aspects of the disease, and makes a reflection on the importance of using bioethical approaches in the design of public health interventions to reduce the impact of the disease, especially in vulnerable populations.

Abstract number: 94

ID: 290

oral

Ethical Considerations for a Tobacco Phase-Out

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Within the tobacco control community, recent years have seen the development of a new literature on a type of public health strategy termed the 'tobacco endgame': the idea that tobacco consumption should not be controlled, but phased out entirely in order to – eventually – eliminate tobacco-related deaths and morbidity. Various countries, such as Finland, New Zealand, Australia, Singapore, and the UK, are already involved in this movement. The most talked-about strategies include: stricter implementation of already-existing measures, such as raising tax and more smoke-free areas; harm reduction, i.e. the replacement of cigarettes with alternative products such as e-cigarettes; and the tobacco-free generation proposal, which would deny tobacco sales to citizens born after a certain date, effectively phasing out tobacco use among younger generations.

Among public health advocates, the general consensus is that the enormous, ongoing scale of tobacco-related public health issues justifies the implementation of a tobacco endgame. However, implementation of a tobacco endgame is likely to receive libertarian criticism: the view that tobacco phase-outs are overly restrictive, and an unreasonable intrusion of the human rights to liberty, self-determination, and privacy. Thus, this paper looks more closely at these ethical aspects in order to answer the question: are tobacco endgames an undue infringement on individual liberty, autonomy, and privacy, or a long overdue and ethical pursuit of life, health, and the common good?

Abstract number: 95

ID: 294

oral

The mission of an ethics committee apropos social studies: the experience of the Ethics

Committee for the Research on Human Beings and Animals of the Pontifical

Gisela Isabel Fernández Rivas Plata, ----

Peru, Pontifical Catholic University of Peru (PUCP)

The Committee for the Research on Human Beings and Animals (from this point forward the Committee) was created in 2009 due to the need of various PUCP researchers to accredit their work at internationally relevant academic spheres. Under several processes improvements realized by

PUCP's Vice-Rectorate of Research, the committee was conceived to generate objective indicators measuring research quality.

During 2012 and 2013, the Committee has perused 724 projects, 355 of which included field work on human beings and/or animals. More than 80 percent of these 355 projects belonged to the field of Social or Human Sciences. In this sense, having examined social scientific research and not biomedical research, the experience of the Committee proves to be particularly relevant since its focus has been granting permission based on different populations, among other criteria.

It is also important to note that, despite the universality of research ethics, the operationalization of its principles regarding social research involves considering the specificities of each submitted project. Therefore, the elaboration of informed consent protocols is one of the main discussion topics, since the work of PUCP researchers on Social Sciences (mainly Anthropology) and Humanities (mainly Psychology) at most times involves contact with particularly vulnerable populations, such us indigenous and rural communities, populations of African ascent, disabled people, female violence victims, minors, illiterate people, among other.

Abstract number: 96

ID: 298

oral

Parental autonomy and choice in the context of prenatal diagnosis. Views and attitudes of healthcare professionals and prospective parents

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Background: With the expansion of prenatal diagnostic options, we have been challenged to redefine our understanding of parental autonomy and responsibility. Parental choices are publicly analyzed, approved or disapproved; some argue that parents have the moral obligation to enhance the genetic makeup of their children, others consider this goes beyond normal parental duties. The public and scholarly attention goes to the social anxiety around the limits of procreative freedom and the increasing tension between individual rights and community interests.

Objectives: Our study focused on the experiences of healthcare professionals (HCPs) and families regarding current counseling practices. On the one hand our objective was to get an insight in HCPs' views on parental autonomy and responsibility and to see whether/ to what extent they influence parental choice in concrete counseling situations; on the other hand we explored parents' decision-making, to see if they experience limitations in their choices and to assess their needs.

Methods: In-depth, semi-structured, face-to-face interviews (n=41) were conducted with HCPs; a grounded theory approach was used to analyze the data. Besides 260 questionnaires were completed online by parents with a recent experience of prenatal diagnosis; we used Qualtrics software for handling the questionnaire.

Results: HCPs expressed a strong striving for non-directivity and commitment to respect parental autonomy and choice. However, they also formulated dilemmatic situations where they experienced tension between this ideal and the challenges of the practice. The great majority of parents were satisfied with counseling, some desired more emotional support and active implication of HCPs in their decision-making. Both groups suggested concrete ways of enhancing decision-making support.

Conclusion: Given that prenatal diagnostic technologies are rapidly evolving, ongoing academic and societal debate are critical. HCPs' and parents' views represent a good starting point in this regard.

Abstract number: 97

ID: 300

oral

Migration o Elderly People in Need of Longterm Care and its Ethical Issues

Christine Bally-Zenger, Dr. med. Verina Wild

Switzerland, Institute of Biomedical Ethics, Center for Ethics of the University of Zurich

The migration-flows of elderly people in need of longterm care from Western countries to threshold countries like Poland or Thailand is a phenomenon that has hardly been analyzed by ethicists. Due to demographic changes and the foreseeable shortage of health-care professionals in the longterm care sector, the likelihood of an increase of this kind of migration is high. Such care-migration is often financially motivated. People in need of care, or their relatives, claim, that they cannot afford a qualitative good care in their home country.

In our presentation we will discuss different ethical arguments of care-migration:

First, the individual who seeks care: It is questionable whether it is ethically right to "outsource" the care of the elderly, frail and therefore vulnerable people – especially people with dementia – and by this to irritate and burden them even more. In contrast, it might be of equal value or be an advantage for the elderly to get care abroad.

Second, care can be seen as a "business", which reacts upon demand and supply. Nurses might therefore prefer working in the higher paid private sector with foreigners than with the local population.

Although the freedom to choose working places should be respected, care-migration could affect the local population negatively – which implications from the perspective of global social justice arise? In which way do affluent countries have the responsibility to provide good and affordable care for their citizens?

And third, the question is elaborated what constitutes “good” care in a distant country within a different cultural context – particularly because qualitative good care is one of the main arguments named in favor of care-migration.

In our conclusion we will argue for a balanced approach to care-migration and for some safeguards that need to be considered from an ethical perspective.

Abstract number: 98 The Three Most Important Ethical Principles in the Prioritisation Debate.

ID: 301 Bert Vanderhaegen,

oral Belgium, Ghent University Hospital

Prioritisation in healthcare is an issue of growing importance, especially in the Western world. Prioritisation has always existed. However, in a democracy people should have the right to know and to influence the grounds on which health priorities are decided. One way of achieving this is to reveal the decision makers’ views concerning prioritisation. However, the debate about prioritisation should also be held on a basic level. The general public must be made aware and eventually choose which principles should be used concerning prioritisation.

In this paper I want to propose three basic ethical principles which should guide the public in the prioritisation process and have to be known and accepted by the public.

The first principle is the principle of human dignity—meaning that human dignity should not be dependent on people’s personal qualities or functions within the community, but is a part of their very existence. The second principle is the principle of need and solidarity—meaning that most of the care resources should be given to those who are most in need. The third principle is the cost-efficiency principle—meaning that the aim should be a reasonable costs/effect relationship, measured in terms of improved health and enhanced quality of life.

Some would like to add a fourth principle which is much more controversial: the principle of personal responsibility for one’s own health. The implication is that one is personally responsible for both the prevention of ill-health and for choosing a healthy lifestyle. Along with that there is also suggested that individuals should take a certain amount of financial responsibility for public healthcare. In this paper we deal with the question concerning which principles should guide prioritisation. We assess if the principle of personal responsibility should be a guiding principle in the debate.

Abstract number: 99 Interpreting the body: bioinformation as a tool of self-conception

ID: 302 Emily Postan,

oral United Kingdom, University of Edinburgh School of Law

Research question:

How should we understand the claim that information about an individual’s body or health could be important to their identity and what determines which information has this kind of value?

Methodology:

This paper provides conceptual analysis intended to inform ethical decision-making about the governance of bioinformation. It is a theoretical discussion illustrated with real-world examples, drawing on philosophical and sociological literature as well as legal and regulatory sources.

Content:

It is increasingly common, in contexts ranging from the European Court of Human Rights, to neuroscience publications, to encounter claims that receipt of information about one’s own biology may be important to one’s identity.

Missing from these assertions, however, is clarity about the nature of the relationship between personal bioinformation and identity. My contention is that, without addressing this omission, it is not possible to understand the nature or scope of an individual’s interests in this information; nor can we ascertain the associated responsibilities of third parties. I suggest that this relationship may be conceptualised as one in which personal bioinformation can provide a valuable tool for the construction of identity as self-narrative.

Practical application of this conception, however, requires that we also examine which kinds of bioinformation are seen as fulfilling this role. I argue that in addressing this it is essential to recognise the central role played by ‘interpretive communities’ in investing some categories of bioinformation with particular ‘identity-significance’. This analysis provides a useful means of understanding the power of bioinformation’s perceived significance, but also its liability to change. It also highlights that, if we wish to protect identity-based interests, it will be inadequate to focus only upon questions of information disclosure; we must also attend to the social practices through which its identity-significance is engendered.

Abstract number: 100	Further Deliberating the Differences between Do-Not-Resuscitate and Allow-Natural-Death
ID: 304	<u>Yen-Yuan Chen, Tzong-Shinn Chu</u>
oral	Taiwan (Republic of China), Department of Medical Education, National Taiwan University Hospital

Do-Not-Resuscitate (DNR) is a “cold” and “brutal” term, thus making healthcare workers (HCWs) reluctant to initiate DNR discussion. Meyer first suggested that DNR should be replaced by Allow-Natural-Death (AND) because the term “AND” is clearer, kinder and more definitive than the term “DNR”. He further clarified the definition of AND by presenting two categories: intermediate-support AND, implying that intermediate-support AND patients are eligible to receive life-extending medical interventions before cardiac or respiratory arrest, though CPR will not be performed when experiencing cardiac or respiratory arrest; comfort-support AND, implying that all life-extending medical interventions for comfort-support AND patients are withdrawn or withheld including CPR.

In this presentation, we will argue that AND is a worse term than DNR because of the following reasons:

As clarified and emphasized by several important guidelines, DNR does not have the implication on withholding or withdrawing any medical interventions or treatments before the onset of cardiac or respiratory arrest. Literally AND not only is more likely than DNR to make HCWs mistakenly assume that the death of the patient is imminent and comfort care should be provided, but also to frustrate the patient who has a reasonable goal of medical care to extend life. Accordingly, AND is even worse than DNR as to relieving the concern about less medical care provided to patients after the order is written.

“Death” is a sensitive, negative, and uncomfortable term for patients who still have reasonable probability to survive, but do not want CPR performed when experiencing cardiac or respiratory arrest. HCWs will be less likely to discuss the term AND than the term DNR because AND includes the sensitive, negative and uncomfortable word—death. As a result, replacing DNR by AND will hamper the discussion of AND (or DNR).

Abstract number: 101	Plain Packaging for Cigarettes: Where Public Health Ethics and Research Ethics Meet
ID: 305	<u>Iain Brassington,</u>
oral	United Kingdom, University of Manchester

The Australian policy under which cigarettes have to be sold in plain packaging has been in effect since December 2012; in November 2013, the UK government announced that it was to reopen a consultation on emulating the policy. The rationale is that making packs less attractive makes smoking less attractive, thereby reducing smoking levels; and a paper published in the BMJ in 2013 (Wakefield et al, BMJ Open 2013;3:e003175. doi:10.1136/bmjopen-2013-003175) suggested some early evidence of success. The strength of the evidence has been consistently challenged by the tobacco industry, though; and stressing its weakness removes *prima facie* support for the policy wholesale.

Now, there cannot be evidence for the policy in advance of its implementation, and the longer the policy is in place, the better. Quite likely, real evidence will not emerge for years or even decades. In effect, it is reasonable to treat any policy introduced in the interim as at least somewhat experimental, with smokers and would-be smokers – that is, more or less everyone – as the research subject. Moreover, it requires blanket implementation: it won’t do to have plain packs in only half of shops.

This raises several possible objections. One is related to a libertarian claim that states should not be trying to influence behaviour, and that attempts to make smoking less attractive are problematically paternalistic. This is compounded by the way that the whole population has been recruited without consent into a trial the “success” of which would be measured in terms that they may actively repudiate.

In this paper, I shall set out these arguments, and suggest that governments may not be able to answer them – but that they may also be able simply to face them down, and avoid having to.

Abstract number: 102	Defending the child’s right to an open future concerning genetic information
ID: 312	<u>Annelien Bredenoord, M.C. de Vries and J.J.M. van Delden</u>
oral	Netherlands, University Medical Center Utrecht

There has been a discussion regarding the ethical acceptability of genetic testing of children for years, resulting in the majority view that minors should only be tested for early onset disorders where treatment or preventive options exist. Two principles underlie this consensus: first, the beneficence-based best interest standard that urges physicians to test for clinically relevant and actionable results. Second, the child’s right to an open future principle that urges physicians not to test for adult onset disorders and carrier status, in order to preserve the child’s future autonomy right to make its own

decisions, also concerning the possible obtainment of genetic information. The emergence of next generation sequencing (NGS) technology, such as whole genome and whole exome sequencing, seems to challenge the previous consensus. NGS is a powerful diagnostic tool, but at the same time paired with a deluge of both solicited and unsolicited genetic (risk) information. This raises the ethical question whether to disclose genetic risk information to parents of children undergoing NGS, particularly for conditions that do not have immediate consequences for the child. There now is a growing list of commentators and examples from practice where adult-onset and carrier status is disclosed to parents. The American College of Medical Genetics and Genomics for example recently proposed to relinquish the current distinction between pediatric and adult genetic testing policy, thereby abandoning the child's right to an open future.

In this presentation we will argue that the right to an open future should remain a leading ethical principle in pediatric genomics. We will discuss the criticism that the principle is too child-centred and not realistic in the NGS era, and present a so-called "thick account" of the right to an open future principle.

Abstract number: 103 ETHICAL IMPLICATIONS OF SURGICAL FLOW PRO-ACTION BY ANESTHESIA INDUCTION ROOMS:

ID: 314 WHAT'S UP FOR THE PATIENTS?

oral

Amitabh Dutta, Shyama Nagarajan, Nitin Sethi, Jayashree Sood
India, Sir Ganga Ram Hospital & Ganga Ram Institute for Medical Education & Research (GRIPMER)

Background

Currently, the number of patients awaiting surgery has outpaced cumulative operation room (OR) time. The advent of anesthesia induction rooms (AIR) where the patients are anesthetized first and then moved to actual surgical-OR have facilitated OR turnover rate and reduced surgery wait-time. This analysis delineates the ethical implications of infrastructure-driven AIR concept vis-a-vis patient's interest.

Methods

We evaluated possible ethical implications of the AIR process where the patients receive anesthesia before getting transported to surgical-OR. A standardized ethics grid ('respect-for-autonomy', 'beneficence', 'non-maleficence', 'justice') was applied to assess the impact of AIR on patient's interest.

Observations

Commonly, either a total absence of relevant information or an incomplete representation in the information brochure for surgery that evades contentious details of potential risks involved, the 'AIR-surgical OR' arrangement, especially without a specific informed consent, accrues breach of Respect-for-Autonomy and Deception.

The AIR entails plausible risks that undermine Non-maleficence, including, an increase in non-surgical general anesthesia duration/waning of spinal anesthesia effect owing to unanticipated delays in ongoing surgery in surgical-OR. In addition, physical injury, physiologic/autonomic disturbances, and a gap in continuity of anesthesia healthcare delivery (anesthesia, monitoring) during AIR-OR transit, the AIR concept tends to outweigh patient benefits. AIR precludes 'surgical-OR personnel-patient' interaction before anesthesia, which may potentially herald queer objectification of surgery-ready anaesthetized patient with related sensitive ethical concerns. Apart from a decrease in surgery wait-time, the 'Beneficence' in AIR is largely surreal.

The influence of infrastructure-related burdens (dedicated space, equipment/human resources) on AIR-facilitated surgical system efficiency undermines Justice and benefits to the target community.

Conclusion

For the overall patient interest standpoint, the AIR concept is ethically-flawed and is unlikely to deliver expected success.

Abstract number: 104 Not a Lone(lly) Process: Healthcare Decision Making as a Relational Process

ID: 315 Anita Ho, Kim Taylor

oral

Canada, University of British Columbia

Background: The primacy of individual autonomy in western bioethics presumes that patients should be the ones to make voluntary decisions regarding their healthcare. Legal provisions for treatment consent generally require patients themselves to authorize clinicians to provide care. It is only when patients are incapable of making decisions that families can decide on their behalf.

Purpose/Methods: This presentation reports findings from a larger study in a cosmopolitan Canadian city on the intersecting factors affecting diverse patients' and families' ability to make complex healthcare decisions. Results derive from interviews with 51 patients from diverse backgrounds. Grounded theory methodology informed an inductive thematic analysis to explore family influence and involvement in patients' decision-making.

Results: Five intersecting themes were salient across cultural groups. First, participants considered

the potential impact of their conditions and treatment decisions on family members or their own familial role and responsibilities. Second, participants were motivated by their family's hopes, fears, and desires in their decisions. Third, while many participants were capable of making decisions on their own, independent decision-making left some feeling alone. Fourth, participants trusted that their family members would make appropriate decisions for them, even if they had not specifically discussed their healthcare preferences. Fifth, participants considered family involvement as an integral emotional support system. Those without family support reported their decision-making processes as a daunting endeavour.

Conclusion: While family considerations influenced some patients' decision-making processes or led them to abandon their original treatment preferences, participants were not concerned about familial infringement on their freedom to make decisions. Participants did not always want to actively engage in care decisions or consider their own priorities as the only relevant considerations. Respect for patients' autonomy thus requires clinicians to attend to patients' relational contexts and engage or enhance their support networks accordingly.

Abstract number: 105

ID: 318

oral

Sen's capabilities approach as an ethical framework for nudging

Hafez Ismaili m'Hamdi, dr. W. Pinxten

Netherlands, ErasmusMC

Behavioral interventions are gaining popularity in shaping public health policy. Insights from behavioral studies show that people are cognitively biased in a predictable way. These biases result in choices which do not benefit or even harm their quality of life. By adapting the choice environment while preserving alternate choices, public policy can persuade or 'nudge' people to make better choices. Nudges, however, have raised ethical concern because of their potential to obstruct people's autonomy and surrender them to the will of choice-architects.

To assess these ethical concerns, we will distinguish between the descriptive component and normative implication of the nudge.

Is it ethically permissible to guide people towards preset choices? The normative implication, that has strongly been centered around the metaphysical idea of autonomy, fails to take the context into account. People's abilities, values and preferences that result from adapting to their socio-economical position are overlooked. Therefore the normative implications may be philosophically appealing but they remain prescriptively impecunious. Alternatively, we suggest Sen's capabilities approach as an ethical framework to determine the ambit of ethically permissible nudges.

Sen's capabilities approach does take into consideration people's interests in terms of ability to do the things they have reason to value or be. This is valuable for at least two reasons. First of all human cognitive fallibility is too low a threshold to justify nudging. Sen's approach is critical of rational choice theory and introduces human capabilities as the justification for (e.g. public health) policy. Second, of all the capabilities approach is sensitive to background distortions (such as socio-economic position) which influence people's preferences. Therefore we will present Sen's capabilities approach as an ethical guideline to determine the scope of ethically permissible nudges.

Abstract number: 106

ID: 319

oral

Integral perspective of a bioethical case.

Jaime Villalba-Caloca, Dra. Leticia Alfaro-Ramos, Dra. Adriana Ruiz-Llanos, TS. Ma del Rocio

Buendía-Valenzuela, Mtra. Juana Arellano-Meneses, Dra Ma. Carmen Navarro-Gonzalez, Dra.

Martha Torres-Torres, Dr. Jose Luis Sandoval, Lic. Guadalupe Gomez-Navarro, Lourdes Espinoza
Mexico, National Institute of Respiratory Diseases

Medical doctors proceeding from Intensive Care Unit presented a clinical case to the Hospital Bioethics Committee. A 22-year-old woman coming from the Women Hospital in Mexico City was referred to the National Institute due to complicated ventilator problems. She required intubation and ventilator assistance. The medical doctors made the diagnosis of Miliar Tuberculosis and a 17 weeks of pregnancy. The case was presented to the Comeete due to in some states of the country, like Mexico City, abortion is prohibited after 12 weeks of pregnancy. We asked some experts in Gynecology from another hospital to evaluate the viability of the product, they commented he was viable. Since the point of view of four Principles, we discussed No maleficence, Beneficence and Autonomy were the relevant ones. In order to discuss, analyze and have in practice grouped decision making process, we followed the model proposed by UNESCO, which includes: Resume of relevant facts, detected problems, ethical problems and prioritization, actors, values principles and rights, possible courses of action and recommendation. Regarding No- maleficence, we discussed the ear toxicity caused by antituberculosis treatment and also the risk of intrahospital acquired diseases (*Klebsiella* and *Pseudomonas*) we made an exhaustive revision of literature in order to have elements for better

decision. Regarding beneficency, we made an analysis taking in account maximum benefit to both the mother and the product, considering both lives are valuable. And finally regarding Autonomy, we also reviewed literature extensively since the patient is not able to decide, maybe the father, her boyfriend will have to take the decision, but the only members of the family we could have contact with are only mother and brother. The Hospital Bioethics Committee, discussed this case taking in account, clinical aspects, social aspects, neonatal aspects, legal aspects, anthropological aspects and of course bioethical aspects. Many actions were taken after this case, so we consider our experience to be transmitted to other Committee Members having this dilemma.

Abstract number: 107 Newer practice of Informed Consent Process in India
ID: 322 Dr. Barna Ganguly
oral India, P.S.Medical College, Karamsad

The informed consent process is the cornerstone of the ethical conduct and regulation of research. It encompasses imparting information related to risks, rights, and benefits of participation in clinical research studies to the human research participants, thereby understanding. This is followed by exercising right to make the informed decision for participating in a research study. Voluntary consent can be obtained by means of inducement, force, fraud, deceit, duress or other forms of coercion or misrepresentation. The challenge of determining whether the participant truly understands the research project and its risks and benefits remains. The principle of informed consent has been driven by two different agenda: legal and moral. Sponsoring agencies approach informed consent documents from legal angle, while researchers should consider the moral basis of consent requirements. Thus the code of conduct during human medical experimentation was, however, largely left to the discretion of researchers and concerned individuals.

In the United States, there are 2 sets of regulations regarding informed consent: regulations found in the Code of Federal Regulations Titles 21 and 45: 21 CFR 50 and 56, the Food and Drug Administration (FDA) regulations, and 45 CFR Part 46 , the Department of Health and Human Services (DHHS) Regulations. Many of the informed consent regulations are identical, but there are some differences. The Union Health Ministry of India has made audio-visual recording of the informed consent of each participant mandatory in a clinical trial, in addition to obtaining his/her written consent. This decision came on October 21, 2013 for lack of transparency in clinical trials. Therefore this is applicable to the new participants to be enrolled in all clinical trials including global clinical trials. Goal of this article is to discuss the challenges in implementing the new practice in India. It is necessary to find out more clarity on how confidentiality of patients should be protected and maintained in an 'audio-visual' context and what processes needed to be followed in instances where, for religious and socio-cultural reasons, patients might not want to be videographed.

Abstract number: 108 Children in clinical drug research: Why do they participate?
ID: 323 Krista Tromp,
oral Netherlands, Erasmus Medical Center Rotterdam

To tackle the problematic high rate of off-label prescriptions in pediatrics it is essential to conduct clinical drug trials in minors. The conduct of pediatric clinical research, however, is a precarious enterprise, because it entails diverse practical, economical and ethical issues. The recruitment and informed consent process is one of these ethical cornerstones. In theory, the ethical and legal requirements of recruitment and the informed consent process may be clear in pediatric research, the practice remains a black box.

Especially, the focus on the minors' decision in this consent/assent process and the motivations they have to participate in clinical drug research are underrepresented in scientific literature. Intensive systematic review of the available research shows us that only a small number of studies has questioned children themselves about their actual motivations to consent/assent to participation in pharmacological research.

This insight in motivations of trial participation of minors is of crucial importance to better tailor the process of informed consent to the perspectives and the needs of minor research subjects, who have the key role in decisions on research participation.

In this presentation I will give you an overview of the motivations for trial participation mentioned by minors in the scientific literature and illustrate them with examples from practice. These examples originate from interviews I have done with children at several pediatric departments of the Erasmus Medical Center in Rotterdam (The Netherlands) who are asked for participation in clinical drug studies.
Keywords: Motivations, children, clinical drug research
Speaker: Krista Tromp, MSc.; Erasmus MC Rotterdam, NL

Abstract number: 109 **Participating democracy in latin america: ethical aspects of indigenous / native communities' research**
ID: 324
oral **Dr. Agueda Muñoz del Carpio Toia**
Peru, Universidad Católica de Santa María

The indigenous communities or native communities' research had increased in the last years. This interest comes from the better geographic access to these zones, the technology improvement and the crescent interest to intervene in their populations with health care and education programs. However the research with native communities has some risks:

- Invasion to the privacy of these communities, even those that were isolated by themselves.
- Investigations without benefits to the community.
- Genetic researches with improper use of samples.
- Publication of stigmatizing, discriminatory and stereotyping results.
- Appropriation of traditional knowledge.
- Negotiations and undue influences to obtain community consents.
- Irruption to their culture and occidental value impositions.

Abstract number: 110 **Contamination of food**
ID: 327
oral **Marta Alicia Bigiardi,**
Argentina, Colegio Público de Abogados de la Capital Federal- Argentina

Contamination.

In latin america we've recognized the human rights declared by United Nations in 1948. One of them, is the right to food. This right is infringed in our countries. It doesn't mean that the government should give the food as a gift or a duty,

It means that the State must guarantee access to food, in enough quantity and safety. This is very related to the capacity to afford it, with the right to work and the access to health.

Only in catastrophes, wars, floods, dry seasons, epidemic cases, governments must provide them.

The duty of the state is to control the elaboration, the safety and the correct way to transfer it from the producers to consumers.

These obligations are not specified so difficult problems arise: as an example, in Argentina we produce a great deal of food, but it's usually contaminated by the same chemicals that we use before and during the harvest, like herbicides, fertilizers, etc.

We grow soya, wheat, cotton and by means of many agrochemicals which are truly and highly agro toxic.

These substances can be liquid, solid or as a gas. They contaminate both our soil and our water.

The people breathe, drink and touch the agrotoxic substances, which are the cause of eyes, skin and pulmonary diseases as well as allergies and neurotoxicity. They have teratological effects in human embryos and usually make them die.

We do advocate the right to people's health and the bioethical principle of non-maleficence.

The present methods of sowing must be changed step by step to get to a healthy and respectful agriculture of the people and the ecology.

Abstract number: 111 **Obesity prevention and tobacco control: similarities and differences**
ID: 329
oral **Céline Brassart Olsen,**
Denmark, University of Copenhagen, Faculty of Law

Although smoking a cigarette and eating French fries are very different experiences, governments often use similar measures for tobacco control and obesity prevention. For example, they increase taxes on sodas, fat products and cigarettes and regulate the promotion, labels and contents of these products. Many experts have drawn a parallel between the tobacco and obesity "epidemics". It has been suggested that obesity prevention could benefit from the experience in tobacco control. But to what extent can tobacco use and the consumption of unhealthy food be compared? Tobacco control regulations have mainly relied on the fact that smoking is harmful to non-smokers. By contrast, overeating does not affect "innocent bystanders". This paper analyses the legal and philosophical rationale for tobacco control and obesity prevention. To what extent can the rationale supporting tobacco control be used for obesity prevention? Should governments go as far as tobacco control when it comes to preventing obesity, and if so, on what philosophical and legal grounds? The paper explores the similarities between tobacco consumption and obesity, from the tactics used by the tobacco and food industries to the socio-economic factors leading to tobacco consumption and obesity, using a legal, comparative and historical method. It also explores the limits of the comparison and their implications for future policy at global level.

Abstract number: 112 Ethical aspects of gender violence and domestic violence: peruvian and mexican cases
ID: 332 Dr. Agueda Muñoz del Carpio Toia
oral Peru, Universidad Católica de Santa María

Introduction: The WHO recognizes domestic violence as a Public Health problem, with serious consequences or problems on people's health and the healthcare system. Violence involves: violation of ethical rules and values those are part of the reality around the world.

Methods and materials: An investigation was performed to know the Domestic Violence characteristics versus the women in Mexico and Peru. Attacked women, and the Social Communities involved with the violence and woman protection; were interviewed.

Results: the Gender Violence on families is a multi-dimensional problem, this problem is: Human, Social, Legal, Cultural and Public Health, constitutes a serious Human Rights violation.

Official information from Peru a Mexico has many things in common, domestic violence against women, like feminicide, are high: every 4 women from 10 a case of domestic violence appears in their life. Women interviewed results shows: no matter the age, women with incomplete school, housewives, etc; the aggressor is always the couple.

Physical and psychological violence prevail, in some cases sexual violence appears.

Victims never denounce because fear or shame. The minority after denounce, feels unprotected by the justice or lay, paperwork are extensive and in many times victims needs to go to Medical or Legal Institutions and start again the denounce against the aggressor.

In bioethical analysis, violence hurts deeply the respect to the dignity, the principle of beneficence, respect and justice are transgresses, because it is society and family commitment; seek the welfare and respect women. Compromises the justice and equity: family violence in old age, childhood, work, etc. are not investigated.

The psychological violence are underestimated.

Abstract number: 113 What is parenthood? What is the moral scope of parenthood?
ID: 333 Rachel Warren,
oral United Kingdom, University of Manchester, UK.

In this paper, I conduct a philosophical analysis of parenthood in all its forms. I define and distinguish between biological (genetic and gestational), moral, social and legal parenthood, and consider the different parental responsibilities of each role. I aim to clarify the ethical nature of parenthood, by defining the moral scope of parenthood, i.e. what is parenthood, what are the ethical demands and responsibilities of the project of parenthood (including the virtues of a good parent), and where do they begin? I investigate whether the ethical demands of parenthood also apply to would-be parents. My hypothesis is that moral parenthood can begin before the child exists, during pregnancy or perhaps even before conception (with the decision to procreate). This is because a future parent's actions that affect their own health or wellbeing, may also impact the welfare of their child. The implications of this for the transition into parenthood, particularly the moral significance of the distinction between potential, prospective and actual parents are identified. If there are ethically significant differences between potential, prospective and actual parents this provides reason to challenge the child welfare assessments before the provision of fertility treatment. The conclusions reached on this issue determine the proper scope of an account of parental virtue, or whether three separate accounts of the virtues of potential, prospective and actual parents are necessary. My hypothesis is that potential, prospective and actual parents require different virtues, because of differences between the facts about what is required to be a good parent at each stage.

Abstract number: 114 Religion as bioethical element that influences decision-making hospital
ID: 334 Dr. Francisco X González Garza
oral México, Montessori de Monterrey School

Who is to obey the doctor or the religious consciousness? For a long time religion has played a key role in personal and community development, the signs, symbols and traditions reinforce the behavior and the human capacity to make decisions. Religion that seeks the truth of the self as well as the Science that seeks a truth may be compatible, large universities began with religious conceptions, when Science was seen as strange, as magic.

From the Sumerians to the modern and postmodern societies have defied reason and logic, they had a capacity of believe, develop their hope and their faith - so important nowadays- religion as part of the social environment and the fundamental variable of collective behavior, as well as of the beliefs, myths, rituals that are seen as facts or actual social phenomena, how religion influences the decision making ethical and bioethical committees and the doctor must learn to respect a number of beliefs but not always accept them.

Religion as seeking the good, love, peace, justice, knowledge and wisdom, but in many cases also the forgiveness and the reflection of the facts or individual events, where the subject learns to be responsible for their actions that affect others or himself.

Hospital committees must question we are considering traditions and belief as part of comprehensive treatment?, is the hospital Committee aware of the importance of the religious variable in the decision-making process of his patients?, when life starts? When death starts?, what is life?, does the doctor affected by their own beliefs and religious values at the time of taking decisions that affect others?, prejudices should not be taken into account?

Another point that we will deal with is how, sometimes Religion can be seen from pseudo-scientific methods, as the chances are “divine gifts” and as pseudo-science can be a negative element for scientific progress that is linked to religious beliefs.

We will analyze how the signs, religious symbols in hospitals can also affect or benefit perception and vision of the patient and the treatment also appropriate from the point of view of marketing and administrative is ethical to sell the image of a Hospital with a cross?, should private hospitals market themselves religiously?, are all patients treated in the same way knowing their religious differences? The health professional should be aware of the relevance of religion as part of life in the patient, as well as the patient your physician should the doctor promote their religious values?

Pain as a source of moral action, how the pain and suffering does not necessarily are the measure of ethical and moral decision, where religion plays a key role in the understanding of the thinking and action of the subject. The blame on religion and science as part of an awareness heals more than distant to the reality of the fact and moral phenomenon.

Let's look at some value judgments about some ethical dilemmas and moral where the hospital Committee has a great social responsibility, as well as we will try to understand the consequences of fanaticism in the private and collective life.

Abstract number: 115

Ethical aspects on mitochondrial replacement – reflections from the Swedish Ethics Council

ID: 335

Karin Wilbe Ramsay, Lotta Eriksson, BA, Kjell Asplund, Prof

oral Sweden, The Swedish National Council on Medical Ethics

BACKGROUND: Mitochondrial inherited disorders may cause severe disease, suffering and premature death. They are inherited from the mother and caused by aberrations in the mitochondrial DNA (mtDNA). Mitochondrial replacement may provide a possibility to prevent children from inheriting the disorders. The technique involves replacement of damaged mtDNA with mtDNA from healthy donors in association with IVF. The technique is banned by Swedish law but in UK a draft law is currently being prepared that will authorize clinical use of the technique.

AIM: The Swedish National Council on Medical Ethics aimed to explore the ethical aspects of mitochondrial replacement and, if feasible, give recommendations to the government.

OBSERVATIONS: The Council recognized two main problems related to mitochondrial replacement:
1) Is the technique acceptable from a principal point of view, i.e. is it appropriate to use germline gene therapies in order to prevent diseases? 2) Do we have sufficient knowledge of the risks in order to apply the technique on humans?

Regarding Q1, the Council considered whether a strict delineation between changes in mtDNA and nuclear DNA would be possible to maintain, vs. the risk for a "slippery slope" towards an increased acceptance of manipulation of the human genome. Regarding Q2, the Council acknowledged that although preclinical research may be regarded as promising, possible short and long term risks in humans are largely unknown.

CONCLUSIONS: A majority of the Council had no principal objections to the technique, provided that the risks eventually would be regarded as acceptable. A minority of the Council raised concerns about the societal development and believed that the principal ban on germline gene therapy should be preserved. In view of the limited knowledge of the risks, there was a unanimous agreement in the Council that it is too early to recommend human trials of mitochondrial replacement.

Abstract number: 116

The ideal human as a guide to human enhancement?

ID: 345

Johann Roduit, Dr. Vincent Menuz; Dr Holger Baumann

Switzerland, Institute of Biomedical Ethics, University of Zurich

In the past few years, one of the most debated topics in bioethics has been the socio-ethical issues related to human enhancement. While many articles have been written on this topic, two major problems remain. First, there is still no consensus on the definition of "human enhancement", making it difficult to discuss ethical issues on common ground. Second, current bioethical standards, such as justice, autonomy and safety seems at first not enough to assess on their own socio-ethical issues related to human enhancement. This article aims to answer to those two problems. Based on a recently suggested definition of "human enhancement", we develop further some philosophical arguments – grounded in the concept of "living a good human life" – that can be used for evaluating

ethical issues related to human enhancements. Adding to other bioethical notions, we argue that the ethical evaluation of a given human enhancement needs to also take into consideration the ideal human life, which once agreed upon, can help assess the morality of a given human enhancement.

Abstract number: 117 **The moral status of embryos: the limits of the philosophical approach on abortion**
ID: 347
oral Telma de Souza Birchall,
Brazil, Federal University of Minas Gerais

The philosophical debate on abortion has been mostly focused on the moral status of embryos and fetuses. It relies, on the one hand, on some interpretation of Biological Sciences' data and, on the other hand, on the metaphysical approaches of identity and personhood. Margaret Olivia Little (2004) has already criticized the fact that in many philosophical approaches the moral status of abortion is usually reduced to the moral status of embryos. Outside the academic world, in the social and political forum, usually the "pro-choice" movement emphasizes the women's rights or public health problems, whereas the "pro-life" movement emphasizes the status of embryos. Nevertheless the public debate has highlighted the status of embryos. In this point Brazilian debate on abortion is not an exception and I will show this by analyzing the recent Supreme Court votes on the topic of abortion in cases of anencephalic fetuses (2012).

In this paper I will argue that: 1- Abortion is a wide topic that includes, other than the moral status of embryos, a discussion on women's identity and rights and a discussion on social justice, 2- The debate focused exclusively on the status of embryos misses the point because it ignores the embryo's existence context (the pregnancy as such).

As a conclusion, I will claim that the abstract discussion on the status of embryos cannot by itself contribute to a defense of the morality of abortion and that philosophers should turn to Social Sciences to reflect on the reasons why the status of embryos has become such an important subject in our days.

Abstract number: 118 **Agency, identity and behavior change: shifting from an individual to a relational model**
ID: 352
oral Norah Mulvaney-Day, Dr. Catherine Womack
United States, Abt Associates

Multiple theories have been developed to explicate the role of the individual in health behavior change. Most implicitly attribute a high level of personal agency to bring about behavior change. Less attention has been paid to how experiences of identity formation, norms and behavior change processes may influence agency. In this paper, we first review theories of health behavior change in social psychology and public health to assess how these theorists assume high levels of individual agency, even within theories that incorporate community norms and environmental influences. We then expand upon the notion of identity-constitutive affiliation as a key factor in understanding the process of health behavior change. Identity-constitutive affiliation is the affective relation that takes as input a person's values for others and the embedded contexts in which those valuations occur (Mulvaney-Day and Womack, 2007). It gives as output a person's behavioral practices, and (just as importantly) helps form, reinforce or shift that person's sense of identity via the behaviors of those to whom she is affectively connected. This affects both the implicit norms used by persons to make decisions and the level and scope of agency with which persons can act based on those norms. Importantly, this theory of behavior and behavior change relies upon a relational concept of identity--- one subject to social influences. We analyze several behavior change efforts within public health through the lens of identity-constitutive affiliation to generate hypotheses for how we might shift the discourse regarding health behavior change, particularly among groups with disproportionately poorer health outcomes. Finally, we argue that an identity-constitutive affiliation is crucial to the account of agency needed for behavior change models in public health, providing a previously missing link between identity and norms through context-sensitive emotional connections.

Abstract number: 119 **The New EU Standards for Aesthetic Surgery Services**
ID: 354
oral Diana Nacea,
Mexico, University of Copenhagen, The Law School

In 2011 the European Committee for Standardisation (CEN) launched a public information and consultation process with the European Union member states concerning a European Standard for Aesthetic Surgery Services (the Standards). The final working draft of the Standards, foreseen to be published in December 2013, developed a comprehensive framework that covers the access, the service provision, the premises and the advertising of aesthetic surgery.

We shall explore the main principles of the Standards, while comparing them to similar and concurrent regulatory undertakings in the UK; furthermore, we shall consider the potential binding force of the new regulations within the EU, considering both professional standards of practice and future institutional obligations, analysing to what extent they protect patients, and whether they address patients' motivational criteria for undergoing aesthetic surgery.

Though the Standards provide procedure-centred guidelines, measures envisaging limitations on advertising and financial incentives have been included within medical professionals' code of ethics; these considerations constitute an implicit acknowledgement of group targeting practices and a corresponding requisite for vulnerable patients' protection. Moreover, we shall argue that the provisions regarding the classification of procedures according to their inherent risks, together with a new "cool off period" reserved for patients' reflection provide an improved adjustment of informed consent standards to the specificities of aesthetic surgery.

Last but not least, we shall analyse whether the Standards tackle some of the motivational factors highlighted by recent studies as elements in the rationalisation process for one million European undergoing aesthetic surgery every year.

Abstract number: 120 **Human enhancement as a basic right**
ID: 355 **Prof. Brunello Stancioli**
oral Brazil, Federal University of Minas Gerais

The presentation aims to demonstrate that human enhancement ought to be a basic right, considering that the concept of person is the epicentre of Western legal framework. A person is an emerging property of a human body (BUNGE). Only when inserted in a complex and informational system can a Homo sapiens originate a person with a sense of self. There is a constant two-way interaction between the brain-in-the-body and the language-as-action. Language and human body affect each other, in a constant process of transformation. The brain is rewired by every linguistic exchange. Therefore, it is fundamental to enhance the human brain through language and symbolic interaction, in order to increase the possibilities of the organized matter, and thus enable the emergence of a person. The development of language enables changes in the structure of our brains. Moreover, due to the incredible plasticity of the brain (NICOLELIS), when confronted with new forms of stimuli (especially those ones that are not "given" by the "natural" environment), it is very plausible that one could develop new forms of personhood. The great novelty as to the possibilities of reconstructing personhood is presented by "human enhancements", understood as "any change in the biology or psychology of a person which increases the chances of leading a good life in the relevant set of circumstances" (SAVULESCU, SANDBERG, KAHANE). Some forms of enhancement, such as language and formal education, are already considered basic rights. This path entails a double foundation for considering human enhancement as a basic right. First, it is a matter of distributive justice as it must be provided to everyone the chance of living good forms of life and new forms of being a person; Second, it empowers every person to pursue their own happiness.

Abstract number: 121 **MORAL BIOENHANCEMENT AND VIRTUES**
ID: 358 **Joanna Rozynska, none**
oral Poland, University of Warsaw

Idea of moral bioenhancement (MB) has received much academic attention over the last decade. In a recent series of papers Savulescu and Persson have argued for the urgent need of bioenhancing human natural dispositions for empathy and sympathy, and a sense of justice, to prevent large-scale risks. They claim that a morally bioenhanced person would be more willing to sacrifice own interests for the benefit of others, and that would be a moral enhancement on any account of morality.

The aim of my presentation is to discuss whether bioenhancement of natural dispositions indeed constitutes a moral enhancement, if analyzed from virtue ethics perspective.

Firstly, I will discuss a classical view on MB that focuses on biomedical regulation of moral emotions and attitudes (Persson & Savulescu 2008, 2010, 2011; Hedges 2004; Douglas 2008). Secondly, I will analyze this view in the context of Aristotelian and Kantian concepts of moral virtues and their relations to natural dispositions. Aristotle believes that true virtue is a disposition, acquired by the practice of good deeds, to have feelings "at the right time, about the right things, towards the right people, for the right end, and in the right way" [NE, 1106b]. True virtue requires rational choice based on the recognition of the value of virtue and the understanding that a given reaction is the right one in a given circumstances. For Kant, virtue is a general disposition to act from duty. Acting from any inclination, either natural or biomedically induced, is not to do what is right. Therefore, I will argue that

the classical view on MB is insufficient for the formation of truly virtuous people. Aristotle and Kant would not agree with Savulescu and Persson that a man who takes a drug which makes him more empathetic would 'automatically' become more moral.

Abstract number: 122

ID: 363
oral

Intergenerational Harm: do we have an obligation to protect the health of future persons?

Isabel Karpin, Professor Roxanne Mykitiuk, Osgoode Hall Law School, Toronto, Canada
Australia, Faculty of Law, University of Technology, Sydney Australia

The human health effects of exposure to synthetic chemicals, ubiquitous in present-day society, call attention to the vulnerability of reproductive and developmental processes to influence by these substances. Cases of exposure to diethylstilbestrol (DES), offer a historically significant example in which exposure to synthetic chemicals had harmful effects for those exposed in utero, and for the children of those exposed in utero. Research into the epigenetic consequences of chemical pollutants and environmental toxins has led scientists to suggest that the effects of these substances on the health and wellbeing of existing persons may not be the full measure of their impact; rather, their complete harms may only be registered two generations later, manifesting in the way our grandchildren's genes are turned on and turned off. Yet there is significant legal and policy resistance to calls for protection against predicted intergenerational and reproductive harm. These claims are often muted or deflected by assertions that the lines of causation are murky or impossible to prove. There is no doubt that important legal and ethical questions are raised by the attribution of interests and rights to imagined future persons, whose development and birth is highly contingent. It is nevertheless clear that current actions and decisions will have an impact on the health and wellbeing of future people. What is not clear is what constitutes a harm and where the interest in preventing that harm should be vested. In this paper we explore the impact of reproductive harms caused by some common synthetic chemicals that have suspected intergenerational effects specifically Brominated Flame Retardants and Phthalates. We ask what legal and ethical obligations we have to act now to protect those who may exist in the future and what regulatory options exist or might be developed to give recognition to these intergenerational claims?

Abstract number: 123

ID: 366
oral

Autonomy: three suggestions for more applications in Costa Rica

Jimmy Washburn,
Costa Rica, University of Costa Rica

Autonomy has become a very important moral input in Costa Rica, as a Bioethics principle it has pervaded Social Security, but also as an argumentation premise in order to assure healthcare customers' rights. Two particular and very well-known cases for Costa Rica are in vitro fertilization's prohibition and an abortion refusal are two examples of another meanings of autonomy are still waiting to be tried. But there is also a third case, quite different of the former ones but related in some ways, it is the Social Security's financial crisis, in which the customers are spoken by others and not by themselves. Somehow, the way this financial crisis has been said, there is a sort of paternalism working on but not in a physician-patient relationship way.

For the last years, some isolated situations have given reasons to try an extension of the meanings and use of moral autonomy and to try other arguments and not only the usual ones related to clinical attention and trials.

The main meaning of autonomy is not independent of the uses the moral agents apply. In Costa Rica, moral autonomy is still related to medical issues and healthcare customers cannot reach a real autonomous performance in relation to their health issues. The purpose of this paper is to show these other meanings and how bioethical debate must give some room to this topic in Costa Rica.

Abstract number: 124

ID: 372
oral

Gathering up the Loose Ends of Dispute Settlement in Clinical Practice

Rodrigo Nava-Diosdado, Ana Beatriz Serrano-Zamago
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Current changes in medical practice, which are the result of global policies and the exacerbated advance of new technologies of diagnosis, promote the development of an evidence-based medicine (EBM) that does not go hand in hand with value-based medicine (VBM), even though both paradigms affect decision making. Such cleavage is the starting point to discuss, from the philosophical sphere, the relationship between facts and values. This paradigmatic rupture between EBM and VBM is untenable, as Nelson Goodman (1990, 2004) mention, facts are human manufactures, the same with values; thinking differently would mean getting into fundamentalisms, as both facts and values would not exist without us. Our objective is not only to realize that there is a relationship between facts and values, but also to highlight that values have a central importance in the development of inductive

inference, which serve us as guides for action. Thus, we will set a second objective: to denote the importance of the promotion and diffusion of an ethical culture in medical practice in order to balance what holds the EBM and VBM. The problems that health professionals face come from and are related to a variety of issues that arise from the interaction between agents; therefore, these issues should be incorporated to the contextual atmosphere in which they develop, so that they learn how to cope with changes and benefit from them. Thereby, it will be possible to obtain more tools to solve the problems faced in dilemmatic situations.

Abstract number: 126

ID: 378
oral

The ethical experiences of stakeholders in stem cell research

Michelle Habets, J.J.M. van Delden, A.L. Bredenoord
Netherlands, University Medical Center Utrecht

Many ethical issues arise in translational research because of a disassociation between risks to subject participants and study beneficiaries. The individual research participant is exposed to risks of a clinical study, to provide knowledge for society, which makes justifying undertaking such studies ethically challenging. This is particularly evident in first-in-human trials, where providing knowledge on risks, per se, is the primary aim of the trials, and the research participant is unlikely to directly benefit. For novel interventions, such as pluripotent stem cells (PSC) these ethical challenges are more acute, as no precedents are available to predict risks, while at the same time the expectations of the medical field are very high. PSCs are capable of self-renewal and differentiation into any cell type of the human body, and can thus be used to construct ex-vivo tissue. These can subsequently be transplanted into patients to correct disorders or cure diseases. The first- in- human PSC trials have started or are imminent, and we believe it is of utmost importance that this rapidly developing field is accompanied by parallel ethics research in order to guarantee ethically sound innovation. To this end, we conducted semi-structured qualitative interviews with relevant stakeholders in stem cell research to illuminate the major ethical issues in translational PSC research. With consent, the interviews were audiotaped and transcribed verbatim. Data analysis is based on the constant comparative method. The information of our study will be used to expand the set of our moral intuitions and will be examined as a means to propose moral guidance for introducing PSCs into the clinic.

Abstract number: 127

ID: 379
oral

The Social and Ethical Consequences of Ambiguous Definitions of 'Population' in Community

Resource Projects: The case of the 1000 Genomes Project
Santiago Molina, Benjamin Merriman
United States, University of California Berkeley

In recent years human genetic research has developed rapidly, and the cost of sequencing and computational technology continues to decline. This research has also been pushed forward by a major organizational innovation: the development of large, open access databases of human gene sequences known as community resource projects. Two notable projects are the International HapMap Project and its successor, the 1000 Genomes Project. The serious efforts to protect the privacy and autonomy of individual participants by irrevocable anonymization make it impossible for participants to withdraw consent or steer the direction of research. This heightens the danger that these projects may create stigmatizing, culturally disruptive, or economically injurious scientific claims. These dangers are amplified by the high accessibility of the data and the ambiguous nature of the term "population": the term takes on at least six distinct meanings in various phases of data collection and publication. This presentation makes two new contributions to the ongoing study of such projects. (1)This paper describes how the meanings of "population" are specific to particular organizational segments of these projects, creating undetected collective risks that owe to shifting ethical frameworks. (2)This presentation examines the 1000 Genomes Project, a community resource project that is exceptionally large and strongly tied to private biotechnology firms. Through a sociological analysis of the structure of the Project and of the bioethical models used, this presentation will discuss the complications that can arise from ambiguous definitions of 'population' and 'community' in the context of biobanks and biomedical databases. The findings indicate a need not only for individual informed consent practices, but binding post-consent consultation with both donor groups and non-scientific publics.

Abstract number: 128

ID: 384
oral

Hanging on to some autonomy in decision-making in dementia – how do people with dementia and their carers do it?

Deirdre Fetherstonhaugh, Laura Tarzia & Rhonda Nay
Australia, ACEBAC, La Trobe University

Background: The capacity to understand, and represent one's values and preferences is integral to decision-making. While participation in the process of decision-making can be affected by dementia it does not necessarily follow that a diagnosis of dementia means a lack of capacity to make, or at least participate in, decisions. In fact, research has consistently demonstrated that people diagnosed with dementia can, and do continue to make choices about many aspects of their lives. However, despite

decision-making being a fundamental component of autonomy and personhood in Western societies, too often a person with dementia's participation in decision making can be curtailed or ignored by others as it is presumed that they know what is in the person's 'best interests' without appreciation of the importance of decision-making to the person's sense of wellbeing and self-determination. Family carers of people with dementia are in a position to facilitate remained involvement in decision-making for people with dementia or alternatively, to take over decision-making.

Methods: This research used semi-structured interviews to explore the essence of decision-making for a group of people with dementia living in the community and the strategies their family carers may develop to facilitate their remained involvement in decision-making.

Results: The essence of decision-making described by participants with dementia involved a fine balance between subtle support and taking over, hanging on and letting go and a conflict between wanting to feel central but being marginalised and excluded. The family carers identified several strategies they had developed to facilitate remain involvement in decision-making for the person with dementia.

This paper will discuss the importance of hanging on to some autonomy in decision-making in dementia and how family carers can facilitate this.

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- Abstract number:** 129 **ID:** 389 **oral** An Analysis of Transfer Process of Stored Human Biological Materials to Bio-repositories: A Practical Understanding of the 2012 Revision of the Bioethics and Sa
YOUNG-MO KOO, Young-Joon Ryu, MD, Ph.D.
Korea, Republic of (South Korea), Department of Medical Humanities and Social Sciences, University of Ulsan College of Medicine

The revised Bioethics and Biosafety Act of Korea went effective as of February 2nd, 2013. The act is written to facilitate the secondary use of human biological materials, i.e., post-diagnosis human specimens that have been stored in hospitals, for research purposes by setting up in-house bio-repositories registered with the government. For analysis, authors divide three periods of acquisition of the human biological materials for the act to apply. We find most dubious the use of human biological materials with no consent forms attached, acquired in the period from January 1st, 2005, the initial implementation of the Act to February 1st, 2013 (the period 2). It is because article 38 of the act requires individual researchers or genetic testing institutions to obtain legal consents from the patients in order to transfer the human biological materials to bio-repositories. This means that the strict application of the article 38 will result in the significant loss of opportunities to utilize tremendous stock of human biological materials that have been acquired in and after 2005. In disagreement with this understanding, we argue that article 16 paragraph 3 of the same act allows, insofar as a couple of requirements are met, the written consent of research participants to be waived with an IRB approval. And we argue that the human biological materials stored in the hospitals do meet these two requirements.

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- Abstract number:** 130 **ID:** 392 **oral** Ethical Issues in the Biobanking of Induced Pluripotent Stem Cell Lines
Gardar Arnason,
Germany, Leibniz University of Hannover

Induced pluripotent stem cells (iPSCs) offer great promise for medicinal research and therapy, so much so that the pioneers of iPSCs won the 2012 Nobel Prize in Physiology or Medicine. Efforts are now underway in Europe to pool collections of iPS cell lines in biobanks for research purposes, in particular for drug development. Such iPS cell line Biobanks pose significant ethical problems. This presentation will focus on three problem fields: (1) Consent for the purpose of procurement and use of human tissue, including problems concerning consent already obtained in different countries and contexts, with different consent forms and procedures, as well as the prospect of developing and using standardized consent forms across jurisdictions and borders for future tissue procurement; (2) data protection, privacy and risk with regard to the biobanking of iPS cell lines; and (3) problems arising from combining commercial and non-commercial use of iPSC biobanks.

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- Abstract number:** 131 **ID:** 393 **oral** GM CROPS DEBATE IN CHINA: FROM A CONFUCIAN PERSPECTIVE
Zhen Cai,
United States, East China Normal University

Since the Chinese government granted safety certificates in November 2009 to two GM rice varieties and a variety of GM maize, there has been an ongoing debate on the promotion of GM crops in China. This article begins by sketching such a debate, and points out that both sides of the debate share a common individualistic perspective of nature. According to this perspective, crops can be

considered as abstract entities that can be examined independent of a specific natural and cultural environment. It then introduces the Confucian perspective of nature as an alternative, and explains how agriculture and food should be viewed from this perspective. Confucian philosophy embraces a holistic view of nature. According to this view, human beings as a whole should be valued in the community of whole universe, in which human beings and other creatures cannot exist with isolated identities. Correspondingly, food preference, production, and distribution are inseparable from local natural environment, political institutions, and cultural conventions. Furthermore, the food-related problems, such as food shortage, can never be solved by merely focusing on how to produce more yields. Finally it makes comparison between these two pictures of agriculture and food, and casts doubts on GM crops by reconsidering their alleged advantages over the traditional crops. I will argue that the promotion of GM crops is very likely only replacing one problem with another by following the individualistic view of nature and enforcing the detachment of crops from their local environment. In conclusion, the Confucian philosophy and its holistic view of nature reminds us that human being as a whole is inextricably related to other creatures in the universe, and the manipulation of nature, including food production is not merely a technology issue, but demands an all-things-considered deliberation.

Abstract number: 132 **Using new genetic sequencing methods in children: Should context matter?**
ID: 394 Ainsley Newson,
oral Australia, University of Sydney

This presentation will use theoretical and conceptual bioethical analyses to explore the question of whether context should matter when reporting incidental findings from genetic testing in children. Next Generation DNA Sequencing (NGS) technology now allows us to look at DNA more closely, more quickly and more cheaply than ever before. Testing using NGS methods is beginning to be used in children, for example to help families who have a child with an unexplained diagnosis. However, much of the information that emerges from testing will be incidental to the initial clinical rationale for testing. A question therefore arises as to whether to report this information. Debates are ongoing between those who sanction the reporting of incidental findings (particularly predictive health information) from these tests in children, justifying them via the benefit to the family; and those who oppose such reporting, on the basis that it is against the interests of the child who is tested. Reporting incidental results that are predictive of future health is in tension with the position that children should not be tested for adult-onset conditions when no intervention is possible in childhood. This apparent contradiction is justified by some commentators based on the context: if a test in a child is being done when there is a known family risk, then reporting incidental findings in a child may not be appropriate. But if there is no known family risk, then reporting an adult-onset risk for a child may be the only opportunity for that family to inform relatives and take preventive action. The rebuttable claim to be explored in this presentation is that the context in which a test is offered (either to determine a known risk; or to screen an individual with no family history) should not dictate the ethical standard to be applied.

Abstract number: 133 **Public Health and the Influence of Incentives**
ID: 395 Becky Brown,
oral United Kingdom, University of Aberdeen

In this paper I consider the permissibility of offering financial rewards as a method of promoting healthy behaviour. Such 'health incentives' provoke a variety of ethical concerns, some of which relate to the kind of influence involved in incentivising healthy behaviour. The difficulty, however, is that the influence of incentives has been described in a variety of ways, including that they are coercive, manipulative, persuasive, bribes, gifts, freebies, nudges, and so on. Such descriptors may have different implications with regards to the justifiability of using incentives to influence health behaviour: a persuasive incentive may be less problematic than a coercive one, for instance. Here, I seek to clarify how we should conceive of incentives as a means of influence. I begin by outlining the concepts of coercion, persuasion and manipulation and identifying the key differences between these methods of influence and their moral significance. I then discuss how incentives fit into these accounts. I argue that judgements about the presence or absence of these forms of influence will depend on a number of factors specific to the context of the incentive situation, including the way the incentive is experienced by the recipient. It will therefore be important to take into account such contextual factors when seeking to evaluate incentive schemes. Moreover, an assessment of the form of influence employed by an incentive scheme will not be sufficient to determine whether or not such influence is justified. I draw some conclusions about the usefulness of applying concepts of different forms of influence to incentives as part of the project to assess their permissibility. Further, I suggest a symmetrical approach toward other (non-incentive based) public health interventions could yield interesting results.

Abstract number: 134	Should there be a right to 'absenteeism' for health care workers?
ID: 399	Søren Holm,
oral	United Kingdom, Centre for Social Ethics and Policy

This paper will discuss whether we can justify a right to be absent from work when ill in the specific case of health care workers.

In the first part it will outline two current public debates. 1) a debate about 'absenteeism' in health care, i.e. the perceived problem that health care workers have too much absence due to illness; and 2) the public and academic debate about the obligations of health care workers in relation to epidemics of infectious diseases, e.g. obligations to have vaccinations, or obligations to turn up to work even if there is a risk of becoming infected.

These two debates occur in isolation and the second part of the paper will try to bring them together. It will be shown that the justifications given for the obligations of health care workers also justify an obligation not to turn to work when ill. It will further be argued that if health care workers fulfil their other obligations, they are more likely to become ill than the average worker, and that it is therefore not strange if they are more likely to be absent; and that considerations of reciprocity provide an independent justification for a right to be absent from work when ill.

In a coda, it will be argued that the concept of 'absenteeism' misrepresents the issue and that the term should be erased from the English language.

Abstract number: 135	A Framing Problem for Public Health Ethics: Addressing the basic Issue of Scope
ID: 401	Christian Munthe,
oral	Sweden, Department of Philosophy, Linguistics & Theory of Science, University of Gothenburg

This talk builds on earlier discussion by myself (2008), Coggon (2010), Dawson (2011), Verweij & Dawson (2007), Wilson (2009) et al regarding the basic (normative) goal(s) of public health (PH). It addresses a fundamental issue regarding the foundations of PH ethics of particular interest to the ethics of global health. Regardless of exact proposal on what values are important, there is consensus that the goal of PH must be phrased in terms of a population. However, when that general notion is to be applied (e.g. the classic idea of promoting population health), the issue of what population is the relevant one arises, possible to phrase in terms of how wide/restricted the scope of the beneficiaries of an ethically justifiable PH policy should be. That query turns into a conundrum, as no possibly underlying ethical theoretical stance that might otherwise readily serve to answer it seems to fit as a PH ethical foundational assumption. This goes, e.g., for the argument for expanding national health concerns into global ones built on the notion of rights (Pogge 2008). Neither does any existing idea about the goals of PH imply anything specific, but seems rather to be compatible with any possible framing of the scope of ethical PH work. E.g. national PH policy may just as well contribute to realising the PH goals for a small minority population, as for the entire global community. The paper works out the details of this basic framing problem and sketches two alternative suggested routes for approaching its solution, based on Derek Parfit's (1984) notion of \"aims\" of ethical theories, and pragmatic metaethical ideas in the spirit of Hume, Mackie, Wong, Rawls and others. A provisional argument is made to the benefit of the second route.

Abstract number: 136	Designing the Best Possible Existence: The non-identity problem, genetics and our duties to future generations
ID: 403	Edgar René Ruiz-López,
oral	Mexico, National Autonomous University of Mexico

Julian Savulescu has defended what he calls The Principle of Procreative Beneficence (PPB). According to this principle, prospective parents are morally required, where choice allows it, to produce the child expected to have the "best life" from among other possible children they could have. Practically, this can be accomplished by selecting from different embryos with the help of pre-implantation genetic diagnosis.

This paper argues that although there may be valid non-moral reasons for future parents to choose one possible child over another, Savulescu's arguments are insufficient for showing how the PPB is morally obligated. Understanding the non-identity problem we realize there's no moral reason to favor a healthier or "better" embryo over a genetically flawed embryo which could grow to become a person whose life is worth living, even if flawed, for its other alternative would be non-existence.

Rather than defending an obligation to create the best child possible, I would like to question the possibility of a pro tanto obligation to follow a different principle called the Best Possible Existence Principle (BPEP). By this principle prospective parents are morally required to procure the best cares for the embryo to be born in order for it to have the best possible existence once a child. What

distinguishes the BPEP from the PPB is that the BPEP creates an obligation to the particular embryo to be born, chosen or not chosen, genetically flawed or not. At first sight the BPEP may seem less problematic than the PPB, but in the context of genetic manipulation it becomes just as controversial and philosophically challenging when trying to define its limits as there is a blurry line between benefiting the existence of a future child and changing the embryo's biological basis for its future identity.

Abstract number: 137 **Post-trial obligations towards research participants: a critical assessment of the Declaration of Helsinki 2013**
ID: 404 **Helsinki 2013**
oral **Dr. Ignacio Mastroleo**
Argentina, National Scientific and Technical Research Council

The transition of research participants to the appropriate health care when they conclude or interrupt a research study is a global problem. It's not just a problem in low and middle income countries but affects high income countries as well, for example, participants testing oncology drugs not available in the National Health System in UK or participants underinsured in USA.

The recent publication of a new version of the Declaration of Helsinki (DoH) and its public discussion is a great opportunity to reconsider post-trial access obligations that address the responsible transition problem.

In this paper, I argue that DoH 2013 presents two different cases of post-trial access, namely, (1) post-trial access for an intervention identified as beneficial in the trial (paragraph 34) and (2) post-trial access to the general outcome and results of the study (paragraph 26). The intended beneficiaries are individual participants of research studies. And the agents responsible for complying with post-trial obligations are the sponsors, researchers and host country governments. I identify these two cases with two different types of post-trial obligations towards individual research participants in the literature of post-trial access ethics, namely, (1) obligations of access to care after research and (2) obligations of access to information after research.

Finally, I advance a critical assessment of the current formulation of post-trial obligations in which I identify four areas of future discussion: (i) the list of objects that fall under the obligation of "provision of trial intervention", (ii) the meaning of the term "beneficial" and its appropriate standard of evidence, (iii) the range of responsible agents of post-trial obligations and (iv) the limitations in the recognition of cases of obligations of access to information after research.

Abstract number: 138 **TOWARDS NEW POSSIBILITIES OF DIGNIFIED PERSONHOOD: SUPERSEDING THE HOMO SAPIENS**
ID: 406 **Daniel Ribeiro, Nara Pereira Carvalho**
oral Brazil, Universidade Federal de Juiz de Fora (UFJF)

The distinction between the terms person and human is extremely complicated, mainly because there is a presupposition, in legal thinking in particular, that the distinction constitutes either a non-problem or that the terms are perfect synonyms. Although there seems to be a conceptual overlap, in the formulation of the modern legal person, the distinction would mean that the human being has the natural faculties and aptitudes to be a natural person, capable of exercising rights, and the person arises as the agent and interactive face that shows itself in the construction of intersubjective relations. What is proposed is an investigation about some of the legal and ethical challenges presented by our biotechnological attempts to supersede the Homo sapiens natural limitations, enhance ourselves and become something more, either posthuman or transhuman. Specifically two issues are to be analyzed: the role of a normative concept of human dignity as a possible impediment to such attempts and if personhood could be autonomously conceived as a bioethical value to guide the direction of human enhancement research and applications.

The method to be employed is a theoretical study of the meanings of human dignity and personhood in bioethical and legal literature to assess its roles in guiding policy, individual actions or promoting goals in biotechnological research in general and human enhancement research in particular.

The content of the presentation will concern a brief assessment of the history and current status of the debate on Human Dignity and Personhood in legal and ethical literature and how both concepts are relevant to analyses of technological attempts of superseding the human condition.

Abstract number: 139 **United Nations Declaration on Human Cloning: 10 years on**
ID: 407 **Chamu Kuppuswamy,**
oral United Kingdom, University of Sheffield

In 2005, the United Nations General Assembly adopted the Declaration on Human Cloning, which is coming up to its 10th anniversary in 2015. This paper analyses international law related to human cloning by revisiting some old questions and introduces new questions that have developed since

the adoption of the Cloning Declaration. The ethical dilemmas surrounding the creation and use of cloned embryos have been the subject of discussion at UNESCO's International Bioethics Committee which in its 2009 report stated that 'the issues surrounding the international governance of human cloning cannot be ignored and a focused international dialogue is crucially needed'. Technological developments since 2005 have led to further uncertainty in terms used in the Declaration, and these have implications for the customary international law that has developed around human reproductive cloning. The wider implications of cloning research, which found expression through provisions (d) and (f) of the Declaration, on exploitation of women and resource allocation in financing of medical research, have gained traction since the 2005 Declaration and it is now possible to scope out these provisions in more detail. Municipal law relating to stem cell research on cloned embryos was a subject of contention in the General Assembly in 2005. Rapid developments in various countries including recent case law surrounding the morality of commercial use of such research has some profound implications for regulating human cloning. This paper will consider all these issues and finally pick up on some observations made in the report relating to a binding international treaty on cloning and comment on the prematurity of such initiatives, but noting that progressive development of international law in bioethics is essential for 'big science' to be conducted ethically and self-regulation is not an option.

Abstract number: 140 **The legal status of animals in Brazil**

ID: 410 Carolina Maria Nasser Cury, Laís Godoi Lopes; Brunello Souza Stancioli

oral Brazil, Federal University of Minas Gerais (Universidade Federal de Minas Gerais)

The status of animals in Brazilian legislation is influenced by the tradition that frequently analyses concepts through dichotomies (INGOLD, 1994). The Brazilian Civil Code delimits a glaring gap between humans and animals – both commonly treated as strictly polarized categories – by asserting that animals are things and all humans are persons. Notwithstanding, current research on animal cognition has shown that animals are far from being mere things. In fact, some of them possess language, are capable of making tools, act based on equity and fairness (DE WAAL, 2010) and can be characterised as moral subjects (ROWLANDS, 2012). Moreover, since LOCKE, it has been developed in post-metaphysical sciences that the notion of person may be overlapped but do not necessarily coincide with the concept of humans (SINGER, 2002). The methodology of the present study includes analyses of cases involving animal research in Brazil and in the European Union. These analyses indicate that the strict dichotomies through which the Brazilian Law elaborates its concepts are far from being accurate. This discussion was recently brought to the fore in Brazil, due to a recent occupation of a laboratory of animal research and experimentation, where activists rescued over 170 beagles and various rodents. The regulatory framework for animal research (Law 11.794/08) as well as the standard Brazilian legislation towards animals is vague and lacunose. It disregards international efforts – such as the recent ban on cosmetic research in animals by the European Union – to implement the most basic ethical guidelines for reduction, replacement and refinement (RUSSEL, BURCH, 1959) regarding animal testing. The legal status of animals as things rises ethical contradictions, and numerous legal systems, such as the German, already indicate that animals are not things. In this context, overcoming the dichotomous perspective of the Brazilian Law is pressing.

Abstract number: 141 **Kant's Political Philosophy and Its Contribution to Public Health**

ID: 415 Diego Silva,

oral Canada, St. Michael's Hospital

One might argue that Immanuel Kant's moral philosophy has greatly influence bioethics, particularly clinical ethics; however, rarely is Kant's political philosophy invoked as a potential guiding theory for public health. The goal of this paper is to present a Kantian articulation of public health ethics based on his political (or juridical) philosophy, which may provide more persuasive arguments for certain public health interventions and policies than those currently put forward.

This paper is divided into two parts: first, I will present an important (though often ignored) distinction between Kant's moral and political philosophy. Whereas Kant's moral philosophy consists of how one ought to act rightfully, his political philosophy consists of those actions that are right and legitimately enforceable by state coercion. Kant's account of private and public law are grounded on his notion that political freedom, which all humans possess and is necessarily equal among individuals. Freedom is the ability for each person to be a master of his or her own life, such that he or she has the ability to set goals and pursue them, such that all other persons have the same right of freedom. As such, an argument will be made that appealing to Kant's moral notion of autonomy and the categorical imperative is inappropriate in public health given the kind of role the state plays in public health interventions.

Second, I will briefly describe how a Kantian understanding of political philosophy might apply in public health and, moreover, help elucidate three traditional challenges in public health: (a) A justification for the redistribution of wealth; (b) the parameters of coercive or police powers in the enforcement of isolation orders for infectious diseases (e.g., tuberculosis); (c) understanding how 'nudges' sometimes may be justified as a means of enhancing freedom.

Abstract number: 142 Is there an ethical obligation to think about one's health, and if so, should we use rewards or penalties for encouragement? The case of health screenings
ID: 416
oral
Harald Schmidt,
United States, Department of Medical Ethics and Health Policy, University of Pennsylvania

Around 70% of deaths globally are due to chronic conditions such as heart disease, stroke, cancer, or diabetes. Health risk assessments and general health check-ups testing cholesterol, blood pressure, blood glucose and body weight can help identify risk factors, empower people through health awareness, and facilitate care transitions. Yet, the evidence for general health check-ups has been called into question by a recent systematic review of randomized controlled trials, that found no effect on reduced mortality. Policy responses differ. In Germany and the UK, healthcare provider are obliged by law to offer general check-ups. Unlike the UK, Germany also uses both financial rewards and penalties to promote uptake. In the US, half of all employers who provide healthcare offer general health check-ups, with almost all use incentives.

This policy situation raises the question of which approach is the appropriate one. Should all health systems desist offering health screenings on the basis of lacking evidence? Or should all offer health screenings, and are those who do not currently do so withholding beneficial care? If all providers should offer health screenings: should they incentivize uptake through rewards? Or penalize non-use through penalties?

Among other things, these options raise issues around the scope and limitations of paternalism and autonomy, and question of whether there is, or ought to be, a right not to think about ones health. My answer to this question is a cautious and qualified 'no'. I contextualize the policies within recent findings from behavioral economics research. The discussion proceeds against the backdrop of a procedural justice account that specifies seven areas in which one could reasonably expect justification, regarding: evidence, rationale, and feasibility; intrusiveness and coerciveness; attributability and opportunity of choice; equity; solidarity/risk sharing; affected third parties; and coherence.

Abstract number: 143 Factory Farming , Global Bioethics and Public Health: New Challenges
ID: 418
oral
Fabiola Leyton,
Spain, University of Barcelona

Factory farming is responsible for a series of bioethics, health and environmental problems that challenge us urgently. Here, non-human animals only enjoy economic valuation, as they live and die exclusively for human purposes.

In my view, the bioethics analysis of this problem has been characterized by its uni-dimensionality, considering the purely instrumental use of nonhuman animals for human purposes; and for its insufficiency, considering the lack of criticism and accommodative response for public health. Both features are related to a narrow bioethical analysis anchored exclusively at the level of biomedical reflections.

Rethinking the ethical problem of our treatment to animals from a global bioethics, requires a redefinition to refer the moral significance of other living beings. Take, for instance, the fact that factory farming practices constitute a harsh reality for animals who live and die there. This raises questions to bioethics, which appeal to a globality, the consideration of their interests and the overpass of bioethical anthropocentrism.

In this global bioethics, citizens must be informed to make global decision, which ultimately affect the political dimension of bioethics, especially as it relates to animal rights, when their exploitation and use is not only part of a personal choices agenda, but becomes a pressing issue that requires resolution from the moral, legal and political areas since it is related to life and death of billions of sentient beings, who have evolved with our species and with whom we share the planet.

Abstract number: 144	Pandemic A H1N1 (2009) Preparedness Efforts, Compliance, and Some Ethical Considerations: A Retrospective Study on Hijli Rural Hospital (RH), Kharagpur I, West
ID: 423	<u>Rhyddhi Chakraborty</u> , Chhanda Chakraborti
oral	India, Indian Institute of Technology Kharagpur, Kharagpur

The paper presupposes that as part of its social justice based obligation towards health, every tier of healthcare system needs to be prepared to mitigate pandemic influenza. One of the means to fulfill such obligation is to follow the national pandemic preparedness guidelines. With this concern, this paper attempts to check the extent of the pandemic influenza preparedness measures of Hijli Rural Hospital (RH) of West Bengal, an eastern state of India. For this purpose, (a) it based its theoretical foundation mainly on the concept of central health capability, the capability to avoid escapable diseases and premature deaths, as propounded by Jennifer Prah Ruger (2010), (b) used Indian national action plan for pandemic influenza preparedness and response (2009) as a guideline, (c) conducted an informal interview with the hospital staffs. Findings suggest that the above mentioned hospital does not exactly follow the national guideline but it has shown some responsiveness within the hospital setting. For example, with the availability of vaccines in the hospital, it was the hospital staffs who were vaccinated as a precautionary measure. Using the case as a learning opportunity, the paper claims; (a) pandemic management efforts are intimately related to the concept of health as a 'capability' to avoid escapable disease and premature death, (b) lack of preparedness efforts, barriers to compliance, less or no execution of strategies as per national guidelines highlight severe ethical lapses in ensuring that capability. Therefore, it recommends that pandemic preparation at all levels of healthcare system, even of rural hospital, in order to fulfill the social justice based obligation, should follow the national guideline to provide the opportunities, to ensure the conditions, in this case those within the healthcare system, that affect the central health capability of people during pandemic phases and disable them to overcome pandemic situation.

Abstract number: 145	Grounded Normative Theory as a Methodology for Empirical Law and Ethics
ID: 429	<u>MA: Jean Frédéric Ménard</u>
Oral	United Kingdom, University College London

The purpose of this paper is to introduce Grounded Normative Theory, a research methodology designed to merge the insights of legal pluralism with empirical methods in bioethics. Legal pluralism holds that formal norms emanating from state institutions represent only a fraction of the normative landscape in any given context. Theorists of legal pluralism are wary to distinguish between legal and ethical norms and would include the various rules, guidelines and principles associated with clinical ethics (generally, 'ethical norms') under the umbrella of the law. Therefore, the pluralist lawyer is compelled to interrogate the beliefs, practices and experiences of agents in order to depict the normative order they create through their interactions. Limiting the inquiry to traditional legal sources – codes of law, statutes, regulations and court decisions – yields a distorted picture. Similarly, as the sources of normativity are manifold, reformist interventions can take many guises. We call our approach Grounded Normative Theory (GNT). It is broadly inspired from Grounded Theory and shares its commitments to symbolic interactionism and pragmatism but also incorporates an enhanced sensitivity to the different forms of norms according to which humans symbolise and organise their lives together. However, unlike Grounded Theory, GNT is also geared to channel the contextual normative knowledge of agents in the development and improvement of normative frameworks and practices. Using examples and preliminary results from our on-going research project on decision-making in neonatology, we will detail the steps in the methodology. We will also address the justification for using empirical methods in law and ethics, as well as some of the theoretical issues raised by the shift from an interpretative approach such as Grounded Theory to an ultimately normative approach like GNT.

Abstract number: 146	Women's ethical dilemmas at the intersection of labour migration and care drain
ID: 430	<u>Sylvia Hübel</u>
oral	Belgium, University of Leuven, Belgium

The past decade has seen a very significant increase in women's labour migration from Eastern Europe to Western countries. This feminization of transnational labour created a deficit of care in their communities of origin. Studies confirm the psycho-social implications of this phenomenon on their children, marital relationships and elderly relatives. Although extensive research has been dedicated to transnational families from a broad social science perspective, studies have paid scant attention to the personal ethical dimensions.

In this paper we focus on the internal dynamics of family relationships, more specifically on how migrant women negotiate their responsibilities. The displacement of their affective and physical care

from their families faces them with intricate ethical dilemmas. Our aim is to examine the conflict of responsibilities in their roles as mothers and caretakers of their elderly relatives. They leave home to seek the wellbeing of their family members but this implies a trade-off between economic well-being and family proximity. Women feel therefore unable to live up to the cultural expectations of care for direct dependents. Moreover, due to gendered norms persisting in their source countries, they are socially blamed for the deficit of care created in their families.

Little is known to date about how gender identities are renegotiated in the context of transnational family arrangements. Women's narrative accounts help us reveal the ways how they rework normative conceptions of care, love and responsibility. "Global heart transplant" as Hochschild and Ehrenreich (2002) coined it, is a multifaceted phenomenon, raising complex ethical issues. The continuing feminization of transnational migration provokes societal anxieties about care drain and the future of families in Eastern Europe. There is an urgent need for a better, culturally sensitive understanding of the impact of labour migration on family ethics.

Abstract number: 147
ID: 431
oral **Vector Borne Diseases and Community Based Participatory Research in Colombia: Empowerment to Establish Sustainable Solutions**
Nadia Lorena Gonzalez Cifuentes, Mylène Baum
Belgium, Université Catholique de Louvain

Vector Borne Diseases (VBDs) are a significant problem in tropical developing countries, they are linked to poverty and inequality, affecting vulnerable populations; they are partly result of an inadequate interplay between population and institutions, thus, a correct gear between them can conduce to more justice and opportunities to achieve general welfare. Since VBDs control and prevention activities are usually governmental, communities are not always involved neither aware of control measures which restricts the community capability, understood as the freedom to build a healthy environment. The aim of this work is to develop a participatory strategy within Amartya Sen's Capability Approach framework to establish an integral VBDs prevention, looking for a mutual learning process between communities and institutions. Drawn from the Capability Approach, Shared Health Governance framework proposes the concept of a shared responsibility as a shared commitment between societal actors to build and maintain healthy environments. In a rural community of eastern Colombia it will be built a communitarian diagnosis of main VBDs and their determinants to develop an integral strategy, built by the interaction between partners involved. The project will be developed in four phases: Diagnosis, Planning, Implementation and Sustainability, through a multilevel participatory process, looking for capability reinforcement and empowerment, participatory evaluations will be made to improve the work according to context. Existent control methods will be the starting point, they will be improved and more sustainable trough community participation. It is expected to generate a social transformation process, characterized by capability development, where deliberations will be made based on community participation. This will conduce build a healthy environment, where VBDs transmission will be decreased through participation of a mindful and capable community, redistributing health responsibilities, bringing autonomy to the population and conduced to a better prevention and control of VBDs, enhanced by community members' agency.

Abstract number: 148
ID: 433
oral **Age Threshold and Assent in Paediatric Research**
Marcin Waligora, Vilnius Dranseika, Jan Piasecki
Poland, Jagiellonian University, Medical College, Department of Philosophy and Bioethics

Assent is one of the most common ethical and legal requirements of paediatric research. Unfortunately, there are significant differences between the guidelines on the details of assent. What often remains unclear is the scope of the assent, the procedure for acquiring it, and the way of determining children's capacity to assent. There is a general growing tendency that suggests that the process of assent should be personalised, that is, tailored to a particular child. This presentation support the idea of personalisation. However, we also argue for placing limits on personalisation by introducing an obligatory requirement of assent starting at a certain age threshold. We gave an example of one of the stages of large-scale genome-wide association study of asthma took place in 14 European countries: the Gabriel study. During Polish part of the Gabriel study, no child was asked to express assent within the official study protocol. It illustrates that suggestions regarding children's participation in the decision process could be insufficient. A minimal age threshold is likely to serve the interests of children better than ambiguous and flexible criteria for personalised age determination. This minimal threshold should be understood as an age from which obtaining assent is absolutely necessary. However, assent can also be recommended for younger children, especially those who want and are able to engage in the decision-making process.

Abstract number: 149	<u>Ethical requirements in research involving children affected by acute lymphoid leukemia</u>
ID: 434	<u>Luciana Matos, Tainá Marques, Dirce Guilhem</u>
oral	Brazil, University of Brasília

Background

Children cannot be considered \"mini adults\" regarding to psychological aspects and clinical needs. Its inclusion in basic or clinical research is mandatory once the evidence produced is the basis to ensure the best treatment available for them.

Central ethical question

To delimit the ethical requirements in biomedical research including children with acute lymphoid leukemia (LLA).

Methodology

Beyond the conduction of the study titled Expression of genes related to pluripotency in patients undertaken by childhood acute lymphoid leukemia, with the inclusion of 43 children and adolescents, a parallel research using the literature was developed to support the analysis of ethical aspects related to the conduction of research involving children affected by acute lymphoid leukemia.

Results

Bioethical principles, such as autonomy (parent's informed consent; children and adolescent's assent), beneficence, non-maleficence and justice are indispensable tools for ethical delimitation during the following steps: revision of research protocols by research ethics committees, implementation and conduction of the investigations, and the subsequent dissemination of the results. Research conducted with children and adolescents affected by LLA require additional care considering the group vulnerability, their exposure to possible risks, obligation to maintain the privacy of participants, contributing to promote the autonomy of those involved.

Conclusion:

The studies for the treatment of leukemia's have been extremely beneficial considering the modification of the profile of morbidity and mortality of the disease and the survival after implementation of treatments developed and less invasive diagnostic tests. The great challenge is to maintain the balance between the responsibility to protect children and the moral obligation to work to produce targeted treatments specifically for children.

Abstract number: 150	TO BE OR NOT TO BE INVOLVED IN MEDICAL DECISIONS CONCERNING RELATIVES
ID: 435	<u>Michael Katz, Galya Hildesheimer, Michal Itzhaki</u>
oral	Israel, Haifa University

This paper is about an empirical study concerning the question at the title above. Questionnaires were administered to 412 Israeli students and professionals, in a variety of disciplines and occupations. Respondents' age ranged from 20 to 74. There were 184 (44.7%) male and 228 (55.3%) female respondents. Of 410 respondents who reported marital status in the questionnaire, 200 (48.5%) were bachelors, 170 (41.3%) married, 6 (1.5%) widowed, 11 (2.6%) divorced or separated and 23 (5.6%) living with spouses. Of 411 respondents who indicated their religious affiliation, 305 (74.2%) were Jews, 84 (20.4%) Moslems, 8 (1.9%) Christians, 6 (1.5%) Druze and 8 (1.9%) 'Others'.

The questionnaire contained the following questions:

Is it appropriate that members of your family will be involved in the process of medical decision making for you when you are (A) seriously ill but capable of making decisions (B) seriously ill and incapable of making decisions.

Is it appropriate that you will be involved in the process of medical decision making for a relative who is (C) seriously ill but capable of making decisions (D) seriously ill and incapable of making decisions. About 80% of the respondents answered 'appropriate' or 'definitely appropriate' to all four questions. Not surprisingly responses were significantly closer to 'definitely appropriate' in cases B and D than in cases A and C. There were practically no significant differences between older and younger respondents, male and female respondents, married and unmarried respondents, Jewish and Arab respondents.

The questionnaire contained additional questions concerning perceived likelihood and desirability that various considerations (economic, emotional and ideological) will be taken into account in the process of decision making. These questions were used to build a multi-attribute-utility-model describing and predicting respondents' decision making.

Abstract number: 151	Perception and Attitudes of Patients, Relatives, Health Professionals and Regulators on Bioethical Issues: The Case Study of the Brazilian Multiple Endocrine Ne
ID: 441	<u>Maria Sharmila Alina de Sousa, Rui Monteiro de Barros Maciel, Barbara Prainsack - work in progress</u>
oral	Brazil, Universidade Federal de São Paulo/King's College London

Today, society creates and defies crucial scientific and ethical issues in the post-genomic era of Translational Medicine, which has become the synthesis model for biomedical research. Thus, advances in basic research offer unique opportunities for new approaches to prevention, diagnosis and treatment for various forms of illnesses, especially in cancer. However, we consider that research in this area should not be detached from the interference of their social, cultural, economic, regulatory and political dimensions, as a way to pursue more balanced legislations between state-of-the-art of molecular and genetic tests with the ethical and humanistic aspects of it. Our case study on Multiple Endocrine Neoplasia type 2 (MEN2) and Familial Medullary Thyroid Carcinoma (FMTC) exemplifies research in Translational Medicine with effective clinical impact, as the diagnosis for RET mutations carriers is one of the few examples in clinical practice where genetic tests can define cost-effective clinical interventions. This subject is, however, still controversial, since there are always new families carrying new or known mutations being described and a series of bioethical issues emerge when physicians/researchers deal with patients and their families within a scarce resources non-advanced healthcare system, as the Sistema Único de Saúde (SUS) in Brazil. Our study is the first investigation on the perceptions and attitudes of patients, relatives, health professionals, within the public and private contexts, and government regulators on bioethical issues such as familial cancer experience, predictive genetic testing and preventive medicine, in light of grounded theory and critical discourse analysis on oral life history narratives besides document analysis. We are also investigating a possible Brazilian profile of comprehension and adherence to personalised preventive medicine, via comparative analysis between Brazil's SUS and UK's rich resources advanced healthcare system (NHS) by deploying the concept of solidarity.

Abstract number: 152 How broad is too broad? Justifying models of consent to research
ID: 443 Mark Sheehan,
oral United Kingdom, The Ethox Centre, University of Oxford

There has been a good deal of ethical consideration given to the acceptability of various models of consent to participate in research, particularly in the context of biobanks. Elsewhere I have argued that broad consent is a valid form of informed consent and so, in appropriate situations, is an acceptable means of enrolling subjects into research.

In this paper I consider other models of consent and the arguments in support of their use (either as required or as permissible forms of consent to research). More particularly, I consider the distinction between broad consent and open consent and focus on circumstances under which broad consent is ethically preferable to open consent. In the final part of the paper I consider the ethical status of forms of consent that may be grouped under the heading 'interactive models of consent', in which participants are able continually to modify elements of their consent to participate in research.

Abstract number: 153 Unpacking the Social Value of Research-Generated Knowledge
ID: 444 Danielle Wenner,
oral United States, Carnegie Mellon University

It is an accepted and codified principle of research ethics that research involving human subjects is ethical only if it holds out the prospect of producing socially valuable knowledge. This requirement is comprised of two components: a requirement that human subjects research be valid, and a requirement that it be valuable. This paper focuses on the value component of this dictum, and asks what it means for research-generated knowledge to be socially valuable. Specifically, I argue that the social value of research-generated knowledge is context-dependent, and that this fact implies ethical limits to the kinds of research which can be conducted within specific contexts.

In unpacking this limitation, the paper explores how the contextual value of knowledge should inform what is often referred to as the "responsiveness requirement." Specifically, the paper seeks to address two complementary questions: First, what constitutes the relevant community for whom research-generated knowledge ought to be socially valuable? Insofar as this requirement implies that the value of research-generated knowledge should primarily devolve to the host community, it has implications not only for the ethical conduct of research in the developing world, but also presumably on research conducted in the developed world targeting diseases or conditions which disproportionately affect the developing world. Second, how should determinations be made regarding the likely social value of an externally-sponsored research endeavor? In order for the social value requirement to govern the ethical conduct of clinical research, a mechanism is necessary for the prospective assessment of the expected epistemic gains of clinical trials. The paper concludes by exploring the implications of the social value requirement for the conduct of externally-sponsored research in developing countries.

Keywords: international research ethics, responsiveness, social value of knowledge

Abstract number: 154	Juridification and Regulationism in Human Pluripotent Stem Cell Research: The Re-Emergence of the State
ID: 446	<u>Calvin Wai-Loon Ho</u>
oral	Singapore, National University of Singapore

Under the mandate of examining 'ethical, legal and social implications' of research involving human-animal combinations, ethical bodies have applied legal reasoning, norms, practices and techniques in co-producing and sustaining epistemic claims and 'things'. This paper refers to this hybridization of the 'legal' with the ethical and other modalities of discursive power as juridification within a power-complex originally proposed by Michel Foucault as governmentality. In Discipline and Punish, Foucault characterises law as the embodiment of sovereign power, or essentially as orders backed by threats. With the rise of disciplinary power (which could arguably include ethico-regulatory discourses and institutions), Foucault considers that the sovereign and its power (i.e. law) must necessarily weaken. Whereas a narrow reading of governmentality suggests the sequestration of state (or sovereign) power by disciplinary (and bio-) powers or otherwise the subsumption of law into ethics, this paper argues for an alternative reading, which suggests a more productive and open-ended relationship between law and disciplinary powers, including ethics and science. To understand the nuances of this power complex, actor-network theory (or ANT) is applied in this paper to explicate particular network configurations of power modalities and their interactive spaces. By so deploying this mode of inquiry, this paper attempts to present an analytic as 'regulationism'. The value of thinking about regulationism not only as particular configurations of power modalities in the way that material and social nodes are linked, but also as 'spaces' within which such interactions are sustained is that it provides a better account of the dynamism of governmentality. Applying this analytic to ongoing research involving pluripotent stem cells, it is argued that ethics and law remain central to our experience of modernity in the pseudo-juridical nature and work of bioethics and policy bodies.

Abstract number: 155	Mandatory neurotechnological interventions: Ethical issues
ID: 449	<u>Farah Focquaert, Prof. Dr. Sigrid Sterckx</u>
oral	Belgium, Bioethics Institute Ghent, Ghent University

Imagine that effective neurotechnological interventions, either involving treatment or moral enhancement, exist for antisocial, criminal behavior and further imagine that these kind of interventions provide a better long-term risk minimizing strategy compared to imprisonment. Would it be ethical to offer such an intervention as a condition of probation, parole or (early) prison release? For example, self-regulation deficits and neurobiological abnormalities in psychopathy, antisocial personality disorders, schizophrenia and pedophilia can potentially be addressed by modulating abnormal brain activity using fMRI neurofeedback. If the neurotechnological intervention is without (severe to moderate) side effects, and if recidivism risk is adequately addressed, then the offer of such intervention as (part of) an alternative sanction is not necessarily ethically controversial. Nevertheless, some and perhaps many will argue that offenders will feel pressured into accepting the intervention out of fear of serving a lengthy prison sentence. However, if offenders feel coerced, to a greater or lesser degree, into accepting the intervention, does this constitute a sufficient reason to withhold the offer? In this paper, we argue that it can be ethical to offer effective, non-invasive neurotechnological interventions to offenders as a condition of probation, parole, or (early) prison release provided certain minimal conditions are met. We address these minimal conditions in detail and further discuss the ethical acceptability of mandated neurotechnological interventions as part of an offender's sentence.

Abstract number: 156	Epigenetics, maternal responsibility and neurological development
ID: 451	<u>Hens Kristien</u>
oral	Netherlands, Maastricht University

Epigenetics provides an explanation of how environmental factors influence organisms on a molecular level. Epigenetic changes are assumed to be heritable and possibly reversible, thus challenging the central dogma of genetics. Also in the field of neurology, it is believed that epigenetics can partly explain the development of neurological conditions. As epigenetic changes often happen in utero, maternal behavior may affect brain development of the fetus. This raises questions regarding the responsibility of the pregnant woman. To which extent is she responsible for the neurological status of the future child? Should she, for example, avoid all stress, if this is shown to lead to molecular changes increasing the chance of the child to develop ADHD later in life? Should she ensure that she takes optimum nutrition for development of synaptic plasticity of her fetus? With of this talk I want to demonstrate first that epigenetics complicates the question of the responsibility of the pregnant woman. To which extent does the constantly increasing knowledge about epigenetics influences in utero further complicate this responsibility, if even behavior of years before the conception may influence a future child? Is this an individual responsibility or also a collective

one? Second, by using the examples of autism and extreme intelligence, I want to demonstrate that, although discussions about parental responsibility towards future children have centered on duties to prevent suffering or to maximize welfare or 'the chance of a good life', the distinction between prevention and enhancement is difficult to maintain in the context of neurological conditions. By analyzing arguments from the neurodiversity movement, whose members often insist that their neurological condition is not a disease, but an integral part of their identity, I shall demonstrate that there is a need for a revisiting of the concept of maternal responsibility.

Abstract number: 157
ID: 454
oral

Determining validity of consent given by organ vendors for transplantation: the significance of regret in output-oriented assessment
Leonardo de Castro, Nur Izzati Binte Soonan
Singapore, National University of Singapore

Determining validity of consent given by organ vendors for transplantation: the significance of regret in output-oriented assessment

The validity of consent given by an individual to undergo a particular medical procedure has to be determined before that procedure is initiated. For this reason, determination of validity has to be done on the basis of what comes as input before consent is given—whether information is sufficient and relevant, and whether the person is competent and acting freely. For evaluation purposes, the assessment of validity can also be done after the procedure. Such evaluation can take into account information that only becomes available after the procedure is completed and outcomes are observed. This presentation about informed consent for the removal of transplantable organs from organ vendors examines validity on the basis of output compared to input, i.e., consequences as opposed to an individual's expectations and draws the conclusion that much of the consent given lacks validity. The mismatch between expectations and actual consequences is highlighted in the regret expressed by organ vendors. It also constitutes proof that the individual's consent was based on misleading information or that the individual lacked capacity to anticipate consequences or relate them properly to expectations. The conclusion is also supported by empirical studies of organ vendors' experiences. The presentation then proceeds to examine options for applying the results to organ transplant procedures in future.

Abstract number: 158
ID: 455
oral

Ontological Exploration of Vulnerability using a Conceptual Model beyond its Epistemological Limitations
Nabeel Mangadan Konath,
India, Public Health & Bioethics Consultant

Vulnerability - a complex topic in the context of global health and research ethics, is often addressed through a very narrow lens. A concept introduced early on as a key aspect of global health and research, it has recently given rise to some controversies too. Debates range from calls for increased protection for 'vulnerable populations'; to the futility of the concept of vulnerability. My study explores the reasons behind these controversies and examines whether and how the concept of vulnerability can still be useful.

Predominant approaches focus towards pre-categorized groups called "vulnerable populations" or categories rather than different types of vulnerabilities of individuals. On one hand, individuals with vulnerabilities tend to miss out from our radars since they do not belong to these pre-categorized groups. Secondly, just because a participant belongs to a particular group, we tend to overprotect them – for example, women, children, elderly, etc. While the former situation can lead to the argument that every participant is vulnerable, the latter situation denies autonomy for some groups. Both these arguments defy the usefulness of the concept of vulnerability.

This paradox can be addressed by shifting our focus away from "vulnerable populations" towards potential "vulnerability factors". To explain this concept, I developed a conceptual model, which shows how individuals consent or not, based on relative perceptions of risk and benefit. Different vulnerability factors of an individual can have varying degrees of push-pull effects on the risk-benefit perception threshold of this decision making model. A limitation of this approach, since it builds on a decision-making model is the potential for a false notion of sufficiency: where one might think that issues of vulnerability can be addressed solely through informed consent. A key factor in understanding vulnerability factors and ways to address them is community engagement.

Abstract number: 159
ID: 459
oral

Introducing an E2 (Evaluation & Enhancement) Social Accountability Framework for Medical Schools
Jeffrey Kirby,
Canada, Dalhousie University Faculty of Medicine

Medical schools across the globe have come to accept that they have an important social mandate beyond the education of future healthcare providers. Since the WHO's initial articulation of the social responsibilities of medical schools in the mid 1990's, several social accountability models designed for use by medical schools have been developed. These models have not been widely adopted for a variety of reasons, including a lack of conceptual clarity about what social accountability should entail in this context, their exclusive focus on evaluation, and their suboptimal accessibility for those without formal ethics/philosophy training.

With these existing limitations in mind, the social accountability committee of a Canadian Faculty of Medicine has recently developed an accessible framework for the evaluation and pragmatic enhancement of the social accountability of medical schools (and their operational units). The framework was designed for collaborative use by the medical school's internal and external stakeholders, the latter consisting of individuals, social groups and organizations in a wide variety of local, regional, national and global spheres. It is informed by four Guiding Social Accountability Values and Principles: 'equity'; 'inclusion, diversity and cultural responsiveness'; 'community/stakeholder engagement and partnering'; and 'justice-fairness and sustainability'.

This paper presentation will begin with a brief history of key research and scholarly developments in the field of 'medical school social accountability'. Descriptions will be provided of: the rationales for developing a stakeholder-driven, collaborative framework that addresses both evaluation and enhancement; the deliberative engagement methodology to be used by the participating stakeholders; the four social accountability performance criteria that are based on the above described guiding values and principles; and the five distinct phases of the framework. In addition, the results of the comprehensive pilot project to be performed in the first few months of 2014 will be shared.

Abstract number: 160 **The immorality of research exploiting unhealthy living conditions in a population**

ID: 462 Marcel Verweij,

oral Netherlands, Wageningen University, Section Communication, Philosophy and Technology

Throughout history there have been examples of biomedical research where patients or healthy subjects were exploited "for the sake of biomedical progress." Concerns about exploitation are still common, for example with respect to studies in developing countries that are sponsored by Western organizations. Such concerns even continue if the study satisfies basic moral principles for research, like informed consent, and the requirement of a reasonable risk/benefit ratio. Think of a company that aims to develop a food product that protects travelers and tourists against diarrhea, and that, for this purpose, tests the product in people living in slums where diarrhea is common. According to the Declaration of Helsinki such a project would be unacceptable if it was not aimed at benefits to people living in those slums themselves. But why is this morally problematic? My philosophical hypothesis is that such research projects 'exploit' the bad conditions in which people live, and even though it might be that no one is wronged by such studies - actually research subjects might be better off by participating - there is still something morally problematic in the attitude of the research team towards (the needs of) such communities. The immoral nature of such exploitation can probably be best articulated in a virtue-ethics approach. I will argue that this conception of exploitation is more fruitful in research ethics than the dominant account of exploitation as developed by Alan Wertheimer. It can explain researchers can exploit whole populations or communities and not just those individuals who participate as research subjects.

Abstract number: 161 **Physician-assisted dying in New Zealand: what do older persons think and why?**

ID: 463 Phillipa Malpas,

oral New Zealand, University of Auckland

Medical practices that hasten death are prohibited by law in New Zealand. The New Zealand Medical Association is ethically opposed to both the concept and practice of physicians assisting their patients to die. Despite this, public support for such practices, in certain qualified circumstances, is high. Leniency has also been shown by the courts toward individuals who have assisted a family member to die. However little research has explored the reasons older New Zealander's have towards physician-assisted dying and the ethical implications such reasoning may have on personal decision-making at the end of life.

Recently we undertook two qualitative studies that explored older healthy New Zealanders views about physician-assisted dying. We were interested in understanding why individuals supported or opposed medical practices that hastened dying and the personal experiences that may have shaped such support or opposition.

In this presentation I will discuss two central themes that emerged from the interviews: the importance of one's prior experiences with healthcare, dying and death; and the tension between individual autonomy versus a communitarian perspective. Personal experiences and views about the benefits and harms of physician-assisted dying profoundly shape decision-making at the end of life and ought to be considered by health care professionals in terms of decision-making.

Abstract number: 162	Deafness as a form of health? Theoretical and ethical issues regarding the holistic understanding of health
ID: 465	<u>Diana Aureneque</u> , Christopher W. McDougall
oral	Germany, Institut for the ethics and history of medicine, University of Tübingen, Germany

This paper will examine certain ethical and theoretical issues about the meaning of health as a pluralistic and culturally relative phenomenon. In order to analyze this in a concrete form – and in light of how different communities in a globalized world may have dissimilar if not even contradictory values – the paper explores the plural understanding of health in the practice of preimplantation genetic diagnosis (PGD). I will first compare competing accounts of human health and their underlying relation to particular ethical, social and cultural values. My aim is to show that health is, and should be regarded, in a holistic theory which is not primarily driven by the aim of restoring biological functions, but rather restoring the welfare of an individual and his or her subjective understanding of quality of life. However, such a view raises important ethical issues when it comes to the regulation of access to health care interventions such as PGD, and specifically PGD for the positive selection of traits whose moral value is disputed, as with for example, deafness. I will then describe a scenario in which deafness as a cultural identity is regarded not as a disability, since for the deaf community, deafness is not incompatible with their way of understanding "good health". I will argue, finally, despite good arguments against understanding deafness as a compatible with individual health, that this case forces us to consider both the boundaries of subjective and holistic theories of health, and the normative power of parental desires within the realm of reproductive decisions, as well as the nature of legitimately pluralistic discussions of the ethics of PGD.

Abstract number: 163	What is the role of cultural relativism in the case of hymen reconstruction?
ID: 466	<u>Verina Wild</u> ,
oral	Switzerland, Institute of Biomedical Ethics

Surgical hymen reconstruction can bring physicians into an ethical dilemma. Can the procedure be justified if 1) it is not clinically indicated, 2) the decision for it might be made under coercive circumstances, and 3) the operation might perpetuate structural patriarchal power? In an attempt to better understand the context and the situation of women opting for this intervention we conducted a qualitative study in Tunisia. We interviewed six women who underwent surgery, four physicians, three accompanying people, and one nurse. We conducted further studies in Switzerland and Germany (key-informant interviews, analysis of data from an online clinic). The results reveal personal stories about hymen reconstruction, and they will be presented as single cases. Women differ in their experiences of moral pressure, freedom to choose and their ability to cope. In the discussion I will show that evaluating this surgical procedure is difficult, because in some cases culturally informed moral values clash with "universal" ethical standards and the understanding of autonomy and freedom. Discussing hymen reconstruction is a particular challenge because the intervention is morally more ambiguous than both the clearly objectionable female genital mutilation and morally almost irrelevant aesthetic interventions. I will discuss: Why and how should hymen reconstruction be approached from an ethical perspective? What should be considered when choosing an empirical study design? Why is it necessary but at the same time so difficult to develop guidelines for physicians? In my conclusion I will reject a relativist stance, and explain why a "universal" ethical assessment – which cannot but evaluate some cases as problematic due to gender injustice – is the only defensible option. I will nevertheless call for a critical reflection of research methods and "universal truths" in bioethics.

Abstract number: 164	Regret in patients with acute and chronic conditions recruited to stem cell clinical trials
ID: 467	<u>Katrine Bavnbek*</u> , Bromage, DI*; Mathur, A; Hauskeller, C; Edwards, SJ * These authors contributed equally to this work
oral	United Kingdom, University College London Hospitals NHS Foundation Trust

Background

Valid informed consent to research requires sufficient understanding, freedom from duress and sufficient information. Failure to satisfy these preconditions has been associated with decision regret, an injurious emotion related to the belief that a different past decision would have led to a better condition today. Regret may also be triggered by lack of personal benefit. Decision regret in clinical trial participants can be abrogated through better information regarding study protocols, side-effects and potential complications. Abrogation may be compromised in emergency scenarios, when the consent process is necessarily abbreviated.

Aims

We examined regret of trial participation in patients recruited to randomized controlled trials of stem cell therapy for acute myocardial infarction (acute group) and dilated cardiomyopathy (chronic group). We explored the abridged consent process to establish whether there is a difference in regret in the acute versus the chronic cohort and secondly whether regret is attributable to lack of personal

benefit in the chronic group.

Methods

This was a qualitative-quantitative study of 92 patients (n=51 acute and n=41 chronic) recruited to the bone marrow derived adult stem cell (REGENERATE) trials between October 2012 and July 2013. A questionnaire survey and semi-structured interview were used to examine patient attitudes towards consent, motivations for participating and reflections on trial participation. Data was analysed using descriptive statistics and thematic analysis.

Results

Abbreviated consent was not associated with increased regret. Regret was evident among individuals who suffered complications, but there was no significant difference between the acute and chronic groups. Patients in the chronic group more frequently considered themselves fully informed and had a better understanding of risk. Regret in the chronic group was not associated with lack of personal benefit. Patients' understanding of risk was highly individual. Altruism emerged as a prominent theme in the chronic cohort.

Abstract number: 165 **Autonomy principle into a counseling genetics service.**
ID: 472 Dr. Nitza Diniz
oral Brazil, State University Of Londrina

The State University of Londrina genetics counseling has been founded at 1970's and more recently has included the reflection on bioethics issues en order to identify moral questions related to this activity.

The autonomy was the main principle identified since the families must take their decision based on information provided before and after the diagnosis in the genetics anomalies cases. The demand for the counseling service by the families for instances should been an autonomy action.

In order to evaluate this issue we designed a questionnaire containing five closed questions specifically about autonomy and the other questions for analyzing the general issues related to the service as psychology and results.

The principle of autonomy even in Kantian perspective or in Belmont Report's one refers to the idea that the individual should have their decisions respected. It was verified by the analysis of the interviews from 2012 and 2013 that in 92,5% of the cases were recommended by the physicians, 79% were informed about the reasons for the counseling; and 48% affirmed that the physicians gave no them no alternative for refusing being included at the counseling .

Most of the interviewed (77%) had no idea about the meaning of genetics counseling, even though 87% agree with the importance of the service.

It can be concluded that the families were no voluntary on looking for the counseling in an autonomy way since most of them had no information about the procedures or have given them the chance for refuse being submitted to.

As a result of this process it was elaborated a detailed brochure about the counseling process in order to help families on their taken decision related this issue.

Abstract number: 166 **Bioethical aspects of intra-familiar relationship in the context of home care**
ID: 474 DIANE LAGO, DIRCE GUILHEM
oral Brazil, UNIVERSITY OF BRASILIA, BRAZIL

Background

The home care is considered an innovation in the social paradigm of the art of caring. In Brazil, this model is present since the end of the 1940s. However, it was expanded in the early twenty-first century with the publication of specific rules. In 2011, The Ministry of Health published a specific policy GM/MS n. 2029/11 and the Program 'Better in House'.

Central research question

Ponder as to the home caregiver profile with a focus on bioethics.

Methodology

The methodological approach used was a sectional and descriptive research.

Results

Most of home caregivers belong to the family, are female and don't choose voluntarily develop this role. Just accept the burden imposed on them by society and other family members. They became vulnerable to social and health issues highlighted by stress and burden associated to the function performed. The caregiver develops a relationship of caring guided by reflection on the meaning of life, the ability to perceive and understand themselves and other. He or she engages directly with others experiences, learning to deal with their own feelings.

Conclusion

Take care for another person implies that the caregiver could be fully available for this function. Involves give him or herself to the function and understand the ethical issues involved in this situation: their own vulnerability and the other, the autonomy of choices, in (equity) and justice of interpersonal relationships. Take care means facing the challenge to find a new balance within the ethical autonomy of each one. Anyway, care of someone involves rethink and rediscover new meanings to the existence.

Keywords: Home care, caregiver, bioethics

Abstract number: 167 **NEONATAL HEALTH IN MEXICO. ANALYZING CHALLENGES FROM THE PERSPECTIVE OF THE VULNERABILITY PRINCIPLE**

ID: 475

oral

IRMA ALEJANDRA CORONADO-ZARCO,

Mexico, INSTITUTO NACIONAL DE PERINATOLOGIA

Since the Barcelona Declaration, vulnerability has been incorporated as a bioethical principle. It is certainly a complex principle in its hermeneutical analysis. Even though, it allows us to complement the perspective about a complicated topic as the health in the neonatal period. Same as in other parts of the world, the epidemiological behavior in terms of neonatal health is opening a huge challenge for Bioethics. If we incorporate to the analysis of the complexity in neonatal health and disease, factors such as cultural diversity, unequal socioeconomic conditions at birth, the fact that Mexico has access to the technological and scientific advance and the particular needs for research in this vulnerable population, Bioethics has a real challenge in the health-disease process. This work pretends to show how through the analysis of vulnerability the situation for the neonatal population can be enormously beneficiated.

Abstract number: 168 **On the Ethics of Dynamic Consent**

ID: 477

oral

Bettina Schmitow,

Italy, University of Milan; European Institute of Oncology, Milan, Italy

Problems in applying informed consent in biobank-based research have long been recognized: failure to take into account genetic connectedness, impossibility to anticipate research use, and insecurity if the right to withdraw can be respected. As technology is advancing towards digitalized, global research networks, these seem likely to increase. Many biobanks have adopted broad consent, and this has been considered as ethically defensible. Recently, "dynamic consent" has been proposed, which is Internet-based, interactive, and envisions to implement a participant-centric approach to genomics and healthcare (Kaye 2011). This contribution aims at elucidating in which way dynamic consent can be considered an ethical improvement, or "transform the debate from questions of public good versus individual autonomy, cost versus practicality to one where the concerns of the patient are aligned with the needs of medical research" (Kanellopoulou 2011). Defenders of broad consent, however, advocate a dichotomy between broad consent and dynamic consent, concluding that dynamic consent could foster an overly individualistic approach and undermine altruism, while implicitly suggesting that passive participation is ethically problematic (Steinsbekk, Myskja and Solberg 2013). It is argued that the supposed opposition between broad consent and dynamic consent is misleading and rests on an implicit assumption of a *per se* value of genomic research benefits. The problems that broad consent reacts to are largely due to the rationale and organization of biobank research itself, and dynamic consent is mainly a consequent technological development that cannot by itself solve any of these. Nonetheless, it might have an important expressivist function of signalling the willingness of cooperation from the research side and in providing a better understanding of the research process. In this sense, dynamic consent could indeed be the beginning of a paradigm shift that in the long run leads to overall more public accountability and social robustness.

Abstract number: 169 **Axiology of the ends of medicine**

ID: 482

oral

Perla Sueiras, Victoria Romano-Betech, Alejandro Vergil-Salgado, Adalberto de Hoyos, William

Ruddick, Silvia Quintana-Vargas, Jorge Méndez, Rodrigo Nava-Diosdado, Ana Serrano, Sergio Islas-Andrade. Nelly F. Altamirano-Bustamante, Myriam M. Altamirano-Bustamante.

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One of the fundamental topics in bioethics and medicine is the axiology of the ends of medicine. In our study we investigate the effects of the representations, views, attitudes, professional roles and habits of healthcare personnel in a daily clinical practice using a cross-functional hermeneutical analysis of illness, pain, suffering and death (IPSD). We reveal that a greater awareness of Values-Based Medicine (VBM) can be promoted by targeted Continuing Medical Education in Clinical Ethics (CME). In order to analyze the views and representations of PSD in 15 pre-CME and 15 post-CME interviews carried out on a random sampling of active healthcare professionals, we resort to Paul Ricoeur

hermeneutical approach. It embraced a naïve reading of the interview transcriptions followed by a structural analysis and a final comprehensive review.

We find out that the most often referenced values by interviewees were: respect, the importance of the healthcare team-patient relationship and empathy. We observed that these values reported a significant change: while healthcare professionals were empathic with their patients prior to CME they tended to maintain a "medical distance", appealing more to their professional experience than to their inner feelings whereas, after CME, the converse was true. Also we notice that the role of healthcare personnel as advisor and educator was reinforced and redefined, giving rise to the new role of healthcare professional as consociate, which implies genuine and empathic cooperative association with the patient and his family.

In this study, for the first time we have identified, fortified and applied to the practice of medicine the values that healthcare personnel have acquired by means of their clinical training and unique life histories.

Abstract number: 170
ID: 486
oral

Beyond dichotomies: an informational approach to personal identities
Laís Lopes, Carolina Nasser Cury; Brunello Souza Stancioli
Brazil, Federal University of Minas Gerais

The notion of personal identity entails a problem that affects different spheres, including legal frameworks. The bibliographical analysis included in the methodology indicated that in search of gauges of identity through time, many explanations were raised, such as the bodily and the memory criteria (NOONAN). Both concepts, although disentangled, indicate that personal identity is determinable through time. These answers were, however, fractured by the development Parfit drew on the notion of identity, by sustaining that identities are not monolithic, but social constructions of continuity and connectedness. Therefore, static analysis on selves and identities are replaced by an informational approach. In this sense, personhoods as emergent properties cannot be developed in a stimuli vacuum, but in an environment permeated by informational and linguistic patterns, whose meanings are produced and shared in everyday interactions. Even the emergence of mental processes (ROWLANDS) indicate that the notion of mind is keenly attached to interactions between brains and environments in which persons and objects affect each other and constantly rewire their neuronal structures (INGOLD). In this context, the information processed and issued to the world by persons come to constitute them, making room for a diffuse informational network. The elements traditionally associated with personal identity - body, memory, consciousness and life narratives - can be analyzed as states of dynamic information (FLORIDI). Contemporaneously, the increasing advances in communication and informational technologies raise challenges, to Law and Bioethics studies. The dissolution of boundaries between virtual and unplugged reality, the tension between the right to privacy and the existence of untamed informational flows, as well as the definition of accountability for online violations, are just some of the situations that require better approaches and regulations. This presentation, hence, aims to examine the dissolution of dichotomies such as information and identity, online and offline performances, law and reality

Abstract number: 171
ID: 487
oral

Early medical treatment of children with gender dysphoria: an empirical ethical study on arguments of proponents and opponents concerning early interventions
Martine de Vries, Vrouwenraets LJJ, Wichmann AB, Cohen-Kettenis PT, Schermer M
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Gender dysphoria is a condition in which individuals experience their gender identity (the psychological experience of oneself as male or female) as being incongruent with their phenotype (their body's external sex characteristics). Children represent a small number of the individuals with gender dysphoria.

Treatment for children is predominantly psychological. When gender dysphoria persists during adolescence, the possibility of puberty suppression has generated a new but controversial dimension to clinical management. Puberty suppression is a hormonal intervention, and is applied to relieve suffering caused by the development of secondary sex characteristics and to provide time to make a balanced decision regarding gender reassignment.

There is no worldwide consensus on the use of puberty suppression. In some countries it is part of treatment protocol. Elsewhere in the world it is not standard of care due to various ethical concerns, including fear for harms of the treatment and doubts about children's competence to make these far-reaching decisions. Debate moves between extremes and discussions are emotional.

The aim of our study is to evaluate the arguments used in treatment discussions and the underlying considerations of proponents and opponents of early interventions.

We performed a qualitative study (semi-structured interviews) to identify considerations of key-informants (pediatric endocrinologists, psychologists, psychiatrists, ethicists) of 10 treatment teams worldwide.

The results show that proponents as well as opponents use the same ethical principles (autonomy,

beneficence, nonmaleficence), but interpret them in totally different ways. This is caused by differing underlying ideas and theories about: the nature of gender itself (dichotomy or fluid), gender dysphoria (mental illness or social construct), child welfare, child participation and the role of medicine in general. We will discuss whether a critical reflection on these ideas and theories can move forward the debate on the conditions for using puberty suppression in adolescents.

Abstract number: 172 **Bioethics and intellectual property. Current debates about pharmaceutical patents: the case of High Cost Medicines (HCM)**
ID: 493
oral Prof. María Sol Terlizzi
Argentina, CONICET/UBA/FLACSO

Access to medicines is an issue that deeply affects the health and life of people. Concern for improving access to medicines by people around the world, especially in poor countries, has been addressed by bioethics - together with the human rights framework - for decades. In turn, access to medicines is closely related to the mechanisms of protection of pharmaceutical innovation and inventions, patents being the paradigmatic case.

A decade ago, the discussion was mainly focused on the role that patents played in access to essential medicines, such as antiretrovirals to treat HIV/AIDS. At present, the attention is placed in a reduced and specific set of drugs that represent a growing health spending across the world –and especially in Latin America– namely High Cost Medicines (HCM). The HCM are drugs for catastrophic (because of the economic impact) chronic conditions that are patented. Concerns about access to such drugs are growing among scientists, academics and the public. In this context, any democratic society must confront the ethical tension between requirements corresponding to the right to health and intellectual property rights, and find the appropriate balance of fostering economic activity and innovation, assigning responsibilities and fair distribution of social resources.

The aim of this paper is to present the ethical issues that arise around access to HCM, especially in Latin America, placing them in the broader context of the right to health and to outline some ways that may lead to better access to HCM under the current intellectual property system.

Abstract number: 173 **Stratifying risk in research regulation and oversight**
ID: 497
oral Annette Rid,
United Kingdom, King's College London

One of the fundamental ethical concerns about biomedical research is that it exposes participants to risks primarily for the benefit of others. Research regulations serve to protect participants' rights and interests in this context. Many regulations adapt subject protections to the level of risk that research procedures or studies pose to participants. In particular, many regulations classify risks as minimal or greater than minimal and reduce requirements regarding ethical review and informed consent in minimal-risk research. In this paper I argue that the categories of minimal and greater than minimal risk have important limitations and propose an alternative approach to stratifying research risk.

Research question: How should we stratify risk to participants in biomedical research?

Methodology: Conceptual and normative analysis.

Content: The current approach to stratifying risk to participants has two important limitations. First, it does not classify the risks of study interventions that offer participants potential clinical benefits; the categories of minimal and greater than minimal risk apply almost exclusively to research-specific procedures without a prospect of clinical benefit. Second, the current approach does not offer enough risk categories to adequately balance the regulatory goals of protecting participants and promoting valuable research. Both limitations make it difficult to develop a systematic risk-adapted framework for regulating research.

To address these limitations, I propose that regulators stratify risks to participants along the two ethically salient dimensions of research risk: net risk and uncertainty about the risk-benefit profile of study interventions. Furthermore, regulators should maintain the existing minimal risk threshold to demarcate net risks that are no greater than the risks of acceptable daily life activities and levels of uncertainty that are comparable to standard care, while introducing 2-3 sub-categories of net risk and uncertainty within the existing categories of minimal and greater than minimal risk.

Abstract number: 174 **Dysthanasia and/or Futile Care in the Intensive Care Units of a Specialty Hospital in El Bajío Region, in Mexico**
ID: 500
oral Enrique M. Olivares-Durán, Alejandra Montserrat Madrigal-Arcos
Mexico, Hospital Regional de Alta Especialidad del Bajío, HRAEB

Objective: To estimate the frequency with which dysthanasia and/or futile care is practiced in adult and pediatric intensive care units (ICUs) of a specialty hospital in El Bajío Region, in Mexico, and to identify the main factors associated with their occurrence.

Methods: A survey on the "Factors Involved in Dysthanasia and/or Futile Care", designed by the

authors, was applied to medical and nursing staff of every ICUs of the High Specialty Regional Hospital of El Bajío (HRAEB) along a period of 5 months. Staff participation was voluntary and the forms were self-reported.

Results: 30 critical care nurses and 20 physicians (adult intensivists, cardiologists, pediatric intensivists, neonatologists) from the ICUs, of all shifts, participated. 72% admitted to have practiced, at least once, dysthanasia and/or futile care, without a significant difference between in physicians (70%) and nurses (76.6%). 56% of respondents stated that the frequency with which they incur in any practice deemed by themselves as compatible with dysthanasia and/or futile care is 30% of their cases. The respondents obtained high or very high grades (from 86% to 98%) regarding their knowledge about: what a terminal illness is, what a terminal patient is, what dysthanasia is and what futile care is. 52% of respondents (physicians and nurses) reported not knowing the patients' rights. The right most mentioned by respondents (24%) was the right to die with dignity.

Conclusions: 72% of the UCI's staff who was surveyed for this project affirmed to have incurred, at least once, in dysthanasia and/or futile care. This was associated with their serious lack of knowledge about patients' rights (52%). This report should lead us to a deep reflection on the urgent need for addressing bioethical and humanization matters of the processes of Intensive Medicine and Nursing.

Abstract number: 175
ID: 504
oral **The Ethics of Introducing GMOs into sub-Saharan Africa: Considerations from the sub-Saharan African Theory of Ubuntu**
Ana Komparic,

Canada, University of Toronto

A growing number of countries in sub-Saharan Africa are considering legalizing the growth of genetically modified organisms (GMOs). Furthermore, several projects are underway to develop transgenic crops tailored to the region. Given the contentious nature of GMOs and the prevalent anti-GMO sentiments in Africa, a robust ethical analysis examining the concerns arising from the adoption, development, and regulation of GMOs in sub-Saharan Africa is warranted.

To date, scholarly ethical analyses concerning GMOs in the global context have drawn predominantly from Western philosophy, dealing with Africa solely on a material level. Yet, a growing number of scholars are articulating and engaging with ethical theories that draw upon sub-Saharan African value systems. One such theory, Ubuntu, is a well-studied sub-Saharan African communitarian morality.

Drawing on the work of philosophers such as Kwame Gyekye, Thaddeus Metz, and Godfrey Tangwa, I propose that using Ubuntu may lead to a novel and constructive understanding of the ethical considerations for introducing GMOs into sub-Saharan Africa. However, I do not apply Ubuntu to the issue of GMOs in order to reach a definitive conclusion, as a full analysis would require significant engagement with Africans. Instead, I reflect on Africa's distinctive history with maize in order to illuminate the relevance of using Ubuntu in guiding future agricultural policy in sub-Saharan Africa.

The final section of this paper asserts that a robust ethical analysis of sub-Saharan Africa's agricultural future necessitates engaging with African moral theory. More broadly, I conclude with a discussion of how bioethics may reconcile its universalism with the particularities of culture and place once applied in the global context. Rather than advocating for a form of ethical relativism, I suggest that local moral theories shed light on salient ethical considerations that are otherwise overlooked.

Abstract number: 176
ID: 509
oral **Why it is ethical to create children with three genetic parents using mitochondrial replacement therapies**
John Appleby,

United Kingdom, Centre of Medical Law and Ethics, Dickson Poon School of Law, King's College London

Mitochondrial DNA (mtDNA) disorders are maternally inheritable and can cause terrible suffering and death. They are also among the most common neuromuscular diseases. Mitochondrial replacement therapies (MRTs), such as maternal spindle transfer (MST) and pronuclear transfer (PNT), are currently being developed to eliminate the risk of mothers passing on mtDNA disorders to their genetically related children. MRT involves replacing mutated mtDNA in the egg (in the case of MST) or the embryo (in the case of PNT) with healthy mtDNA derived from a donated egg.

However, several ethical objections have been raised against the prospect of MRTs resulting in the creation of children with three genetic 'parents'.

In this paper I respond to these ethical objections by arguing that it is morally permissible if the use of MRTs result in children with three genetic parents. I consider three of the main objections to my position and respond to each.

The first objection is that having genetic ties to three parents could be confusing and result in children suffering from psycho-social harms. I respond by identifying evidence that suggests children's psycho-social development is not dependent on their genetic ties to others.

The second objection is that the experimental use of MRTs to create 'three parent embryos' is unethical unless we know they are safe (and we do not). In response I argue that no experimental technology is 100% safe, but safeguards can be put in place to minimise the possible risks of MRTs.

The third objection is that the use of mtDNA from a third 'parent' would violate the integrity of the human genome. I respond by arguing that MRTs may be germ-line therapies, but it is not clear that they harm the integrity of the human genome by replacing mtDNA that may otherwise cause a disorder.

Abstract number: 177
ID: 515
oral

Bioethics, Donation of medicines and disease of poverty. Analysis of a case of Public Health
Katya Rodriguez, Jose Sebastian Ponce
Ecuador, Ceiseb

A multinational Pharmaceutical gave a donation of medicines, to the health authority of Ecuador, in order to be medicated to people of a little poor town who were suffering from a disease of marginalization and poverty, calling, river blindness, (Onchocerciasis), six years later, this drug was just approved by the FDA sources for human use, the medication until then, was only registered as suitable for equine use.

The analysis in this case brings the consideration that the donation of a multinational enterprise could appear as a way to get human subjects in whom experiment drugs tests which have not been made until that moment in humans, likely, for just obtaining evidence necessary by the FDA for drug registration.

Abstract number: 178
ID: 516
oral

Gender-dependent participation in cardiovascular genetic research: An analysis of consent forms reveals 'participant categories'
Charles Dupras, Gregor Andelfinger, Michèle Paré, Maryse Thibeault, Béatrice Godard
Canada, University of Montreal

Background: The recruitment of research participants for studies involving genomic technologies calls for a comprehensive view of the ethical, legal and social issues related to consent forms and procedures. Studies endeavouring to identify such issues have largely focused on the content of consent forms and on the process of consenting as experienced by research participants and researchers. Very few studies have brought attention to participants' demographic characteristics or associated patterns of research participation and their answers to specific, consent form questions. **Methods and findings:** In order to shed light on such patterns, an analysis was performed on consent forms obtained from 600 research participants belonging to 127 families enrolled in a genetic research project on congenital heart disease (CHD). We assessed the demographic characteristics of research participants (age, gender, parental lineage) and their answers to specific consent form questions (DNA banking, use of cardiac tissue, disclosure of a cardiac condition, creation of cell lines, recall of a participant). Data for minors was provided by a parent/legal guardian. We observed that the level of their participation and their answers to questions were largely variable depending on their demographic profile, especially gender. Besides gender, we found that other participant categories (e.g., position of the participant in the family, proband's disease) correlated with distinct participation and answering patterns. **Conclusions:** We argue that such categories should be taken into account for improving consent forms and procedures, and that this calls for a 'working alliance' between genetic researchers and bioethicists, so as to: 1) minimize possible misinterpretations of answers given during the consent process, and 2) better orient efforts deployed to improve research consent forms and procedures.

Abstract number: 179
ID: 522
oral

Empowering Children and Caregivers in Pediatric HIV Disclosure: Insights from Kenya
Maureen Kelley, Kristin Beima-Sofie, Dalton Wamalwa, Grace John-Stewart
United States, University of Washington School of Medicine

An estimated 3.4 million children are living with HIV despite important strides toward preventing maternal-child transmission. Fortunately, as access to pediatric HIV treatment improves in the highest burden regions of Sub-Saharan Africa, more children are surviving and living with HIV into young adulthood. However, many of those children do not know they have HIV, as disclosure rates throughout the continent remain remarkably low into adolescence. While ethical analyses have been offered to guide disclosure of cancer and HIV diagnoses in children, much of the literature reflects the experience in developed countries with low rates of HIV. To better understand the complex ethical,

psychological, cultural and social factors that affect disclosure in the context of highest disease burden, we conducted a qualitative interview study at five clinical sites in Kenya, with three cohorts: pediatric clinicians, parents or caregivers of children living with HIV, and children who have had their HIV status disclosed to them. In this presentation, rather than present the primary data, we will use the ethically significant findings to inform an alternative ethical model for pediatric HIV disclosure to children. Discovering that one has HIV can be devastating for a child if not done carefully and with support. Not being told can be harmful to the child and pose public health risks. Many children are discovering their status inadvertently in the least supportive circumstances. Most parents resist early disclosure and report significant stigma, impact on personal and family relationships, and psychological stress. We consider two models of medical decision-making in pediatrics used to guide conflicts between the child's and caregiver's interests—constrained parental autonomy and the best interest standard. Based on insights from the Kenyan context, we offer an alternative model of disclosure rooted in an ethics of care and relational autonomy.

Abstract number: 180 **Ethical Aspects of Research into Gender and Domestic Violence**
ID: 527 Aqueda Muñoz del Carpio Toja, Patricia Sorokin, Pollyana Aníco Magalhães
oral Peru, Middleton International Fellows Association MIFA

In 2006 the General Assembly of the United Nations recognized that violence against women is one of the most systematic and widespread violations of human rights in the world, affecting all societies regardless of age, socio-economic status, education and geographical origin. Violence affects women in their homes, at work and in society. It is a public health and rights issue that impacts on the daily lives of families, communities and society. Society allows it and it happens silently and is kept quiet, especially in Latin American countries. This social permission and complicity make for a real ethical dilemma. For all the above reasons, researchers are working on studies including investigation of what sparks violence and the consequences of violence.

Social research has long addressed the issues of gender and domestic violence, but has not specified ways of giving protection to prevent harm coming to the victims of aggression within the study, which is why we propose some strategies:

Research on gender and domestic violence against women must be implemented with the greatest attention to ethics, ensuring the ethical quality of the research and the researchers, and with independent ethical monitoring. Some recommendations in the field of bioethics:

Respect for human rights victims

Dignified treatment (not re-victimizing abused women and their children)

Justice. Where there is a suspicion within research on domestic violence that one of the minor children has been abused as well as the woman, it is necessary to intervene to report the violence against the minor.

Benefits. To ensure that the research on violence brings with it a direct benefit to the participating victims of violence, such as: to propose that care services for women who have suffered from violence have a comprehensive life-cycle approach, i.e. to offer protection to females at all ages, from children, adolescents, young adults and mature adults and to propose comprehensive rehabilitation therapy programs.

Ensure data confidentiality.

Respect the autonomy of victims.

Engage all stakeholders in the research.

When researching boys and girls who suffer from violence, use playful and indirect strategies of data collection, so as not re-victimize the boys/ girls.

Listen to complaints and proposals, in other words social research into types of gender and domestic violence should not just collect statistical data, but should provide tools to enable the intervention work.

Finally, we recommend that research results are disseminated among civil associations and among political decision makers.

Abstract number: 181 **INTERPRETATION OF ARTICLE 4.1: REVIEW AND ANALYSIS OF THE ULTERIOR PRACTICE OF STATES MEMBERS OF THE AMERICAN CONVENTION ON HUMAN RIGHTS**
ID: 532 Aracely Ornelas Duarte,
oral Mexico, Center for Advanced Social Research

The recent ruling by the Interamerican Court of Human Rights on the case Artavia -Murillo (IVF) vs . Costa Rica (2012) is the subject of many discussions , particularly with regard to interpretation by the Court of Article 4.1 of the American Convention on Human Rights; the Court arrives to the conclusion that the human embryo can not be considered a person for the purposes of the Convention, the protection of the right to life can not be absolute , but is gradual and incremental according to its development, and it is not an absolute and unconditional duty.

We believe that this work can be a contribution to the interpretative work of the Court in relation to

Article 4.1 of the Convention, looking attentively to the subsequent practice of States member of the Convention, in conjunction with other interpretive means, established by the Convention Vienna, may help to unravel the will of the States Parties to the Convention and to make a correct interpretation of article 4.1.

It makes a brief review of constitutional law, constitutional court decisions, civil laws , criminal , special orders , regulations regarding in vitro fertilization of the 25 signatories to the Convention.

In light of legislative developments since the signing of the Pact of San José is shown as clear that the States Parties to the American Convention explicitly granted protection to life from the moment of conception in Article 4.1 , recognizing the unborn child as a subject and protecting rights , regardless of their state of development , protecting him of any act that could intentionally cause his death or destruction , because in their legal protection of the right to life has never been " progressive and gradual " because with few exceptions, States have not made any distinction in legislation on providing legal protection to the unborn child .

Abstract number: 182 Teaching ethical standards for the performance of healthcare professionals

ID: 533 Mary Ana Cordero Diaz, Maria del Pilar Gonzalez, Graciela Medina Aguilar

oral Mexico, Escuela de Medicina y Ciencias de la Salud del Tecnológico de Monterrey

The CanMEDS Physician Competency Framework describes the knowledge, skills, abilities, and professional attitudes that physicians need for better patient outcomes, is based on the seven roles that all physicians need to integrate as Medical Experts in their provision of patient-centered care, and is the basis for all specialty specific objectives of training. In residency education the Scholar and Professional roles are particularly related to clinician educators and the teaching and learning of medical professionalism, i.e. the ethical standards for the performance of healthcare professionals.

This session will present, discuss and recommend practical options to address key issues on three principal areas of concern: the increasing complexities of medical professionalism and the learning environment, the influence of personal and environmental factors on professionalism in medical education, and the institutional challenge to address professionalism's hidden curriculum in medical education. Evidence will be presented from medical education research reports, expert commentaries and a literature review.

This session will explore an analysis of medical professionalism as a complex system and its impact upon the clinical learning environment; the influence of personal and environmental factors on professionalism in medical education; the relevance to address professionalism's hidden curriculum in medical education as an institutional challenge; clinician educators' role fostering professionalism in the learning environment; and innovative faculty development programs for educating in medical professionalism.

This session will discuss recommendations for clinical educators to reinforce their roles in residency education regarding professionalism as well as their CanMEDS Physician Competency Framework roles as scholar and professional. Participants will be able to recognize current trends in medical professionalism education, describe future directions for faculty development in this key issue and will be provided an opportunity to debate how the recommendations presented may impact the clinical learning environment and how we teach and learn medical professionalism.

Abstract number: 183 The Bioethics in the Biomedical University Teaching

ID: 535 Antero Enrique Yacarini Martínez,

oral Peru, Santo Toribio de Mogrovejo Catholic University

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Introduction

Biomedical university education in Peru and Latin America is in a process of curricular changes and innovations in teaching and learning by integrating the ethical and bioethical component (1)

The importance of a bioethical analysis in biomedical university education proposes: 1) professional profile Exit 2) knowledge of current bioethical issues 3) a methodology for reflection and ethical decision making on technical and scientific progress and 4) responsible action .

What is the role of bioethics in biomedical university training?

Bioethics is a relatively young science of medical ethics arises however today its scope has been extended to all sciences.

Currently there are a number of ethical problems in the beginning of life , sexuality , procreation , illness , death , scientific research and vulnerable populations , the distribution of health resources

and environment.

New technologies are being developed that have led increasingly abysmal gap between the development reached the biological and medical sciences and in the field of law, politics , academia , business and the media (2)

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Abstract number: 184

ID: 539

oral

Bioethics Experts? Criticism, necessity and previsions for our future IRBs

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Growing harsh criticism against bioethics must be known and discussed. This paper will review 1) Donna Haraway, who says that bioethics is "...one of the most boring discourses to cross one's path in technoculture", because it acts as a regulatory discourse after or before the action (When Species Meet, 2007:136). 2) Santiago Ivan Guerra, legal anthropologist studying drug trafficking, resents that his IRB "...were focused on safeguarding the institution rather than protecting the research informants or the researcher" ("Becoming An Il/legal Anthropologist", 2013). Finally, 3) Tom Koch exposes how bioethics has failed on deliver on its promises, hijacking traditional ethics of medicine and bringing "a bookkeeper's recording rather than a moralist's accounting" (Thieves of Virtue, 2012:9). Beyond this accurate criticism, this paper exposes the necessity of functional existence and autocorrecting practices of IRB/CEI in Mexican universities, where there are none. Teaching, testing and researching can be acknowledged and ethically discussed. The touchstone of this justification despite criticism is a paradoxical condition: collegiate authority to hold the line against looming ethic troubles, considering that ethicity must be anybody competence. I am hoping that resonance of concerns and demand for justification can make a difference. I propose two previsions for the future operation of IRB in our institutions: to encourage critical mass of committees connected to regional and national networks, and to widely disseminate some cases, guarding confidentiality.

Abstract number: 185

ID: 543

oral

"THE INSTITUTIONAL BIOETHICS IN MEXICO: PERSPECTIVES AND FUTURE"

Beatriz Eugenia Cárdenas-Morales, Ma. del Carmen Cid-Velasco, Alba Cerna-López. Ángel O. Cruz-Iriarte, Manuel Ortega-González

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In the development of Bioethics converge various circumstances and facts that have been paradigmatic in the history of humanity, primarily related to the life sciences and health, which can be circumscribe in 5 areas: 1. Environmental care. 2. Protection of humans in scientific research. 3. Quality and efficiency of health programs (health care, public health and social assistance). 4. Risks and benefits of scientific and technological advances, and 5. The need to institutionalize the Bioethics. The beginning of institutional bioethics (or Social Bioethics) in our country is situated in the decade of the years 90's within three areas: health, education, and non-governmental organizations.

- Health area: the most important organization is CONBIOETICA (National Bioethics Commission) and its state chapters.
- Education area: at that time some universities initiated formal bioethics courses (like UNAM and IPN) most of them in medical schools.
- Non-governmental organizations (like ANMB, A.C).

With all the unobjectionable achievements of Bioethics nowadays, there is still much to be done, and we could start by asking ourselves the relevance and feasibility of the following proposals: 1. Promoting that the National Bioethics Commission (CONBIOETICA) as its state chapters be constituted as autonomous organisms, which would help to avoid potential conflicts of interest and would facilitate the achievement of its objectives. 2. Create bioethics committees in all government institutions, as instances of advisory or consultancy and accompaniment in decision-making. 3. Expand the action space of the Hospital Bioethics Committees (CHB) with greater participation in all activities concerning with provision of health services, (especially medical care), as a strategy to improve quality and conflicts prevention. 4. Improve bioethics educational programs and establish bioethics committees in all educative institutions, to impact in the development of a necessary bioethics culture and contribute to humanizing the institutional social context.

Abstract number: 186	DATA FROM MOBILE DEVICES AND CLINICAL HEALTHCARE DECISIONS: A NEW PARADIGM?
ID: 545	<u>Alexander Capron,</u>
oral	United States, University of Southern California

Changes in our understanding of the psychology of decision-making and behavioral economics' challenge to traditional models of how people make choices have become prominent features of current efforts to improve human health through "nudges"—the steps taken by governments or organizations (such as employers) to overcome threats to health that arise from behaviors such as smoking, over-eating, and lack of exercise. The measures include changing default rules, framing choices, and creating financial incentives and disincentives. The extensive databanks being created—not principally by healthcare organizations but by companies that sell goods and services and that monitor mobile device use—may turn out to be a potent source of information that could make nudges more effective. But alongside this use of "big data" for population activities and outcomes, it may also be possible to use "small data" (information about individuals' habits, actions, including travel and purchases, and general preferences) to alter their health-related choices about diagnosis and treatment in the physician-patient relationship. The use of nudges in this context is ethically fraught because much of the impetus for bioethics was to replace professional dominance and medical paternalism with "autonomy" and informed consent. Yet the sophisticated view of consent propagated by Jay Katz, while rejecting coercion, fully accepts the role that unconscious processes and unexamined assumptions play in the process of mutual decisionmaking by doctor and patient. This paper describes the wide range of data that mHealth devices as well as routine collation of personal commercial activities will be able to provide; it then examines whether such data should be returned directly to patients or can and will be used by physicians as "clinical nudges" to influence their patients' actions and, if so, how such behavioral economic uses compare to traditional paternalism aimed at controlling patients' choices.

Abstract number: 187	Ethical aspects of the move towards Universal Health Coverage: focus on LMICs
ID: 547	<u>Anant Bhan,</u>
oral	India, Independent Researcher

This paper will examine the ethical aspects of the current move towards the promotion of Universal Health Coverage (UHC), with a focus on low-and middle-income countries (LMICs). It will examine the challenges, opportunities in achieving UHC and explore the underlying ethics issues embedded in the individual, societal and research aspects of this important global health goal.

Grounded in historical global health experiments and events which led to the Alma-Ata Declaration in 1978 and subsequent work on Social Determinants of health as well as the experience of trying to achieve the UN 2015 Millennium Development Goals, UHC aims to ensure that individuals and communities have access to equitable and just health services. UHC is now being strongly promoted by agencies such as the WHO.

The movement for UHC, especially in LMICs will face ongoing health system challenges such as the need for a strong focus on prevention, accessible and affordable health services and research with social value which leads to efficacious interventions being adopted on a priority basis. All of these elements of UHC will require addressing ethical challenges at the clinical, research, public health and health systems level. These include ensuring fairness/justice, addressing needs of vulnerable populations, risk mitigation, 'evidence' generation, resource allocation, and implementation of efficacious interventions in a transparent manner.

Drawing on examples and experiences from LMICs, this paper will argue that efforts to achieve UHC should integrate efforts to identify and address ethical elements of interventions. The need to ensure that interventions are scalable and sustainable would be highlighted. The paper will reiterate the integral links of UHC efforts to ongoing debates in global health ethics around healthcare worker shortages and migrations, financing, social justice, intellectual property and access.

Abstract number: 188	Science and Crime: The impacts of bioanthropological research in law and in contemporary society
ID: 554	<u>José Eduardo Ribeiro Balera, Nilza Maria Diniz</u>
oral	Brazil, Universidade Estadual de Londrina (UEL)

The violence and crime phenomena have been studied by some scientific parameters such as bioanthropological. This study aims to examine the possible benefits and harms from scientific investigations relation between individual skills and behaviors and biological elements to the society, for example, neurological and genetics factors.

The hypothetical deductive method was applied to identify the possible effects of bioanthropological research and compare their impact on the moral, political and legal context in contemporary society. It was analyzed reports widely published in the media in 2008 but never officially confirmed about a

research in which it was proposed a neurobehavioral study of institutionalized young offenders. This kind of research could describe possible factors to be treated, enable the development of more efficient and consistent criminal policies based on the realities of the individuals who practiced criminal act, additionally could prevent unjust and disproportionate judgments. On the other hand, there is a weak boundary between the beneficial and harmful.

This research was planned to include young offenders a socially vulnerable group, which could aggravate their condition of inequality and exclusion.

The scientific results arising from such research could acquire an ideological character, marked by reductionism or determinism biological, as in other periods of history.

This way, it would be possible to observe a relationship between scientism and punitive power of the state, in which the emphasis would be given to socially dangerous individual and not to the illegal and culpable conduct. Therefore, one can conclude that this kind of research is not ethically acceptable, since it is possible to observe disadvantages as worsening situations of unequal research subjects, as well as social and legal risks that could arise from scientism not concern about political theories and modern criminology, as in other periods marked by the Criminal Law of the Enemy.

Abstract number: 189

ID: 556

oral

A Concept of 'Legitimate Coercion' for the Regulation of Access to Emerging Biotechnologies

Kyle Edwards,

United Kingdom, The Ethox Centre and Uehiro Centre for Practical Ethics, University of Oxford

Arm's length governance is currently the preferred method in many liberal democracies for regulating access to a range of emerging biotechnologies, in areas that include assisted reproduction, genetics, and pharmacology. In the UK, regulatory or advisory decisions in these areas concerning whether access to novel procedures, tests, devices or substances should be restricted are made by deliberative committees that sit within arm's length bodies (ALBs). Recent empirical research suggests a great deal of confusion within these committees about how such public decisions ought to be made, particularly with respect to the role of reason and argument on the one hand and representation of 'stakeholders,' the 'affected public,' and the 'general public' on the other.

These deliberative committees thus face a set of practical problems that stem from the question of whether and on what grounds the state may restrict individuals' access to these emerging biotechnologies. In this paper, I propose and build a concept of 'legitimate coercion' as a vehicle for working through this question. The concept of legitimate coercion allows for novel interplay between two rich but fairly detached literatures that offer divergent accounts of 'legitimacy' relevant to the context of public policy decision-making about novel biotechnologies. The first concerns the nature of ethics expertise, while the second concerns the nature of procedural and/or substantive constraints on public reasoning within a liberal democratic society.

After constructing the concept of legitimate coercion and arguing for a particular account of it, I propose a set of reforms for the structure and function of both deliberative committees and the ALBs within which they operate. I use case studies of currently existing ALBs, like the Human Fertilisation and Embryology Authority and the Medicines and Healthcare Products Regulatory Agency, to illustrate what these reforms would look like in practice.

Abstract number: 190

ID: 557

oral

Direct-To-Consumer Information: An Insidious Means of Drug Familiarization leading to

Therapeutic Misconception

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Promotion of prescription drugs may appear to be severely limited in some jurisdictions due to restrictions on Direct-to-Consumer Advertising (DTCA). However, in Canada and other countries, strategies exist to raise consumer awareness about prescription drugs, most notably through the deployment of Direct-To-Consumer Information (DTCI) campaigns that encourage patients to seek help for particular medical conditions. DTCI can build consumer confidence and increase the credibility and thus the persuasive effect of the message, a process that we call familiarization. While DTCI is presented by industry and regulated by Health Canada as being purely informational activities, the design and integration into broader promotional campaigns raises very similar ethical concerns as for DTCA. Specifically, DTCI can be an effective means of familiarizing the public with the scope and benefits of a particular prescription drug, and so like DTCA, can promote increased patient-consumer demand due to a therapeutic misconception among consumers who may see DTCI as an objective and well-intentioned mechanism for raising public awareness about an important health condition, rather than as being part of a promotional drug campaign. From a population health and policy-making perspective, this can lead to a problematic increase in prescriptions and the use of medications that may be neither the most appropriate nor the most cost-effective. Yet, with DTCI the industry is playing within the existing rules and regulations set by health regulators. To respond

appropriately to this regulatory incoherence, we argue that DTCI should be regulated as a type of indirect direct-to-consumer advertising. Even if the case and specific regulations presented here are Canadian, the implications extend to every country that has a partial or total prohibition on DTCA.

Abstract number: 191
ID: 563
oral

Stigma, mental health and peace process in Colombia
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Colombia is a country with two centuries of republican life marked by war, fronted partisan struggles and against a backdrop of economic disputes by maintaining power. The current armed conflict in Colombia has more than 50 years, in which there has been a degradation of the war, with systematic violation of human rights and international humanitarian law. As a consequence, more than 200,000 people, civilians and fighters, have been killed, nearly five million have been forced internal displacement and millions suffer from physical and psychological wounds. The displacement creates a stigma for the victims of the armed conflict in different contexts. To this are added the stigma related to other characteristics such as gender, ethnic or cultural. The situations of violence and discrimination experienced related to the displacement are major stressors that put them at psychosocial vulnerability to victims of armed conflict. Consequently, a comprehensive psychosocial care for victims, it reaches beyond categorization or medicalization of emotional or behavioral manifestations, which generate an additional stigma and suffering. The invisibility of mental health in the Colombian conflict is particularly relevant in the current peace process between the government and the guerrillas, since the suffering of the victims at risk of medicalization, generating a re-victimization through the systematic denial of suffering associated with own sociopolitical dynamics model of state and society and the economic system.

In this situation it is imperative a dialogue of the professions in the field of mental health to society from an ethical perspective.

Abstract number: 193
ID: 570
oral

Does Human dignity have nothing to do with the physical body?
Han Yuehong, Zhang Yunlian
China, Faculty of Social Sciences, Kunming University of Science and Technology

In history there were two different perspectives to understand human dignity. One is from psychological perspective. For example, the ancient Greek's concept of superior dignity, Kant's rationality-based dignity, and Mill's autonomy-based dignity. All of them understood dignity based on rationality, morality and autonomy. Another perspective is to understand the basis of human dignity as the whole person. It emphasizes both the psychological dignity and the dignity of human life. This is Christian conception of dignity, and hence Christianity has been the credo of human life's dignity. The view that dignity has nothing to do with the physical body never been closely argued. Besides, there is no evidence to support this view. When a person is physically hurt, tortured, brutally destroyed and killed, the way his/her dignity being damaged is more severe than the way his/her autonomy being denied. Under general circumstances, when both the life and autonomy are threatened, most of the people would give up autonomy in order to save life and reduce physical pain. This shows that dignity is related to the physical body. Besides, the dignity of human life is more fundamental and important than psychological dignity. To deny the relationship between human dignity and the physical body would lead to the discourse that dignity is useless. This is the case of Ruth MacLaine, who proposed the view that "Dignity is a useless concept---it means no more than respect for persons or their autonomy."¹ We argue that the relationship between dignity and the physical body is affirmative. And we acknowledge that human dignity should include the dignity of human life and psychological dignity, so that it can fit into the theoretical and empirical application of Bioethics.

Abstract number: 194
ID: 571
oral

Medical empathy in Iberoamerican physicians-in-training: Similarities and differences during their professional practice at a Teaching Hospital in Spain
Luis Vivanco-Sierralta, Adelina Alcorta-Garza
Spain, Center for Biomedical Research of La Rioja - CIBIR

Professionalism is a basic core competency of physicians that should be taught and assessed during the residency period. Several studies suggest that achieving medical professionalism among health personnel is paramount for reaching a consistent improvement in health care. Clinical and humanistic competences are core characteristics of professionalism. Empathy is one of the main humanistic competences of professionalism. Those competences could be influenced not only by the effect of formal curriculum; also by the effect of informal curriculum, that refers to lessons that are not explicitly

taught and come mainly from social interactions during the clinical practice; and hidden curriculum, that refers to all that is taught from the organizational culture and institutional environment. Our study was focused on medical empathy in physicians-in-training from Iberoamerican region. Empathy is a cognitive attribute that involves an understanding of the inner experiences and perspectives of the patients, combined with a capability to communicate this understanding to them. This presentation summarizes a preliminary cross-sectional study to identify factors that could be affecting the medical empathy of physicians-in-training along their professional learning process at the hospital. Information was collected from 104 questionnaires from all 190 physicians-in-training in our Hospital. Empathic interactions were measured using the Jefferson Scale for Physicians Empathy. Differences between empathic scores with statistical significant differences were found for: geographical origin ($p<0.05$), exposure to hospital environment ($p<0.01$), professional ideal models ($p<0.001$), contact with good professional examples ($p<0.01$), and successful continued education ($p<0.05$). We conclude that acquisition of medical empathy is influenced by internal and external factors not directly related with formal curriculum. These results confirm the importance of hidden and informal curricula into acquisition of medical professionalism at teaching hospitals.

Abstract number: 195

ID: 572

oral

Animal research and the three Rs, updates in legislation in South America

Carmen Alicia Cardozo, Salvarrey A, Serna H, Lescano AR

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Animal research is a scientific and social concern but its practice has yielded considerable progress in both, human and animal health. Since some types of research cannot be ethically conducted in human beings, and thus, it is conducted with animals, the need to disseminate the three R principles: Reduction, Replacement and Refinement.

International guidelines are available with technical specifications on production, care and use of laboratory animals and these have led to countries enacting their laws and regulations that allow research while at the same time, protecting the principles of the three Rs. The last decade has seen advances in this area for countries in South America and several associations created by the civil society with the support of FESSACAL-ICLAS have played an important role in highlighting the challenges.

This is a review of the legislation available in 9 of the 10 Latin countries in South America.

Five of the ten countries have laws, but 3 of those 5 have actually implemented those laws. These laws were issued between 2008 and 2013. These three countries have started efforts to register animal research investigators and facilities, as well as Institutional care and use committees within their national boundaries. There are only 4 animal research facilities accredited by international standards.

National regulations are needed to ensure proper use of animals in research in keeping with the three Rs, and the experiences of the existing country association is essential to establish training programs for animal handlers and investigators, develop standard operating procedures for quality assessment, self-inspection checklists for Institutional facilities, as well as for the establishment of well-constituted IACUCS to oversee animal research in South America.

Abstract number: 196

ID: 576

oral

Pain Relief is a Human Right

Michel Daher,

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Epidemiologic evidence has proven that chronic pain is a widespread public health issue. Studies of cancer patients' pain control consistently reveal that up to half of patients receive inadequate analgesia and 30% do not receive appropriate drugs for their pain. In the developed world, this gap has prompted a series of declarations and actions by national and international bodies advocating better pain control. One response to the worldwide undertreatment of pain has been to promote the concept that pain relief is a public health issue of such critical importance as to constitute an international imperative and fundamental human right. The importance of pain relief as the core of the medical ethic is clear.

Pain clinicians promote the status of pain management beyond that of appropriate clinical practice or even an ethic of good medicine. They advocate a paradigm shift in the medical professions' perspective on pain management, from simply good practice to an imperative founded on patient rights. There is a need to promote policies which create conditions where human beings can bear even incurable illnesses and death in a dignified manner. This must help health professionals or lay groups to initiate a powerful agenda to reform local statutes.

The essential components of such legislation are: 1. Reasonable pain management is a right. 2. Doctors have a duty to listen to and reasonably respond to a patient's report of pain. 3. Provision of necessary pain relief is immune from potential legal liability. 4. Doctors who are notable or willing to ensure

adequate analgesia must refer to a colleague who has this expertise. 5. Pain management must be a compulsory component of continuing medical education. The main goal is to relieve suffering and improve quality of life of the cancer patients, and advocate pain relief as a human right.

Abstract number: 197
ID: 588
oral

Transforming conceptualization of Health and Disease: Bioethical and epistemological implications of the interaction Microbiome-Human
Dr. Ximena González-Grandón
México, Universidad Nacional Autónoma de México

Nowadays, the paradigms of the health/disease process are constructed through the adoption of the biomedical model, which promotes genetical individualism and its reliance on normality ranges based on good genotype and microorganism free. The mainstream bioethics has predominantly focused on respect for the living autonomy person in terms of this genocentrism in the clinical setting and in the research site. Nonetheless these assumptions are problematic. That characterization, the taxonomy and self-determination of the healthy human being, is not complete if it is just about human genome mapping, because a big percentage about the human being genes is not humanDNA, rather is microbiomeDNA (the number of micro-organisms which inhabit an adult human body is estimated the 90%: Pregnolato, 2011) . In general terms, the microbiome are microorganism communities surrounding the human body and giving support to it that co-exist and co-evolve with it (Azetzop, 2010). So that human/not human is intimately connected. In fact, in functionalist terms, many basic human processes depend on them right immediately after birth and along the whole ontogenetic processes. Therefore, when a person is sick, is the microbioma sick? How important is the viability of the microbioma for healthy people? Do we have to learn to take care of the microbiome? What happen with the microbioma when antibiotic treatment? Here I present an explanatory analysis about the research on the human microbiome and the integration possibilities in the human being individual category. I argue that may lead to new conceptualizations and epistemic definitions, some of which are very valuable in bioethics and medical epistemology, particularly about the division between the normal and the pathological and the normativities around it. I also relate, the new epistemic tools that are giving hard evidence about the necessity in new research lines for pharmaceutic antibioticotherapy.

Abstract number: 198
ID: 590
oral

Genomics, Commercialization and Benefits in Africa
Subhashini Chandrasekharan, Robert Cook-Deegan
United States, Duke University, Center for PublicGenomics

Progress in genomics/ genetics research in Africa, and the Human Heredity and Health in Africa (H3Africa) initiative are fostering technology, bioinformatics and bioethics capacity building in Africa. The translation of such genomics research into products and services that can improve health and economic development of African populations will likely require development of institutional and national policies for commercialization as integral elements of capacity-building. Such policies will be more effective if they are grounded in empirical data on the experiences and perspectives of relevant stakeholders, and tailored to the specific needs of each country. Special attention to distributive justice concerns, fears about exploitation of indigenous peoples and transparent benefit sharing mechanisms is needed. There is however limited information about current capacity for IP management and commercialization in African institutions. The overall objective of our research is to identify ethical, legal and social issues surrounding commercialization of genomics research in Africa. Through literature analysis and expert interviews we are gathering data on: (i) views about benefits of genomics research and its applications; (ii) experiences with translation of genetics/genomics research; (iii) technology transfer capacities and patenting and licensing policies of African institutions; (iv) national and regional policies in Africa related to biotechnology and biomedical research (including laws on patenting DNA, exporting DNA samples, genomic sovereignty laws); and (v) relevant international policies and guidelines related to benefit sharing. We also organized a one-day interdisciplinary workshop, which brought together thought leaders to identify critical gaps in empirical data on these topics and their policy implications. Together our preliminary findings highlight the need for a broader research agenda, and greater engagement between national and international actors on these issues to anticipate specific needs for policy development going forward.

Abstract number: 199	Qualitative determination of care ethics elements in Nursing in institutions in Mexico City
ID: 591	<u>Claudia Villanueva Sáenz, Luz María Pichardo García, Amanda Lobato Victoria</u>
oral	Mexico, Universidad Panamericana

Abstract.

Background. One of the most important for nursing progress in recent years has been the concern for defining \"health\" as the foundation of the health-disease process, which has served as a starting point to reflect on the theoretical, methodological and technical content which support the practice of nursing not only practicality but professionalizing it. To establish the elements of care that are the basis for ethics in nursing, is necessary to determine some indicators of their professional practice to identify the human model that inspires bioethics. These indicators were obtained based on the ethical dimensions defined by Tronto (1990).

Methodology . Descriptive qualitative design, through focal groups on nurses and semi - structured interviews with patients in private and public institutions in Mexico City. Data will be analyzed by the grounded theory and frequency analysis tables.

Discussion. The four aspects of care were evaluated a) caring about: worrying about others; b) caring for: respect of the individuality of the patient; c) caring giving: care giving to the activity and to the patient; d) care receiving: having the ability to identify and implement suffering game skills (technical, moral habits) to achieve an adequate degree of reaction.

Conclusion. The results confirmed that care is primarily an activity of the nurse, with strong features of female identity. Who is responsible of care, develops an unequal relationship with the patient, similar to that of the mother and child. On one side is the vulnerable and dependent person and on the other, the \"caretaker\". It is essential to have a special degree of sensitivity and human response in the relationship for both parties, respecting all aspects of human dignity.

Abstract number: 200	Medical empathy in Iberoamerican physicians-in-training: Similarities and differences during their professional practice at a Teaching Hospital in Spain
ID: 571	<u>Luis Vivanco-Sierralta, Adelina Alcorta-Garza</u>
oral	Spain, Center for Biomedical Research of La Rioja - CIBIR

Professionalism is a basic core competency of physicians that should be taught and assessed during the residency period. Several studies suggest that achieving medical professionalism among health personnel is paramount for reaching a consistent improvement in health care. Clinical and humanistic competences are core characteristics of professionalism. Empathy is one of the main humanistic competences of professionalism. Those competences could be influenced not only by the effect of formal curriculum; also by the effect of informal curriculum, that refers to lessons that are not explicitly taught and come mainly from social interactions during the clinical practice; and hidden curriculum, that refers to all that is taught from the organizational culture and institutional environment.

Our study was focused on medical empathy in physicians-in-training from Iberoamerican region. Empathy is a cognitive attribute that involves an understanding of the inner experiences and perspectives of the patients, combined with a capability to communicate this understanding to them. This presentation summarizes a preliminary cross-sectional study to identify factors that could be affecting the medical empathy of physicians-in-training along their professional learning process at the hospital. Information was collected from 104 questionnaires from all 190 physicians-in-training in our Hospital. Empathic interactions were measured using the Jefferson Scale for Physicians Empathy. Differences between empathic scores with statistical significant differences were found for: geographical origin ($p<0.05$), exposure to hospital environment ($p<0.01$), professional ideal models ($p<0.001$), contact with good professional examples ($p<0.01$), and successful continued education ($p<0.05$). We conclude that acquisition of medical empathy is influenced by internal and external factors not directly related with formal curriculum. These results confirm the importance of hidden and informal curricula into acquisition of medical professionalism at teaching hospitals.

Abstract number: 201	From Kant's categorical imperative to Fritz Jähr's bioethical imperative: toward an ethics of globalization
ID: 593	<u>Maria Isabel Cornejo Plaza, Eduardo Rodríguez-Yunta</u>
oral	Chile, Interdisciplinary Center for Studies on Bioethics, University of Chile

Among the moral principles and maxims of Immanuel Kant : "treat other human beings as ends in themselves, never as means"; "one should never act in a way that one could not also will that this maxim should be a universal law" and \"Fritz Jähr's bioethics imperative \"respect every living being in general as an end in itself and treat it as such, as much as possible\", there are evident coincidences since both ethical maxims consider humans as a superior being, provided with dignity and autonomy. Human beings have the freedom to decide with good will about themselves due to their capacity of discernment.

The Jahr's bioethical imperative can be considered "hypothetical" while the imperative of Kant is "categorical". Jahr states to respect nonhuman living beings "as much as possible", going a step further by incorporating the effects of human decisions to other living beings, that live with humans in a delicately interconnected ecosystem.

In a globalized world, this vision is more relevant than ever since technological advances impose dilemmas and challenges that can not be addressed locally. Efforts to find relevant solutions for a multicultural and globalized world require a universal ethics. This is a position rooted in continental European tradition rather than in North American bioethics, perhaps more appropriate for a globalizing proposal. For the role of bioethics it could be a good way to revitalize the Kantian ethical principle that humans act with such responsibility and dignity so that their actions could be considered as a moral principle. But in a global world, the ethics given by Jahr is even more ambitious and necessary in the fragile world in which we live

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- Abstract number:** 202 **Use of Rapid Ethical Assessment to Improve Health Research Informed Consent Processes in a Low-Income Setting**
ID: 599
oral Adamu Addissie Nuramo, Gail Davey, Bobbie Farsides
Ethiopia, Addis Ababa University (Ethiopia) and Brighton and Sussex Medical School (UK)

Background: Rapid Ethical Assessment (REA) is a form of rapid ethnographic assessment conducted at the beginning of research to guide the consent process with the objective of reconciling universal ethical guidance with specific research contexts. The current study is conducted to assess the perceived relevance of introducing Rapid Ethical Assessment as a mainstream tool for addressing ethical issues for health research in Ethiopia.

Methods: Mixed methods research was conducted in July-September 2012, including 241 cross-sectional, self-administered and 19 qualitative, in-depth interviews among health researchers and regulators including ethics committee members in Ethiopian health research institutions and universities.

Results: In the evaluation of the consent process, based on their experiences, only 40.2% thought that the consent process and information given were adequately understood by study participants; 84.6% claimed they were not satisfied with the current consent process and 85.5% thought the best interests of study participants were not adequately considered. Commonly mentioned consent-related problems included lack of clarity (48.1%), inadequate information (34%), language barriers (28.2%), cultural differences (27.4%), undue expectations (26.6%) and power imbalances (20.7%). About 95.4% believed that consent should be contextualized to the study setting and 39.4% thought REA would be an appropriate approach to improve the perceived problems. Qualitative findings concurred with quantitative results in mapping the -mentioned gaps in the current research consent process in Ethiopia. Further suggestions included conducting REA during the pre-test (pilot) phase of studies when applicable. The need for clear guidance for researchers on issues such as when and how to apply the REA tools were stressed.

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- Abstract number:** 203 **"BUILDING ETHICAL SENSITIVITY FROM THE SUBJECTIVITY OF NURSING STUDENTS AND PROFESSORS"**
ID: 603
oral Bertha Alicia Alonso Castillo, Dra. María Magdalena Alonso Castillo; Dra. María Teresa de Jesús Alonso Castillo; MCE. Nora Nelly Oliva Rodríguez; Dra. Nora Angélica Armendáriz García; Dra. Karla Selene López García

Nursing education requires development of awareness and ethical sensitivity in appropriate decision making for quality care of the patient, helping professionals to understand their role and responsibilities. However, in México were not located studies about factors that influence ethical sensitivity in nursing students and professors. Social representations of nurses may be a factor explaining ethical sensitivity.

Objective: Explain ethical sensitivity from social representations constructed during patient care provided by nursing students and professors. **Methodology:** A qualitative method was used with social representations approach (Moscovici; 1983; Jodelet, 2002) and theoretical sampling, considering data saturation criteria, 23 students and 10 professors of nursing from Monterrey, México participated. **Results:** The main categories of the meaning of ethical sensitivity emerged: Beliefs, Attitudes, Emotions and Values of ideal models of behavior and ultimate goals. **Conclusions:** Beliefs factors that obstruct quality care were reported: Resources, professional competence, work routines and behavior of the patient for their disease condition. Factors that promote quality care; Confidence given by the patient, ethical sensitivity of nurses. Ethical sensitivity was defined as a skill that one is born with but can be developed. Empathy was identified as essential component of ethical sensitivity. Positive attitudes were identified: Be more accepted by the patient, and a faster recovery of the patients, negative attitudes as envy or competence with colleagues. They narrated the important values in quality care as responsibility, respect, equity as well as the consequences of ignorance of Bioethics and values in nursing practice.

Abstract number: 204	MORAL STRESS IN HEALTH CARE PROFESSIONALS
ID: 607 oral	<u>María Teresa de Jesús Alonso Castillo</u> , Dra. María Magdalena Alonso Castillo. Dra. Bertha Alicia, Alonso CastilloMCE. Nora Nelly Oliva Rodríguez; Dra. Nora Angélica Armendáriz García; Dra. Karla Selene López García , Mexico, Facultad de Enfermería, Universidad Autónoma de Nuevo León

Introduction: The health care professionals face a complex load (moral stress) in their professional practice in health services because they are confronted with moral and ethical challenges created by discrepancies between what they know is right, in other words the ideal and what the health system allows them to do. **Objective:** Understand the social representations that build physicians and nurses respect to which ethical climate factors may cause moral stress. **Conceptual Framework:** Moscovici states that social representations are a theoretical construct that stands among the social, psychological and the image that reproduces what is real. The perceptions and concepts are products, derivatives modes to meet the iconic and symbolic respectively. **Methodology:** Qualitative study within social representations framework of the perception of ethical climate and moral stress that physicians and nurses perceive and experience through individual semi-structured interviews where they deepened into the subject in 2 to 3 sessions with the key informants. **Results:** Were identified beliefs which lead to moral stress when confronted with ethical dilemmas as: Patient prognosis, lack of resources, lack of training and camaraderie, demands from family of the patient. Also were identified positive and negative emotional and affective states that are triggered and cause from satisfaction for moral fulfillment to moral stress. **Recommendations:** To carry out a request to authorities in order to classify moral stress as a pathology that can actually cause temporary or permanent disability.

Abstract number: 205	The latest version of the Declaration of Helsinki: Changes and Challenges
ID: 611 oral	<u>Urban Wiesing</u> , Germany, Institute of Ethics and History of Medicine

The presentation will describe the latest version of the Declaration of Helsinki of the World Medical Association, adopted by the General Assembly in Fortaleza, Brazil, October 2013. The changes compared to the version of 2008 will be highlighted. The ethical principles behind the changes as well as the global influence of the changes will be identified. Which changes are important for resource poor countries, which for wealthy countries? Is the latest version based on important ethical changes or a more precise and detailed version based on the known ethical principles of the Declaration of Helsinki? Will the new version change the position of the Declaration in the world? The presentation will inform about the major controversies during the public revision process and the public conferences. Which issues were discussed, which proposals were accepted in the final version, which were rejected? Remaining contradictions and challenges will be identified. Tasks for future revisions of the Declaration will be addressed. The author was a member of the workgroup of the World Medical Association for the revision of the Declaration of Helsinki.

Abstract number: 206	Faithful bioethical judgements: negotiating personal, social and faith group norms
ID: 614 oral	<u>Jackie Leach Scully</u> , Professor Sarah Banks, Dr Jackie Haq, Dr Robert Song United Kingdom, Policy, Ethics and Life Sciences Research Centre, Newcastle University

People making biomedical decisions navigate between personal, community, and cultural norms and, in an increasingly globalized world, international regulation too. Religious affiliation plays a central role in many people's (bio)ethical decision making, but while theology has always made a significant contribution to theoretical bioethics, little attention has been paid to lay faith group members. So bioethics knows very little about their real experiences in health care, and how faith influences their everyday bioethical thinking.

This presentation discusses findings from an empirical bioethical study of Christians and Muslims making ethical judgements about new reproductive and genetic technologies (NRGTs). Using qualitative methods, we explored their personal experiences and their processes of bioethical evaluation when making both real-life and hypothetical judgements.

Although many features of our faith group participants' experiences and evaluations were shared with non-religious, they faced additional questions and difficulties that were more distinctive. Many felt their faith was not sufficiently acknowledged by their healthcare system and that they did not have the opportunity to discuss faith concerns. Participants often felt they did not have the knowledge or skills to apply their faith traditions to the novel situations they faced, but they also found that their faith group leaders were themselves unable to give relevant religious advice, especially in rapidly advancing areas of biomedicine. Many participants had difficulty reconciling their personal bioethical decision-

making with the official position (or sometimes, lack of position) of their faith, the beliefs of their community, and the norms of wider secular society.

Our findings help identify areas where health service and training and communication could be improved, faith groups may need to engage more fully with biomedical expertise, and theological and bioethical resources could better support people of faith in their private bioethical judgements and public deliberation.

Abstract number: 207

ID: 615

oral

Assisted reproduction and adoption stigma: Deepening ethical challenges in 21st century family-making

Mianna Lotz

Australia, Department of Philosophy, Macquarie University

Rates of assisted reproduction continue to rise, and substantial resources are invested in the development of technologies that enable infertile couples to achieve the persistent and widely accepted ideal of a (somehow) biologically connected family. Uterus transplantation represents the latest and most extreme medical development in the service of that ideal – the willingness of hospitals, surgeons and patients to resource and undertake it implicitly disclosing, amongst other things, just how highly esteemed biologically-tied families continue to be.

Alarmingly, recent research in adoption studies also reveals the presence of ongoing social stigma towards families formed through adoption, even though its existence as a social arrangement dates back to antiquity, and in spite of the fact that growing divorce rates and expanding rights for same-sex couples are spearheading a proliferation of non-traditional family formations. Adoption stigma takes many forms and finds expression in public discourse in a multitude of ways, including recently in debates over 'adoption disruption' and the 'return' of 'problematic' adopted children; and in media portrayals of children assumed to have been abducted by Roma people largely on grounds of the child's alleged physical non-resemblance to other family members as well as their non-conformity with (inherently racist) constructions of supposed Roma physiognomy.

For those who take a critical eye to the valorization of biological relatedness, the confluence of persistent stigma with the development of increasingly extravagant means of assisted reproduction, is noteworthy and concerning, and in some respects dismaying and disheartening. This paper discusses the ethical implications of the latest findings on adoption stigma, and examines the challenge for those who want to both respect procreative autonomy and, at the same time, militate against the unfounded biological valorizations that fuel adoption stigma and thereby cause harm to families and children.

Abstract number: 208

ID: 622

oral

Which Autonomy? Supportive Decision-Making in Mental Capacity Law and Philosophy

Camillia Kong

United Kingdom, The Ethox Centre, University of Oxford

The right to autonomy has been recently extended to individuals with impairments, as shown in human rights instruments (such as the UN Convention for the Rights of Persons with Disabilities) as well as statutory developments (such as the Mental Capacity Act 2005 in England and Wales). In both the UNCRPD and MCA, individuals with impairments should be provided supportive mechanisms to facilitate the exercise of autonomous decision-making abilities regarding their care and treatment. However, the specific nature of supportive decision-making remains ambiguous and controversial. Recent legal judgements of capacity in England and Wales indicate deeply contradictory judicial attitudes towards the question of whether relational support can indeed promote or impede autonomy and decisional capacity.

This paper argues that such legal confusion can be mitigated by clarifying the specific model of autonomy that is, and should be, promoted in such human rights and statutory instruments. If one accepts that supportive decision-making is a necessary constituent of autonomy amongst individuals with impairments, this will suggest that autonomy should be conceptualised relationally rather than individualistically. I argue that the feminist model of relational autonomy proposed by Diana Tietjens Meyers is particularly useful, and discuss how Meyers' account of how relationships develop individual autonomy competencies is a promising way of conceptualising both the aim and constitutive practices of supportive decision-making. This discussion will help provide normative guidelines for judicial practitioners as to how supportive decision-making can promote individual autonomy in the context of capacity adjudications.

Abstract number: 209	Vulnerability: Considerations on the Appropriate use of the Term in Bioethics.
ID: 624	<u>Martha Tarasco,</u>
oral	Mexico, Universidad Anáhuac México Norte

This paper explores the concept of vulnerability in terms of its potential usefulness in bioethics. In order to do this, the author discusses some definitions and descriptions of the term. Subsequently, the term is compared with the concept of fragility, a concept that seems more appropriate for the circumstances of medical ethics. The nature of the term is dealt with, and examples of how it has been wrongly used are given. Among the incorrect uses, we find the search for "vulnerability" in circumstances in which, from the point of view of a realist anthropology and a recognition of the sufferers' objective good, the concept does not seem to apply.

This paper poses a question on the use of the term \"vulnerability\". Is this polysemous word often abused today? Is it an analogical term? Or does it have only one meaning? The expression \"vulnerable groups\" is mentioned and used in many fields, often in reference to human rights. It is used particularly in situations of economic marginality, sexual preference, or most commonly, when referring to women. The term is also used when seeking to protect the terminally ill, the subjects of clinical tests, or human embryos. It is, therefore, worth examining the use of this term in different areas. In this paper we intend to show the existence of certain abuses in the use of the term. Certain uses of the term "vulnerability", from a strictly bioethical point of view, are confusing or linguistic misunderstandings. From the author's point of view, it would perhaps be more accurate to say that there is a certain progression from a legitimate use of the term to an inconsistent one. We can get the impression that there is a latent risk of turning the apparent vulnerability into a supposed new category of metaphysics.

Abstract number: 210	IPAT-ethics: Some normative considerations with respect to reducing humanity's aggregate environmental impact
ID: 629	<u>Wouter Peeters, Jo Dirix, Sigrid Sterckx</u>
oral	Belgium, Free University of Brussels (VUB)

The causes of and strategies to reduce aggregate environmental impact are summed up by the well-known IPAT equation, in which environmental Impact depends on Population size, Affluence, and Technology. The aim of this paper is to explore some normative issues involved in reducing environmental impact.

Economical, social, and cultural considerations constrain the plasticity of each factor. For example, fertility reductions [P] as well as frugality [A] meet significant resistance, since both strategies are perceived to infringe upon some core individual freedoms. These issues relate to normative conceptions regarding well-being, society and economy, which environmental policies should take into account.

Moreover, interdependencies between the factors lead to external rebound effects, such as the well-documented fact that increasing A and P cancels out technological efficiency [T] gains. Even more interesting are internal rebound effects, which lead to displacement rather than reduction of environmental impact. For example, increasing frugality [A] in developed societies will reduce global prices, which in turn will lead to increased consumption in developing societies. We will argue that current inequities are determinant factors in the causation of these internal rebound effects.

In addition, socio-economic inequities are pervasive issues regarding each factor and cannot be ignored by environmental policies. For example, although technology and knowledge transfers to developing societies are highly important for mitigating inequities, the development of more efficient technologies [T] remains the prerogative of advanced societies. Furthermore, the burdens involved in reducing humanity's aggregate environmental impact should be distributed fairly. Therefore, rather than leaving it to national policies to decide on the most desirable and efficient mixture of strategies (as has been advocated in the literature), we will argue that only a transnational policy that simultaneously includes measures regarding P, A, and T is able to fairly reduce aggregate environmental impact.

Abstract number: 211	NEUROETHICS OF MEDICAL THERAPY IN ATTENTION DEFICIT DISORDER WHIT HYPERACTIVE.
ID: 631	<u>MARCELA PATRICIA VAZQUEZ VALENZUELA,</u>
oral	Mexico, COLEGIO EDIA

Attention Deficit Disorder with or without Hyperactivity (ADHD) is a disorder that not being treated in a timely manner deteriorates significantly the development of the patient in the social, behavioral or academic area. Currently there are protocols and clinical practice guidelines to enable effective care of the problem, however the lack of adherence to treatment generates a high economic cost, and a lot of instability in achievement, hence the importance of identifying some of the factors that affect

the initiation and hamper maintenance pharmacotherapy as a treatment option for children with ADHD and its relationship with the ethical principles that physicians should take into consideration during their clinical practice.

In this research, a non-probability sample that included 70 parents of children diagnosed with ADHD currently enrolled between first and sixth grade education and whose age ranges between six and twelve years were used.

ADHD being a disorder of neurobiological origin medication use allows us to reduce symptoms and improve the academic, social and behavioral functioning of the child. The drug is the first-line treatment for ADHD attention because it is among the most studied and safest of all those used in children and adolescents medications. Drug treatment must be supplemented with psychoeducation, training in behavior management and academic support.

Attend the 4 fundamental ethical principles: Non-maleficence, Justice, Benefit and informed consent allows us to maintain good practice in the practice of medicine and improve adherence to recommended treatments, significantly increasing the quality of life of patients and of his family.

Abstract number: 212 Climate change and obligations of justice

ID: 632 Andries De Smet

oral Belgium, Department of Philosophy and Moral Sciences Ghent University

The characterization of anthropogenic climate change as a violation of human rights is gaining wide recognition. However, how this characterization affects the corresponding obligations remains controversial. As long as this allocation problem ("Who owes what to whom?") is not clearly solved, we are at risk of emptying the human rights discourse of any meaningful content. The aim of this paper is to provide a robust account of allocating responsibilities regarding climate change.

Human rights are traditionally divided into negative rights of noninterference and positive rights of assistance or charity. In this paper we give priority to negative rights, a minimalist normative position which is widely accepted. We take the active violation of negative human rights as our baseline for determining harm, and we defend this conception of harm as the decisive benchmark between obligations of charity and obligations of justice. We argue that we are in a special relationship with the people whose human rights we violate and that we bear responsibility towards them, regardless of whether we actually value this relationship or not.

If a relationship of harm is established through climate change's adverse effects, fulfilling positive duties is no longer a matter of general charity, but has become a special obligation of justice. Accordingly, human rights and corresponding obligations gain important normative weight. Therefore, we conclude that, through our contribution to climate change, we are violating the human rights of a specific and large subset of persons and, consequently, we bear a special responsibility towards them. At the least, we bear the stringent obligation of justice to recompense those harmed and to enable them to adapt to climate change, i.e. this should no longer be characterized as a duty of charity or aid.

Key words: climate change; distributive justice; human rights

Abstract number: 213 Developing Ethical Guidelines for Nanotechnology in Sri Lanka

ID: 633 ANOJA FERNANDO, ENOKA COREA and DEEPTHI DE SILVA

oral Sri Lanka, National Science Foundation, Sri Lanka

Nanoscience (NS) and Nanotechnology (NT) are newly emerging fields in Sri Lanka. The establishment of a National Nanotechnology Initiative (NNI) was approved by the Cabinet of Ministers in 2006, and subsequently a National Nanotechnology Policy (NNP) was drafted by the National Science Foundation (NSF). The objectives of this policy included the establishment of a regulatory framework for the promotion of nanotechnology to suit the needs of Sri Lankan society and industry, while paying attention to the ethical, environmental and safety aspects.

In order to further the objectives of the National Nanotechnology Policy, the National Science Foundation developed a project titled "Developing a regulatory framework for nanotechnology related activities in Sri Lanka" comprising six components. One component of this project was to study the "Ethical and Moral Challenges related to Research and Development in Nanotechnology", with the objectives of identifying ethical issues involving NS and NT and defining the ethical and moral obligations of stakeholders. The three authors were responsible for this component of the project, and after two years of work, produced two documents, Ethical Guidelines for Research in Nanotechnology and the Code of Ethics for Application of Nanotechnology in Sri Lanka.

The Ethical Guidelines are intended to promote the safe, responsible and ethical conduct of

nanoscience (NS) and nanotechnology (NT) related research in Sri Lanka. The aim of this document is to encourage high quality research while minimizing harm to humans, animals and the environment. The Code of Ethics is a voluntary code for the safe, responsible and ethical conduct of research in and application of nanoscience and nanotechnology in Sri Lanka, and aims to guide the behaviour, actions and decision making of all stakeholders in these fields.

This paper describes the methodology followed by the three authors in developing these two documents.

Abstract number: 214
ID: 634
oral

Real-time responsiveness and disaster research ethics
Lisa Eckenwiler, Renaud Boulanger; John Pringle; Matthew Hunt
United States, George Mason University

Conducting research in situations of disaster raises a range of ethical and pragmatic challenges. Such research needs to be rolled out quickly and may demand adaptation in a context of rapidly changing circumstances. At the same time, victims of disaster may be in particularly elevated states of vulnerability. Questions of how best to provide ethics review and oversight for such research have garnered increased attention in recent years. Innovative strategies have been developed for rapid review of study protocols and the idea of pre-review is now gaining traction. However, to date, few mechanisms to ensure ongoing ethical oversight have been proposed.

In this presentation, we examine the implications of the volatility and unpredictability of disaster environments for research ethics. In doing so, we consider the distinctiveness of disaster research in comparison to other types of research where risk profiles are likely to evolve. We argue that attentiveness to the changing nature and magnitude of risk is essential to disaster research ethics. We propose the concept of "real-time responsiveness" (RTR) as a key component for the oversight of disaster research. RTR shifts the temporal nature of research oversight by not only mandating rapid and early review of such protocols, but also emphasizing the importance of ongoing engagement between researchers and research ethics committees. We argue that RTR is particularly important as risks and potential benefits of research projects are altered by evolving circumstances. Overall, RTR seeks to ensure that research procedures (e.g.: informed consent, measures used to secure data) remain ethically sound and efficient over the lifecycle of every disaster research project, while at the same time lessening the potential to exacerbate vulnerabilities and deepen injustices. We conclude by suggesting mechanisms for the operationalization of RTR throughout disaster research projects.

Abstract number: 215
ID: 635
oral

Applying a health ethics policy framework to the case of healthcare user fee exemption in West Africa
Boulanger Renaud, Matthew Hunt; Valery Ridde
Canada, McGill University

Access to public healthcare services is limited in much of West Africa. One factor explaining this poor access is its prohibitive cost. Citizens in several nations have been critical of their governments' efforts to address this situation (Abiola et al, 2011). This broad dissatisfaction has contributed to a recent movement towards the development of public policies of user fee exemption for healthcare services (Olivier de Sardan and Ridde, 2013). Of note, user fee exemption policies have mostly not been influenced by international funding mechanisms—contrary to many other health policies in West Africa—but they are often developed with values of equity and social justice in mind. Although they share the official objective that all citizens gain access to healthcare, West African exemption policies have generally not been submitted to ethical analysis.

In this presentation, we address this gap by situating our analysis within the emerging field of inquiry of health policy ethics (Kenny and Giacomini, 2005). Ethical issues related to health policies can be divided between those that concern substantive values, procedural values, and terminal values (i.e. those related to goals and objectives). We assess user fee exemption policies along these three lines using data from empirical studies that have been conducted in West Africa. The three processes of policy (emergence, formulation, and implementation) will also be discussed in turn (Lemieux, 2002). Our analysis suggests that while the West African user fee exemption policies tend to meet substantive and terminal values, they raise concerns related to procedural values. We suggest that the jurisdictions studied may have used decision-making methods that ultimately undermined the expressed objective of promoting social justice. Our work confirms the importance of further developing the field of health policy ethics, while offering a replicable evaluation framework.

Abstract number: 216 Bonding and it's impact on public policy to decrease violence \ "Applied Bioethics
ID: 636 Dr. José Arturo Vela Staines
oral México, Colegio de Bioetica de N.L.

Neurobiology of bonding during gestation published in "Nature, Science", indicate that the approach towards newborns in greater western world are criticizeable: Better understanding of maternal biology during gestation, endocrinological phenomena in CNS, increments in oxytocin, progesterone, dopamine and prolactin indicate transfer towards the mother's brain during late pregnancy. Maternal CNS is better understood and better bonding via contact with the newborn has been confirmed through MRI evidencing greater limbic activity, increased oxytocin; this explains the mother's ability to translate and validate the newborn's needs, diminishing stress evidenced by decreased crying of the lactating newborn and prolonged lactation over time. Separation leads to maternal anxiety in the neonatal period, propitiates a vicious cycle, increased stress, including neonatal stress, reduced/interrupted lactation and increased domestic violence. Epigenetic changes as reported in "Nature Neuroscience" to receptor NR3C1 gene for glucocorticoid in the hippocampus plus chromosome 5, methylation in children suffering intense stress caused by early abuse alterations in the adrenal hipofissary hypothalamus, making stress intolerable in later stages of life as reported by Meany et al, February 2009. "Baby Friendly" hospitals propitiates skin to skin contact facilitates prolonged lactation and lowers maternal-newborn stress; Sweden leads world with 100% hospitals certified. USA 6.5% BFH hospitals, Great Britain less than 5%, and Mexico has fewer still. Maternity leave reduces maternal-newborn stress, and there is a correlation of BFH with prolonged maternity leave and decreased violence. Poverty, promiscuity, lack of dignified habitation, family disintegration, plus epigenetic effects caused by infant stress in early development may trigger for violence. Our proposal is to make more BFH facilities a reality in our country in conjunction with UNESCO certifiers motivating hospitals to pursue such certification with ongoing vigilance. Motivation of Congress to extend maternity leave to six months is imperative.

Abstract number: 217 The rise of direct-to-consumer genomic tests and its implications to science, society and the individual in the developing world. A case study in México.
ID: 638
oral Miguel Angel Contreras Sieck, Jesús M. Siqueiros-García, Garbiñe Saruwatari-Zavala, Alessandra Carnevale
Mexico, Instituto Nacional de Medicina Gnomónica.

The rapid drop of the costs to sequence a human genome has spawn the opportunity for direct-to-consumer companies to thrive selling genetic tests for variants associated to sickness, ancestry, heredity and recently fitness. Direct-to-consumer companies goals are focused towards findings candidate variants for profitable drugs, in contrast regarding publicly funded research which looks towards improving health. Direct-to-consumer companies might take advantage of the fact that knowledge about genomics and its implications is low in the population, which can lead to misinterpretations and statistical ambiguities to be exploited. In developing countries such as Mexico, there is also a legal gap about direct-to-consumer regulation. We argue that these consumers' knowledge and legal gaps, allow direct-to-consumer genomic companies to take advantage of peoples curiosity and willingness to know about their genes in order to (1) sell targeted genetic diagnostics for variants associated with certain penetrate sicknesses, and (2) accumulate mass quantities of genomic information to be used for further analysis for the discovery of potentially lucrative genomic variants. To investigate this we explore the recently case of 23&me and also investigate a newly marketed genetic test in México called "Metric" which aims to characterize the consumer genes in order to improve their performance in the gym. Our work aims to identify the potential ELSI due to such new scenario. We consider that it is a critical moment for the debate about direct-to-consumer companies in Mexico and the developing world.

Abstract number: 218 ¿How can we demonstrate inequity in distributive justice in patients with spina bifida?
ID: 640
oral Sergio Francisco Camacho Gutiérrez,
Mexico, CENTRO DE REHABILITACIÓN INFANTIL TELETÓN PUEBLA

¿How can we demonstrate inequity in distributive justice in patients with spina bifida? Methodology. A retrospective, observational and descriptive study. Objective. In this report I show the deficient distributive justice that patients with spina bifida have received before they were admitted in Centro de Rehabilitación Infantil Teletón Puebla, Mexico. Material and method. I report 71 myelomeningocele patients, 42 males and 29 females, data were collected from medical record: age, residence, ingestion of folic acid by mother, prenatal ultrasound,

site of congenital defect, age at surgical repair, history of clean intermittent catheterization.

Results. Of the 71 patients, 60 of them live in the state of Puebla, only 34 mothers ingested folic acid, only 57 prenatal ultrasounds were carried out, of this only 25 ultrasounds reported structural anomalies, the most affected anatomical region was the lumbosacral area, the spinal surgical closure was done in the newborn period in 54 patients, only 16 patients learned how to perform bladder catheterization before they were admitted in our rehabilitation facilities; we teach how to perform clean intermittent catheterization to 43 patients ages 5 months to 18 years, with an average age of 7 years.

Conclusion. With this data we confirm the following:

- 1.- There is a deficient prenatal evaluation.
- 2.- Lack of knowledge when should a fertile woman ingest folic acid.
- 3.- Prenatal ultrasound was not indicated in all pregnant women, the ultrasound report was inaccurate.
- 4.- Lack of knowledge in regard clean intermittent catheterization.
- 5.- One of the basic Bioethics principles was injured: Distributive Justice.

Keywords: myelomeningocele, bioethics, justice.

Abstract number: 219

ID: 641
oral

Ethical implications of research ethics review of social science research

Karolyn White, Lisa Wynn; Colin Thomson; Louise Carey-White; Mark Israel
Australia, Macquarie University

Ethical implications of research ethics review of social science research.
Karolyn White, Colin Thomson, Lisa Wynn, Louise Carey-White, Mark Israel

The epistemic, political and practical importance and value of social science human research to individuals and communities is axiomatic. Social science research, like medical and health research however, also involves risk. This risk can accrue to research participants, communities, and to the researchers conducting the research. Professional/disciplinary codes of ethics are one way of ensuring research participants are protected during the research. Another way of mitigating risk is to ensure that social science research conforms to ethical standards by subjecting it to ethical oversight by a committee or board.

However, the idea that ethical review of social science research: ensures research is beneficial; mitigates risk inherent in the research, and protects research participants' rights is contested. Indeed, social science researchers have criticised ethics review on the basis the process is unnecessarily bureaucratic (Israel 2012; Scharg 2010), disrespectful of social scientists (van den Hoonaard, 2013), naively universalist, and hopelessly bound in a biomedical discourse (Haggerty 2004; Lederman 2006; Langlois 2011).

In this paper we present data from a mixed methods study that tests these claims by: surveying a large cohort of randomly-selected, university-based researchers across Australia and ascertaining their experience of ethics oversight; and, by presenting data from interviews with researchers and ethics administrators. We explore whether some disciplines are more resistant to ethics review than others and whether there are particular methodologies that are better or poorly served by ethics review bodies.

Abstract number: 220

ID: 645
oral

BIOETHICAL ISSUES IN THE RESOLUTIONS OF THE INTER-AMERICAN COURT OF HUMAN RIGHTS

SANDRA LIZBETH CARRIZOSA,
Mexico, UNIVERSIDAD NACIONAL AUTÓNOMA DE MÉXICO

Bioethics has achieved an unexpected impact in the public agenda all over the world. The judicial institutions are an illustrative example of that fact. In Latin America, we can perceive this phenomenon in the resolutions of the Inter-American Court of Human Rights.

The purpose of this conference is to expound the strong impact of Inter-American jurisprudence in the development of the bioethical discussion in the continent and to demonstrate the dialectic relation between human rights and bioethics, as a necessary association to encourage the effective protection of human dignity.

Just to mention some relevant precedents, we can examine the arguments in the cases of Artavia Murillo and others Vs Costa Rica about assistant reproduction, Ximenez Lopes Vs Brasil related to the attention of people with mental disabilities and Albán Cornejo and others Vs Ecuador discussing the high standards in healthcare services.

In all of those resolutions, the Court takes into account bioethical aspects such as informed consent, protection of vulnerable persons and groups, relations between patients and health professionals, and social justice.

Additionally, this jurisprudence has contributed to the democratic debate in Latin America in sensitive

issues for our societies. Just to mention some of them, we can talk about ontological status of the embryo, rights of homosexual people and the access to scientific progress.

Although the jurisprudence of the Inter-American Court has shown the criteria to promote and further Human Rights, in many of the countries in the region there is a resistance to apply it.

For that reason, in order to achieve the human rights objectives regarding Latin America, it is essential to spread and to stimulate open dialogue not only within the academic community but throughout all parts of society. The 12th Congress of Bioethics is a great opportunity

Abstract number: 221

ID: 650
oral

Child abused detection by bioethics committee

Claudia Vilchis, Octaviano Dominguez, Carolina Manrique
Mexico, Instituto Politecnico Nacional

The Mexican Human Rights Commission recognizes that, in Mexico six out of 10 children, aged between one and fourteen years old suffer acts of violence that injure their dignity; and in the world about 20% of women have experienced sexual abuse during childhood. In this paper, a case of a intrafamily violence preschool victim is presented; in which "Research-Action" Methodology and two years monitoring case was applied. In this case, a preschool girl was presented to a general hospital by her parents due to abdominal pain; during her staying, doctors detected Battered Child Syndrome and Sexual Abuse and a multidisciplinary / interdisciplinary team worked through "Research-Action" Methodology with bioethical basis to defense rights of the child, and keep her safe from the aggressive environment, Social Services retain tutors rights and later performed her reintegration into the family unit safeguarding her dignity and physical and emotional integrity.

We propose that the Hospitals Bioethic Committee must be aware of such cases and the social worker is empowered to track case actions and perform the case monitoring up to case close. Additionally we strongly recommend Hospitals Bioethics Committee should be trained in human rights topics, specially in childrens' rights and its recommendations drive hospital actions

Abstract number: 222

ID: 651
oral

The moral discourse of uncertainty in clinical genomics

Jennifer Marshall,
Canada, University of Toronto

In the search for truth, imprecise measurements can be morally judged and minimizing uncertainty seen as ?doing good.? The development of increasingly higher resolution genomic technologies toward disease diagnosis may reflect a current-day valuing of precision and its normative value. The literature surrounding the development and application of these technologies reflects the desire for ?precision ! medicine.? This literature is also laden with cautionary instructions for the careful consideration of the complexities and difficulties inherent in the application of genomic findings to the clinic. This admission of uncertainty can lend to researchers a reputation for sobriety and responsibility. Standards also reflect the ethics and values of research and professional communities. Similar cautionary instructions can be used to direct the ways in which standards and guidelines should be developed to aid with the interpretation of clinical genomic data. In the clinical genomics literature, standards and guidelines reflect the struggle with uncertainty and the responsibility to be precise. These are different ways, within the scientific and medical literatures, in which the moral discourse of uncertainty in clinical genomics has been expressed. This presentation aims to elaborate on this discourse toward a better understanding of directions taken and explanations used within this field of research and development.

Abstract number: 223

ID: 652
oral

Narratives of health and disease, illness and care

Lucia Galvagni,
Italy, Bruno Kessler Foundation

This presentation intends to show how narratives of health and disease, illness and care can be relevant in order to understand what is the morality of a specific context, in terms of ethical and political visions, reference values, behaviours and attitudes.

Listening to stories and analysing the metaphors used in them yield a 'snapshot' of a specific context: narratives and images enable also an analysis of the correspondence between the values declared by the organization and their perception by practitioners, so that the normative value of these images and these stories can be highlighted. The presentation will concentrate on identifying the moral components present in some of these narratives.

The starting hypothesis is that these stories operate at two main levels: existential and interpersonal, on the one hand, communitarian and institutional on the other. Examination of these narratives and their analysis can also reveal important dynamics of medicine, in terms of good practice and

communication.

A narrative approach can complete and enrich the most traditional ones present in the bioethical debate and helps to give attention to some crucial dynamics, that are existential and contextual and need to be considered and balanced in order to express good choices and decisions regarding disease, illness and care experience.

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- Abstract number: 224 Cross-Cultural and Global Bioethics: The Elements of a Transcultural Approach
ID: 653 Jing-Bao Nie,
oral New Zealand, Bioethics Centre, University of Otago

In the age of multiculturalism and globalization, or what can be called "the New Axial Age", the simultaneously large-scale and intimate interactions between and within different cultures and civilizations is a phenomenon that distinguishes our times from previous eras. Contemporary bioethical issues are thus inherently cross-cultural and global in their scope. Moral challenges in healthcare, life sciences, and biotechnology do not respect natural and human boundaries, the boundaries between and within nation-states, ethnicities, cultures, communities, and social groups. As a result, bioethics—as both a domain of public discourse and an academic discipline—has to be transcultural and global in order to address bioethical issues adequately. Some deeply rooted and popular approaches to cultural differences, especially the habit of dichotomizing cultures, have proved to be intellectually flawed and politically contentious. An alternative methodology for cross-cultural and global bioethics—a "transcultural" approach—is proposed. Its key elements include overcoming stereotypes to appreciate the complexities of cultural differences; highlighting the great internal plurality not only between cultures but within every culture; upholding the primacy of morality and ethics, as opposed to the tyranny of cultural practices; recognizing common ethical values amid significant cultural differences; acknowledging the essential role of individual moral experience amid the intricacies of local ethical worlds; and taking seriously the challenges offered by anthropology and the other social sciences. Through this approach, a global bioethics founded upon different cultures is shown to be both necessary and possible.

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- Abstract number: 225 Informed Consent process in intercultural contexts
ID: 654 Marcia Mocellin Raymundo,
oral Brazil, Hospital de Clínicas de Porto Alegre

The diversity of societies is expressed in different areas, that's why informed consent should also be used appropriately to different societies and cultures. The capacity of a person to understand and decide it is not only dependent on their chronological age, but also by cultural and social factors. It is very important that responsible people for the consent application take concerns about the cultural characteristics of the patients or subjects of scientific studies, since the preparation of the document until the moment of obtain the consent, passing through the process of information and understanding. It is also very important to notice that the different worldviews should be considered and respected when the consent process develops. If we consider consent as a process involving mandatory interaction of different people based on exchange of information and expectations, it is necessary to consider both the specificities of the construction of identity as the interaction generated from the interrelations between different identities. This allows us to consider the consent is the result of the exchange or the interrelations. However, the interactions and relations established during the consent process should consider that culture and identity are also dynamic. Those interrelations are given by intercultural exchanges and are constructed from an ethical perspective of relations. The intercultural approach does not simply mean mixed cultures; it is the interaction that results from the relations established. Respect diversity in different areas also includes that decision-making and the consent process are permeated by respect for freedom of conscience of each person, a way of promoting exchanges how the ethics of relations, i.e., interculturality.

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- Abstract number: 226 Biopolitics of Euthanasia in Colombia
ID: 662 Yolanda Guerra,
oral Colombia, Universidad Militar Nueva Granada

Key words: Euthanasia, human life, human being, dignity, biopolitics

Biopolitics of euthanasia in Colombia

Abstract

In May of 1997, Colombia was the first country to decriminalized euthanasia. However, the discussion for over 16 years has focused not in the convenience of euthanasia in Colombian society, but on the legality of the procedure that decriminalized euthanasia: a Supreme Court sentence, instead of a law

created and passed by the congress.

Central research question to be explored: What is the consequence in the application of euthanasia in Colombia, considering it was decriminalized through a Supreme Court sentence instead of a formal law? Have cases of euthanasia increased in Colombia because of this jurisprudence? Have medical doctors who have applied euthanasia been prosecuted because of the lack of formalization of decriminalization in Colombian law? How can this gap between jurisprudence and law be filled in order to offer juridical and biopolitical certainty to the Colombian people regarding the treatment of euthanasia in Colombia?

The methodology used complies with the empirical analytical approach of the research. Interviews were conducted with medical doctors, care services personnel and family members of patients who died through active or passive euthanasia. Also, jurisprudence and law were reviewed to see if doctors who have applied euthanasia have been prosecuted.

Content of the presentation:

Antecedents of euthanasia in the world; discussions in Colombia; content of the jurisprudence that decriminalized euthanasia in Colombia; the four objections of the Supreme Court judges that made the decision in a panel of 9 judges; the practice of euthanasia in Colombia; the gap between law and jurisprudence; and conclusions.

Abstract number: 227 Competent research participants: vulnerable or powerful?

ID: 664 Heike Felzmann,

oral Ireland, National University of Ireland, Galway

The primary goal of research ethics is often considered to be the protection of vulnerable participants. In the bioethical debate, the concept of vulnerability has received significant attention in recent years. Vulnerability has been most frequently linked to limitations of participants' autonomy, particular risks of harm and features of the research environment. Much attention has been paid to the identification of particularly vulnerable groups, with an increasingly inclusive and differentiated understanding of relevant risks and contextual features. At the same time, there is an increasing awareness of the importance of more individualised assessment of vulnerability, and the ethical importance of not overestimating a participant's vulnerability and appreciating their individual strength.

In this paper I will explore the question of vulnerability in relation to a type of research participants that would be usually considered least vulnerable. I will use the example of participants without noticeable impairments of their autonomy who do not belong to a disadvantaged group and who participate in social science research that uses qualitative interviews addressing non-traumatic life events - research that is frequently considered to be ethically innocuous enough not to merit full research ethics committee review. Does the concept of vulnerability add anything to understanding the ethical characteristics of such research? I will argue for the value of analysing vulnerability from a dialogical and transactional perspective by showing how this particular research situation is characterised by intricately intertwined aspects of vulnerability and power for both participant and researcher. While this micro-analysis of vulnerability highlights the ethical significance of considerations of vulnerability and power even in presumably "low-risk" situations, it would be difficult to capture by standardised research ethics committee documentation. Instead, researchers need to be sensitised to the particular manifestations of vulnerability and power (both their own and the participant's) in research.

Abstract number: 228 Posteriorizing Marginally Beneficial Treatments – Practical Considerations

ID: 665 Daniel Friedrich,

oral Germany, Institute for Ethics, History and Philosophy of Medicine

Patients who suffer from a fatal cancer as the non-small cell lung cancer (NSCLC) have a poor prognosis. All patients are dead three years after diagnosis of NSCLC. In high powered studies therapies with antibody agents like Erlotinib or Cetuximab show an advantage for over all survival by ten days to six weeks. These data are statistically significant – but they mark „a major disappointment“ (Fojo und Grady 2009). These agents are only minimal effective but in the same time the price for such a treatment is horrendous, since a QALY costs up to \$800.000.

Priority setting in health care is a high urgent international project in times of fast increasing medical costs for poor performing innovations. In that project "minimal clinical benefit" (mcb) should be a minimum threshold criterion. Our suggestion is to cut any intervention from publicly funded health care systems that does not reach a predefined threshold of direct clinical effectiveness and which is in this sense minimally beneficial.

That there are only small losses for patients not receiving minimally beneficial treatment is one appealing assumption in favor of mcb as a criterion for rationing. But this assumption is only fulfilled, if there are no subgroups benefiting more than minimally from mcb-like treatments. In this respect the interpretation of study results can be difficult and some questions occur. How should divergent

ends of an actuarial survival curve be interpreted? What, if the superior curve has a distortion? In this talk we clarify what kind of characteristics the results of clinical trials must show to fulfill the criterion of mcb.

Abstract number: 229
ID: 667
oral

Encouraging Conscientiousness in Risk Associated Areas of (Medical) Research

Jan-Ole Reichardt,

Germany, University of Münster, Institute for Medical Ethics, History, and Philosophy of Medicine

Clinical trials are important instruments on our way to scientific progress – especially in the life sciences. But while they are of utmost importance to our translational efforts, they are also expensive and thereby a limiting factor in regard to our scientific capabilities. So efficiency wise, the relocation of clinical trials into low-cost countries seems promising. Unfortunately, worker protection and safety precautions are also driving costs. For that reason, a race to the bottom in regard to ethical standards is imminent and clinical trials move to countries where the least is demanded by those who are offering themselves as “human guinea pigs”. Although such relocation is not necessarily condemnable, as those in charge might still adhere to high ethical standards, it is, where and whenever less restraint in regard to the profitable exploitation of vulnerable participants can be observed. However, almost all of these research-conducting institutions are interested in the commercial usage of their findings and strive for a patent based market monopoly to do so. This protection is usually granted for research and development achievements to honor and encourage a researcher’s contribution to the welfare of the awarding community.

Regarding this form of acknowledgement, I argue that it should depend on the compliance with those ethical standards set by the WMA Declaration of Helsinki, and that any misconduct, which could be attributed to a neglect of the duty of supervision, should be regarded as undermining an otherwise legitimate claim to registrability. By regarding the compliance to ethical standards as a presupposition for the granting of intellectual property rights, I try to disincentivize the willful acceptance of external costs by merely economically motivated protagonists, provide an important complement to medical research in risk associated areas and support a socially reasonable translation of risk associated therapies into clinical practice.

Abstract number: 230
ID: 668
oral

Principals and principles: utility, duties, and justice in the H5N1 case

David Koepsell, Keelie Murdock

Netherlands, delft university of technology

The H5N1 case provides an example of a variety of principal-agent relationships: between scientists and the public, contractors and contractees, business and investors, and governments and citizens. Some have already noted that miscommunications among the various parties exacerbated the effect of the actions of Ron Fouchier and others, and that better transparency, or at least more careful communication, might have helped to diffuse issues. One way of developing strategies to help avoid such problems is through principal-agent models because these may help to define duties and rights among the parties. Sorting out the various relationship and duties may help with designing institutional safeguards to prevent such problems in the future.

In the context of the H5N1 controversies, there are several parties that are privy to information that others are not, in virtue of their functions and expertise and about their interests. We examine the nature of these interests and how they may conflict. Conflicting interests are essential to the creation of principal-agent problems. Solving these problems requires developing measures to help better align interests and overcome the effects of informational asymmetries. We will therefore also examine the role of these potential asymmetries and the institutions that may have maintained them via, for instance, deliberate or unintentional failures in transparency for both legitimate and potentially illegitimate reasons, ethically. Finally, we will apply a utility analysis to illustrate how principal-agent problems were played out in the dynamics of the relationship between governments, scientists, policy-advisors, the public, and other relevant actors in the H5N1 saga and how institutional modifications and adaptations can potentially help alleviate tensions and prevent similar problems in the future.

Abstract number: 231
ID: 670
oral

Meanings of menopause. Body, gender and experience.

Gabriela Pineda Hernández,

Mexico, Comisión Nacional de Bioética

During the stage called maturity or middle age, menopause is an important process in the life cycle of women, because the physiological and psychological changes that occur. From an anthropological approach and a gender perspective, this qualitative study examined the relationship of a group of women in Mexico City, on the use and selection of diagnostic and therapeutic knowledge and

practices, identifying the extent to which knowledge and practices acquired reflect the phenomenon of medicalization of menopause, a concept that allowed reflect on the conception of the body of women from scientific and medical view and the cultural representations that are created on this stage in the life of women. From the narrative of the participant, the investigation confirmed that menopause is a bio-psycho-social experience permeated by gender, where women give new meaning to social and medical discourses, as well as the relationship with service providers health, to translate their body experience.

Abstract number: 232 International Cooperation in HIV/AIDS from a bioethics perspective
ID: 674 Raquel CHILD, -----
oral Chile, Independent consultant

Developed countries are committed to provide monetary cooperation to support country development; global organizations such as GFATM, UNITAID, and Clinton Foundation also contribute to progress, specifically in the health area. The way these economical resources are invested should be negotiated with countries; however this participatory process doesn't always occur, countries facing a "donor driven funding".

From an ethical perspective, international cooperation should be guided by principles facilitating good governance mechanisms at country and global levels; these principles include ensuring country ownership, facilitating participation of affected populations and developing partnerships, guaranteeing sustainability to maintain lifelong treatment and care, being complementary with other country level initiatives, being accountable and promoting equity access to services, as well as following specific ethical principles. Ethical principles need to be applied in the substance and the processes when designing and implementing international cooperation; ethical principles can be used to select and justify actions or policies designed to protect people's rights, maximize their welfare, and avoid harming them. Ethical analysis uses those principles to assess the various possibilities and consequences of choices (WHO 2005).

UNITAID is a young organization working in the global health arena, intending to impact in markets of products for HIV/AIDS, tuberculosis and malaria; this, providing newly produced commodities to low income countries through implementing organizations. The mechanism to design and implement their projects is agreed between UNITAID and the selected implementing partners, while countries and affected populations usually don't participate in this process.

This presentation will discuss the analysis and use of ethical principles in the selection and implementation of two different UNITAID projects in the HIV/AIDS area, compared to GFATM strategy to formulate projects at country level. A recommendation to UNITAID will be proposed, to respect ethical principles and increase the effectiveness of their investments.

Abstract number: 233 Bioethical Analysis of Public Policies to Counteract Obesity and Malnutrition: the Mexican Case.
ID: 675 Maria de los Angeles Marina Adame Gayoso,
oral Mexico, Comisión Nacional de Bioética

Since 2010 the Mexican government has implemented public policies such as the National Food Safety Agreement (ANSA is the acronym in Spanish), the Self-Regulation Code for Food and Soft Drink Advertising Targeted at the Children's Market (PABI is the acronym in Spanish) to counter current rates of malnutrition, overweight and obesity in Mexico. At the end of 2013 it presented the National Strategy for the Prevention and Control of Overweight, Obesity and Diabetes. It is necessary to analyze the implications of these policies from a bioethical perspective, asking how they impact on the health and quality of life of Mexicans suffering from such diseases and also on the rest of the population, since these diseases evidently have an impact on the health system and productivity. Obesity and malnutrition have undeniable impacts on the health of individuals, but they also have a collective impact, which has implications for public health, causing ethical dilemmas at individual and collective levels. Questions arise on how we should address these, and whether we should favor the autonomy of the individual or the wellbeing of the community. If the state is responsible for caring for the health of its citizens, what are the limits? Who protects vulnerable populations, such as children with obesity? What is the role of public policy, and who evaluates the impact this has on the population? This paper looks at bioethics as a potential tool that will allow us to develop solutions to combat malnutrition and obesity. It also looks at the effect of individual responsibility and lifestyles on health.

Abstract number: 234
ID: 676
oral

Bioethics and Islamic Government: Iran Experience
Ehsan Shamsi Gooshki, Dr Mahmoud Abbasi, Dr Akbar Shahrvari
Iran (Islamic Republic of), Iran Medical Assosiation

Iran is a Middle Eastern country with population of 78,000,000. The Shiite, a branch of Islam, is the official state religion and to which about 90% of Iranians belong, dominates religion in Iran. Persians have attempted to regulate medicine and to protect patients' rights in the known ancient world from about 1750 BC which continued in medieval and so far medical ethics was a part of traditional and modern medical school's curriculum until 1979 after which an Islamic government came up to power and based on the new constitution all laws, acts and regulations including those related to biomedical ethics had to be based on or compatible with Shiite interpretation of Islam. Therefore ethical issues are highly sensitive mainly because traditionally ethical issues were discussed as a part of Islamic jurisprudence. Despite this sensitivity an acceptance of emerging technologies with minimal resistance among Shiite religious authorities in Iran could be seen which in some cases are exceptional among Islamic countries, for example Deceased or Brain Dead Patients Organ Transplantation Act (2000), Embryo Donation to Infertile Spouses Act (2003) and Iran Therapeutic Abortion Act (2005) which are passed through Iran parliament as a formal pathway and some other activities such as Related and Unrelated Living Donor Organ Transplantation which is based on the viewpoint of the Iran supreme leader presented as an Fatwa (Jurisprudential Decree) as an informal pathway. In this paper we are going to explore the reasons of the above mentioned acceptance and also the process of passing these acts and laws to derive a model through which such regulation could be ratified in an Conservative Islamic state and to illuminate the way for more acts in Iran and other Islamic countries in which Islamic bodies have a great influence on ethical aspects of biomedical issues.

Abstract number: 235
ID: 678
oral

Factors that inhibit and factors favoring the exercise of autonomy in health sector
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The autonomy, symbol inadvertant of the modern rights, sometimes it concibes more of a metaphysical illusion than a right that could emerge in plane sector of biomedic. just as the investigation as well as the clinical activity seem to mark an aspect of intentions and external factors of the patients will, as a result of his right to be informed with clarity, and offering a reasonable consentment to his prerrogatives of doing something against his will, being unclear and inspecific concrete situation in which it seeks the autonomy be respected.

It should anticipate that autonomy conceives as an intellectual exercise that becomes manifest in the expression and materialization of the will.

Therefore in the situation where the manifestation of the autonomy distored the possibility of exercising its intellect and prohibits concretion of the will and exercises the autonomy will be uncertain and questionable.

Of which procuration is found emarked for discussion and internal and external intentions which prohibit the consolidation of the right, but at the same time pretend to offer a set of minimum standards that would serve as a reference both biomedical research and clinical practice, so that the right patient autonomy achieved a less questionable expression

Abstract number: 236
ID: 679
oral

Justice in health decision making
Ixchel Itza Patiño González,
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In public hospitals the resources are limited. Distributing resources involves seeking what their ultimate destination and it is therefore important to analyze the different options or pathways that are held for distribution. We have on one side of the scale to maximize the resources that facilitates efficiency and avoiding other inequalities distribute resources among members of a society have the same conditions of receiving a health service. These positions can be grouped into two, one that addresses the consequences and one that caters to independent duties set of consequences. Justice as a principle in bioethics seek guidance to hospitals from these positions in the distribution of resources reasonably avoiding decisions that tend to be arbitrary or discriminatory. However, there are several views that justify a fair distribution position : they give everyone the same, give each according to his need , to each according to his contribution or to each according to merit. I believe that the decisions made in a health care institution are varied , this means that their nature is different from being in a position to support justice . In this regard, it is important to identify : what kind of decision is , what good is at stake , what is the justification offered by the position of justice on which it rests. The purpose of this release is to analyze several distinct decisions that are supported by several points of view of justice in bioethics.

Abstract number: 237 INDIVIDUAL HUMAN EXISTENCE IN THE LIGHT OF BIOETHICS
ID: 680 Boris Yudin,
oral Russian Federation, Moscow

The term "individual human existence" will be used to designate a human as a finite entity placed in particular space and time as opposed to a human perceived not as an individual but as representative of mankind or someone who belongs to any social community or group. Besides, it is only physical and psychical and not any kind of spiritual existence. Biomedical interventions into humans usually are performed inside this span of individual human existence.

There are some areas inside and nearby individual human existence which are the most appropriate for effective application of biomedical technologies. One example is a zone between human life and death. This zone can be thought of as a span of uncertainty between two states of individual human existence: definitely alive and definitely dead. In comparison with both these adjacent spaces the span is extremely thin one, to the extent that in our everyday life we usually take no notice of it. Yet if we, to be armed with means of modern science and technology, will scrutinize this span more intently, we shall discover many subtle, smallest details and particularities.

One of the well-known objects of study in physical sciences is systems in the state of so called phase transition (say, transition of water into ice and vice versa). Usually phase transition is rather fleeting process, when the system is in unstable state. Due to such instability relatively weak actions can cause rather serious effects, bring to cardinal changes of the system. Interventions performed in the transitory zone bring forth, along with biological, technological, etc. problems, also a lot of ethical dilemmas.

Similar arguments can be unfolded with regard to other boundary zones of individual human existence: zone before birth of a human being, zone between human and animal, between human and machine, etc

Abstract number: 238 Ten criticism thesis about bioethics
ID: 682 MA. Raúl Héctor Rodríguez Otero
Oral Mexico, CONBIOÉTICA

From the epistemological point of view, some disciplines that involving scientific aspirations, the bioethics have to break their own paradigms to further progress. The key purpose of the bioethics is becomes in a modus vivendi within contemporary societies that necessary involves in its deconstruction, formally named analysis and criticism of their standard forms to be designed and executed. So ten guesses on bioethics are presented: from the possible affinities or similarities with biopolitics, the scope of institutions versus aspirations by undertake a bioethical culture practiced by everyone, even the demand to return a detail about the original thought of those who are conceived, all in the order to constitute a reasonable discourse that enable the reinvention of bioethical tasks from wider understanding of the significance and interference in the lives and daily experiences of human begins, with special emphasis in the post-humanist vision that is based of increasingly on the biotechnology development.

Abstract number: 239 THE LEARNING OF BIOETHICS BASED ON PROBLEMS (ABBP)
ID: 683 Fabio Alberto Garzón Díaz,
oral Colombia, Universidad Militar Nueva Granada

This communication is the result of the research project from Military University of Nueva Granada, HUM 948 Bioethics group, research line bioethics, education and culture. The communication presents a novelty proposal on the teaching of bioethics, the learning of bioethics based on problems (ABBP, for its Spanish words). The text is composed by 7 parts: 1. An introduction wherein the educability and the ability to teach the bioethics. 2. The main characteristics of PLB. 3. The psycho pedagogical fundaments of PLB. 4. The essential criteria of PBL. 5. The epistemological fundaments of PBL are analyzed. 6. How do we understand the learning of bioethics based on problems ABBP. 7. Finally as a proposal we will take the 5 aspects that must be taken in consideration if one wants to propose a curriculum based on problems and competencies.

Abstract number: 240	Perceptions of informed consent by patients from four areas of health care in Bogota, Colombia
ID: 684	2013
oral	<u>Maria Teresa . Escobar Lopez,</u> Colombia, Universidad Militar Nueva Granada

In Colombia, informed consent (IC) has been established in recent decades. It has incorporated theoretical elements mainly from law and bioethics. It has become a legal matter for patients requiring, which is verifiable in Colombian legislation. It is included in laws, resolutions, management protocols, quality requirements of regulators of clinical activity in different health care settings. Confidence and citizenship just beginning to be taken into account, and only recently the patient's perception about the CI is addressed. This study seeks to answer the following question: What perceptions and experiences with CI have the patients included in four different categories of health care?

Descriptive cross-sectional study carried out in two phases. First phase: IC 78 written documents from journals indexed articles were reviewed from 1995 to 2012. Articles do not realize difference between the various types of care fields and only five of them focus exclusively on patients. In general, difficulties of information, warning of risk confirming that IC is an issue in progress. It is evidencing the need to involve patients in future studies.

Second phase: patients were surveyed in four categories, 1) prolonged high-risk procedures; 2) prolonged low-risk procedures; 3) short high-risk procedures and; 4) short low-risk procedures. After analyzing the information collected from patients is concluded that there are problems of understanding, lack of information, time, explanation of procedures and therapeutic distinctions. On the other hand, the information does not take into account the different levels of education, family characteristics and social status, among others important issues around patients

Abstract number: 241	Is this real promise or real dilemma? An Ethical Evaluation of Human Embryonic Stem Cells as a Therapeutic Agent
ID: 686	<u>Mukadder GUN,</u> Turkey, Turkish Gendarmerie General Command

Human embryonic stem cells (HESc) have the potential to differentiate to form various cells that grow in to nerves, bones and various internal organs. Therefore HESc cells should promote regenerative medicine near future because of the their biologic properties. Moreover HESc research promises an increased understanding of the molecular process underlying cell differentiation. Translating of embryonic stem cells or their obtains may, in the future, offer cures for human diseases.

In this respect for many people (scientists, medical staff, philosophers, ethicists and the other people) carry moral status. Using different sources of human embryonic stem cells for research and therapies raises a lot of different ethical dilemmas. Some of this conflict area are on the cutting edge of science, politics, law, bioethics, and religion. The basic and particular issue is the moral problem created by the destruction of the embryo.

The objectives of this literature review study are: (1) to present the fundamental arguments on the side of and in opposition human embryonic stem cell researchs (2) to conclude HESc as therapy agent from the ethical perspective.

Abstract number: 242	Implicit bias in health care professionals: a systematic review
ID: 687	<u>Chloë FitzGerald,</u> Switzerland, iEH2 (institut Ethique Histoire Humanités)

Implicit biases are associations made below the level of conscious awareness that lead us to evaluate a person negatively on the basis of characteristics such as race or gender, even when explicitly committed to equal treatment for all. The widespread existence of these biases in the general population and their effects on behaviour have led to their investigation among health professionals; however, the strength of the evidence has not been systematically evaluated. This review examines the evidence that fully-trained health care professionals display implicit biases towards patients. We searched PubMed, PsychINFO, PsychARTICLE and CINAHL for peer-reviewed articles published between 1st March 2003 and 31st March 2013. Two reviewers assessed the eligibility of the identified papers based on precise content and quality criteria. The references of the eligible papers were examined to identify further eligible studies.

27 articles were identified as eligible. Of these, 15 used an implicit measure (the Implicit Association Test in 13 studies and evaluative priming in 2 studies), to test the biases health care professionals. A further 12 articles employed a between-subjects design, using vignettes or similar methods to examine the influence of patient characteristics on health care professionals' attitudes, diagnoses, and treatment decisions. 13 studies examined racial/ethnic biases; 8 other biases were investigated, including gender, psychiatric illness, and obesity. 26 articles found evidence of implicit bias in health care professionals; the studies that investigated correlations between implicit bias and treatment decisions found a number of significant relationships.

The evidence strongly suggests that fully-trained health care professionals exhibit the same levels of implicit bias as the wider population. Correlational evidence, predominantly from vignette studies, indicates that biases influence treatment decisions and levels of care

Abstract number: 243

ID: 690

oral

Biotechnological Challenges to the Conceptual Foundations of the Right to Life under the Constitution of India
Kelly A. Dhru.
India, Gujarat National Law University

While there has been much concern about the infringement of legal and human rights through emerging biotechnologies, historically, the ambit of 'rights' has been fluid. Moreover, the Will and the Interest Theories of Rights have fought an inconclusive battle since the Middle Ages, without a clear winner. While the Will Theory representing the Kantian view looks at individual choice as the justification for rights, the Interest Theory with Jeremy Bentham as the torchbearer considers well-being as the decisive factor in defining rights. The philosophical uncertainty is even higher in the context of defining a right-holder, as is evident through the on-going debates about rights of animals and embryos.

The aim of this paper is to explore what these legal and moral philosophical questions surrounding the nature of rights might mean in the context of emerging biotechnologies, particularly in the context of developing countries. To analyse the legal implications, I will focus on the right to life under the Constitution of India, which has been interpreted widely in the cases following Maneka Gandhi v Union of India. I will question whether it is possible to have a coherent legal interpretation of the right to life as it exists today, in the context of technologies such as artificial reproductive technologies, genetic engineering, brain-machine interface, organ transplantation, stem cell research, cloning, sentient machines, mind-uploading, biomedical gerontology and relate it to the debates within the theories of legal rights.

This paper will argue that while legal rights have often been used as tools to regulate emerging biotechnologies, these technologies in turn might end up changing the way we understand human and legal rights, leaving us wondering what it really means to be a legal right holder and have a right to life.

Abstract number: 244

ID: 691

oral

Ethical presentation of AIDS in Africa

Baraka M. Morris.

Tanzania, Muhimbili University of Health and Allied Sciences

HIV/AIDS an enemy which by 2011 had killed more than 30 millions and about 34 millions people were living with it. About 68% of all people living with HIV and 70% of new HIV infections in 2010 were from Sub-Saharan Africa that constitutes only 12% of the global population. It is these facts caused the UN security to highlight HIV as a security threat. This is due to the fact that in any regions where HIV/AIDS epidemic has reached, it destroys the very good of what constitutes that community: individuals, families, communities, economic and socio-political institutions, and the security force. Although the photographic presentation of HIV/AIDS has is very important in increasing the knowledge about the disease, it can be interpreted wrong in different settings hence send the wrong information. This is because very act of recording and representing PWAs is as ethically relevant as the act of treating them. There are three photographic methods that have been used by media to represent HIV/AIDS in Africa: naturalist, humanist, and pluralist. Each of these carries different forms of representation through which can be interpreted differently in different part of the world. The photojournalistic series from a 2008 issue of Time magazine entitled "Africa's AIDS Crisis(Stoddart, 2008) is a good prototype that can be used as case to describe the three types of photos mentioned above. Does the images in this series humanize or dehumanize their subjects?

Abstract number: 245

ID: 693

oral

Medical Futility: Is Policy Development an Option?

Alireza Bagheri.

Iran (Islamic Republic of), School of Medicine, Tehran University of Medical Sciences,

Medical futility refers to the inappropriate application of medical intervention that is unlikely to produce any significant benefit for the patient. The inevitability of human death, limitations of medical science, scarcity of health resources, and various socio-cultural issues shape decisions regarding end-of-life care in general and medical futility in particular.

In everyday clinical practice, physicians are under pressure to make decision about futile care and in some cases there are disagreement between healthcare providers and patients' family about futile care.

Except few healthcare systems in the United States, there is a lack of regulation or policy in dealing with medical futility. Such guidelines can help healthcare professionals- as well as family members-

decide how aggressively to treat patients and when it is morally permissible to withhold or withdraw futile treatments.

By providing a review of the issue, this paper examines how developing futility policy may help physicians make decisions about futile treatments, potentially decreasing disagreements between healthcare providers and patients' family members.

Abstract number: 246 **Review of Instruments for Assessing Decision-Making Capacity in**
ID: 694 Lorna Luco, María Inés Gómez, Sebastian Solar, Nicole Grossman
oral Chile, Clínica Alemana – Universidad Del Desarrollo Faculty of Medicine

Population aging generates the condition of elderly people who face complex diagnoses such as chronic degenerative diseases and cancer. Decisions about indicated treatments warranting informed consent of individuals most often occurs in distressed environments paired by the anxiety generated by the first information. Even in people with good general physical conditions, there is no certainty regarding the cognitive abilities to understand the information and consequences of decisions.

Assessing the capacity, therefore, is an imperative need and is the reason for this review.

Considered elements:

- Aging as a bio-psycho-social process and its implications for health decision-making.
- Definition of "capacity".
- Instruments to measure capacity, developed internationally.

Having revised existing instruments used in measuring "capacity" of patients with and without neurological and / or psychiatric impairment, it may be determined that in this age group:

- There are no capacity assessment criteria, standards or protocols.
- Capacity assessment directly influences the implied clinical decisions.
- There are ethical and legal responsibilities of health care teams in assessing the capacity of their patients and considering them capable or incapable of making health decisions has implications for these areas.

The health team monitors the capacity of patients, based on a combination of clinical experience, caution and common sense. They have been welcomed and accepted by their family members; therefore, there is a solid base for gradually building a methodology for assessing capacity that is ethical, legal and scientifically sound.

Abstract number: 247 **Fate of cryopreserved human embryos produced by IVF: new scientific and bioethical and legal implications**
ID: 697 Manuel J. Santos, Paulina Ramos; Angela Arenas, Alejandra Carrasco, Mauricio Besio and Patricio
oral Ventura-Juncá.
Chile, Facultades de Ciencias Biológicas, Filosofía y Medicina, Centro de Biética, Pontificia

Human embryos produced by In Vitro Fertilization (IVF) show more epigenetic alterations than those conceived naturally. These alterations could be even higher when embryos are frozen before implantation. Along with these new discoveries new ethical questions have arisen and need to be elucidated. The fate of the embryos produced by IVF -and eventually cryopreserved- may be: (a) implantation in the mother, (b) waste, (c) use for experimental research and (d) adoption. The first three alternatives have already been discussed enough in the field of ethical theory. However, the adoption of cryopreserved embryos is an ethical issue that has not been fully settled: Is ethically acceptable to have a heterologous pregnancy to save the life of a human being that otherwise will be discarded?

To address this issue we have: 1) gathered the new scientific findings about epigenetic alterations (malformations and developmental disorders) in animal models and in children born after IVF followed by cryopreservation, 2) discussed the moral permissibility of potential destinations of embryos produced by IVF, especially the more recently emerged option, which is the adoption of abandoned cryopreserved embryos and 3) discussed the absence of IVF legislation in Chile and the destiny of the IVF embryos, making visible the need to regulate the applications of these techniques to protect human life.

Supported by project # 1573/DPCC 2012 VRI, from the Pontificia Universidad Católica de Chile.

Abstract number: 248	Twenty years of bioethics in UNESCO: what is the perspective for the coming years?
ID: 699	<u>Dafna Feinholz,</u>
oral	France, UNESCO

The aim of the presentation would be to introduce the work on UNESCO in bioethics for the past 20 years focusing on the social aspects of the Universal Declaration of Bioethics and Human Rights, as well as the new orientation of program.

Since 1993 and the establishment of its Bioethics programme, the Organization has helped identifying and exploring emerging ethical challenges by acting as a laboratory of multidisciplinary, multicultural and pluralist ideas on the ethics of science and technology.

Within UNESCO, unique international legal instruments in bioethics have been developed and adopted, such as The Universal Declaration on Bioethics and Human Rights (2005)

UNESCO seeks to disseminate these standards and to assist Member States to transpose them into national law and has supported the development and strengthening their bioethical capacities. Until January 2013, 17 countries had established a bioethics national committee with the support of UNESCO. In 2008, UNESCO published 2008, the Bioethics Core Curriculum which is already applied in twenty universities around the world.

The whole UN system is now looking at establishing new goals to achieve sustainable development and a fairer world. Science and technology need to be used to eradicate poverty and promote health and the protection of the environment. Faced with a multidimensional crisis that threatens to further increase the gap between rich and poor - in a context where the pursuit of profit risks being accompanied by the abuse of human dignity, the principles of universal human rights must be respected in the scientific and technological development.

UNESCO's bioethics programme will be focusing now to contribute to global justice- a pillar of sustainable development and the UN post 2015 Development goals- contributing to develop further the concept of benefit sharing, both and beyond the research context.

Abstract number: 249	BIOETHICAL ISSUES ON THE POSSIBILITY OF FETAL PAIN
ID: 700	<u>María Antonieta Flores Muñoz,</u> Pérez Tamayo R., Breno I., Álvarez A
oral	Mexico, Programa de Maestría y Doctorado en Ciencias Médicas, Odontológicas y de La Salud UNAM.

Background: Advances in Medical Science and Technology have allowed a better understanding of fetal neurophysiology and have influenced the practice of fetal surgery and other prenatal interventions. That knowledge has led to legislation based on fetal pain. There is controversy and an ongoing debate in relation to the presence of pain and the need to provide anesthesia and/or analgesia to the fetus during some surgical procedures. Medical procedures which have not included analgesia have been based on the longstanding belief that the fetus was insensate to pain.

Aim: Review the Scientific evidence, Legislation and Bioethical issues related to fetal pain.

Discussion: The fetal pain controversy touches four problems: Scientific, skeptical, conceptual and bioethical. Two perspectives are observed: skeptical and sympathetic. Both invoke the same data about neurophysiology and behavior, but the interpretation leads to opposite conclusions. A Bioethical analysis is made by Bioethical Principles vs. Utilitarianism. Bioethical principles aren't enough to face the problem; Bentham's Principle of Utility is based on pain and pleasure; for John Stuart Mill all living things seek pleasure and avoid pain; the Practical Ethics of Peter Singer is based on pain; Ryder's Painism gives us further understanding of these issues.

Conclusion: Scientific evidence including pain-specific behaviors, sensory cortical activation, neuroendocrine or hemodynamic stress responses have strengthened the possibility that the human fetus may experience pain from 20 weeks of gestation. In view of this possibility and the philosophical framework of the above mentioned thinkers, it would be unethical to deny the provision of analgesia to the fetus

Abstract number: 250	Toward a Proper Comprehension of the Human Zygote
ID: 702	<u>Rodrigo Guerra López,</u>
oral	Mexico, Centro de Investigación Social Avanzada. CISAV.

One of the most difficult debated topics on the global world is the one around the beginning of the human life during the earliest stages of the embryo development. The human embryo in unicellular stage (zygote) provides a set of features that can characterize him as a full organism of the human species. There are new evidences that allow understanding in the field of development biology, the characteristics of the zygote as a full organism and at the same time invite to a philosophical reconsideration of his stringent ontologic status. Understanding the

human zygote in an appropriate way we can distinguish him from other biological structures merely embryoids and find more fine criteria in order to promote his respect and protection. The study of the earliest human embryo –the zygote- helps in an important way for a better understanding of the beginning of the human life not only in this moment but also in all his intrauterine life.

Abstract number: 251 Dysthanasia – The futile and/or useless medical treatment in Brazil: From the anguish of the decision to the serenity of the bioethical dialogue
ID: 705
oral Leo Pessini, William Saad Hossne
Brazil, Saint Camillus University Center

Prolonging a painful dying process, which adds just more pain and suffering to a prolonged dying process, more than extending life, is one of the most complex and debated bioethical and medical issues, in the context of end-of-life care, today. The literature and media discuss much about euthanasia, and forget to face this one, the dysthanasia. Our discussion on this subject starts with the definition of this bioethical problem in itself. Our search is marked by "creative anguish" that search to identify terms and neologisms to define this bioethical issue. In Brazil is called dysthanasia, in USA, futile and/or useless medical treatment, with the same meaning: a medical treatment that does not bring any kind of benefits to the patients in their final stage of life. To deal with this bioethical problem, we have relied on medical and scientific literature and on international bioethics literature, as well as on the tradition of the Brazilian medical ethics, in its codified version. Although a certain treatments can be considered futile and therefore useless, care it's always a necessity to be considered. In the heart of every single action of health care professional, there must be "philia" (love, friendship) and professional competence (Technical expertise), as allies!. We can surely be cured from a deadly illness, but not from our mortal and finite human condition, that is not a pathological reality. This article presents a methodology to deal with this ethically conflictive issue by deepening the understanding of some key ethical concepts, such as the process of deliberation, decision-making, medical responsibility and suggests the implementation of palliative care and bioethical dialogue and discussion.

Abstract number: 252 ETHICAL ASPECTS OF GENDER VIOLENCE AND DOMESTIC VIOLENCE: PERUVIAN AND MEXICAN CASES
ID: 717
oral Manuel Vargas Almaraz, Iraclis Montoya, Andrea Valdez, Agueda Muñoz del Carpio Toia
Mexico, Universidad Panamericana Campus Bonaterra

Introduction: The WHO recognizes domestic violence as a Public Health problem, with serious consequences or problems on people's health and the healthcare system. Violence involves: violation of ethical rules and values those are part of the reality around the world. Methods and materials: An investigation was performed to know the Domestic Violence characteristics versus the women in Mexico and Peru. Attacked women, and the Social Communities involved with the violence and woman protection; were interviewed. Results: the Gender Violence on families is a multi-dimensional problem, this problem is: Human, Social, Legal, Cultural and Public Health, constitutes a serious Human Rights violation. Official information from Peru a Mexico has many things in common, domestic violence against women, like feminicide, are high: every 4 women from 10 a case of domestic violence appears in their life. Women interviewed results shows: no matter the age, women with incomplete school, housewives, etc; the aggressor is always the couple. Physical and psychological violence prevail, in some cases sexual violence appears. Victims never denounce because fear or shame. The minority after denounce, feels unprotected by the justice or lay, paperwork are extensive and in many times victims needs to go to Medical or Legal Institutions and start again the denounce against the aggressor. In bioethical analysis, violence hurts deeply the respect to the dignity, the principle of beneficence is transgresses, because it is society and family commitment; seek the welfare and respect women. Compromises the justice and equity: family violence in old age, childhood, work, etc. are not investigated. Complaints of psychological violence are underestimated

Abstract number: 253 PARTICIPATING DEMOCRAZY IN LATIN AMERICA: ETHICAL ASPECTS OF INDIGENOUS/NATIVE COMMUNITIES' RESEARCH
ID: 718
oral Agueda Muñoz del Carpio Toia, Damián del Percio, Octavio Márquez, María Isabel Rivera.
Peru, FOGARTY- FLACSO

The indigenous communities or native communities' research had increased in the last years. This interest comes from the better geographic access to these zones, the technology improvement and the crescent interest to intervene in their populations with health care and education programs. However the research with native communities has some risks: - Invasion to the privacy of these communities, even those that were isolated by themselves.- Investigations without benefits to the community.- Genetic researches with improper use of samples.- Publication of stigmatizing, discriminatory and stereotyping results. - Appropriation of traditional knowledge.- Negotiations and

undue influences to obtain community consents. - Irruption to their culture and occidental value impositions. We propose some strategies to protect the native communities during the research: Inclusion of a community member, on the Ethics committee, that has respect of his culture, dignity, vision, opinions and autonomy. Collaboration of experienced personal on the following themes: tribes, communities, and community leaders. The Ethics committees should execute and ethical monitoring by visiting the research centers, talking to the study subjects and observing the process of the informed consent. Request de investigator, the cultural adequacy of the consent with plenty knowledge of these communities context. Take advice from the community about social, cultural and economic aspects, and get involved with their values, needs and demands. Protect the moral and physical integrity of these native communities. Propose investigations that have direct benefit and an adequate scientific justification. Consent must be individual and community, with cultural appropriateness. The work concludes that the task of protecting the Ethics of a native communities' research requires to, ensure the ethical quality of the investigation, the ethical quality of the investigators, an independent ethical motoring and continuing education to the community for their self-protection.

Abstract number: 254
ID: 730.
oral

The achievement of the parental Project by plural families through the use of assisted human reproduction
VALERIA SILVA GALDINO

The Brazilian Federal Constitution of 1988 expanded the concept of family when recognized other entities besides the family, arising out of marriage. Today, the family can be defined as an institution plural, tied to the values of human dignity, equality, solidarity and family living, having as purpose the affection, independently of sexual orientation. The right to parental project realization is guaranteed in the Constitution and in law No. 9.263/1996 and may still be used, the techniques of assisted human reproduction, however since observed the principles of human dignity and the exercise of responsible parenthood, thereby ensuring the comprehensive protection and the best interesting of children from these proceeding. There's no legislation in our country that regulates the use of these techniques. The most prominent techniques are the heterologous artificial insemination, in vitro fertilization and substitute motherhood, for couples homoaffectional, transaffectional, asexual, etc. As well as the donation of semen or ovum, without profit, preserving the secret of the identity of the donor. They can also adopt embryos of other couples, as long as there's the express consent of those. The non-exercise of responsible parenthood gives opportunity to conflicts when the use of these techniques, such as abandonment or dispute paternity/ maternity of the child, the difficulty in registering, the genetic manipulation when used for the practice of eugenics inside out, etc. From the above, it's up to Judiciary, while there's no law, solve the conflicts when the realization of the project homoparental, basing on the principles listed above and in the current CFM resolution No. 2013/2013, since the Law of Biosecurity is incipient.

Abstract number: 255
ID: 750
oral

Ethical Considerations in Genomic-based Personalized Medicine
Alan Warner, Dr. Kerry Bowman
Canada, Mount Sinai Hospital

Genomic-based personalized medicine is an exponentially growing direction in cancer research. Yet, equity in cancer care is a mounting concern due to sharply rising drug costs. It is not yet clear if personalized medicine approaches will reduce cost or improve distributive justice. This research study primarily focuses on the "lived experience" of contemporary drug cost as well as patient attitudes towards personalized medicine in cancer care. This presentation however will primarily highlight the qualitative data gathered on patients' attitudes, hopes, fears and perspective on justice in relation to genomic-based personalized medicine. In addition, the challenges of autonomy and obtaining true informed consent will be explored in relation to genomic-based personalized medicine.

This research study is a component of a Genome Canada study that is developing genomic-based cancer therapeutics which requires a GE3LS research angle. GE3LS research explores Genomic, Ethical, Environmental, Economic, Legal and Social challenges and opportunities that are related to the responsible application of genomic-based technologies. GE3LS is the Canadian equivalent to research on the Ethical, Legal and Social Implications (ELSI) of human genomics in the U.S.A. Qualitative methodology was used with open-ended interview questions for focus groups, individual patients and key informants.

Projects such as GE3LS and ELSI represent a turning point, where integration of social realities with scientific research can help improve social equity. Bioethics can act as a bridge between public needs, understanding and ongoing scientific research, especially at the point of change that genomic-based personalized medicines create. Embodying this approach may act as a precursor towards equity for the greatest portion of citizens.

Abstract number: 256	The re-examination of the Council of Europe Biobank Recommendation: current status
ID: 751	Kristof Van Assche,
oral	Belgium, Free University of Brussels

The Council of Europe Recommendation(2006)4 on research on biological materials of human origin is a reference international legal instrument dealing with ethical issues raised in the field of biobanking, with considerable authority in Council of Europe Member States and beyond. A process of re-examination was initiated in 2011 to update the Recommendation in the light of developments in the field since its adoption in 2006.

In order to provide a basis for the re-examination of the Recommendation, the Committee on Bioethics of the Council of Europe in close cooperation with the European Commission organised a Symposium on Biobanks and Biomedical Collections in June 2012, which was attended by over 150 stakeholders. During the symposium several developments were identified as raising challenges with respect to the ethical and legal principles enshrined in the Recommendation. On that basis, a revision of the Recommendation was prepared, focusing on issues including conditions regarding information and consent, protection of persons not able to consent, data protection, ethics review, feedback on incidental findings, access and transborder flow, and governance.

A public consultation is now being carried out. In the light of the comments received during the consultation, a revised draft will be elaborated and presented for adoption to the Committee on Bioethics.

Abstract number: 257	BIOETHICS AND INTERCULTURALITY
ID: 754	<u>JOSÉ GILBERTO RODRÍGUEZ-RODRÍGUEZ</u> , ANTONIO LUÉVANOS-VELÁZQUEZ, RAFAEL RIVERA-MONTERO
oral	Mexico, COMISIÓN ESTATAL DE BIOÉTICA E INVESTIGACIÓN DE JALISCO

Our country is multicultural , yet their peoples still live are characterized by high levels of poverty and in a position of significant disadvantage. The challenge is to contribute to poverty reduction through the elimination of inequalities and optimize access to health services. Traditional medicine is a set of systems of health care that is rooted in deep knowledge about health and disease founded on a different interpretation of the world and feel the convenience of articulating these therapeutic forms our operational structures because attention to the health of our indigenous communities have a cultural relationship ineffective. That is, bioethics " our " is different to bioethics " traditional doctors " . The relationship between multiculturalism and bioethics is on respect for the patient as part of respect for life, human dignity , human rights and environmental health . That is, in respecting your body, respect for their beliefs and respect their privacy. Consider culture bioethics developed through hospital bioethics committees and research ethics committees and to improve health conditions of indigenous peoples is recommended by the World Health Organization (WHO) through the Organization Pan American Health Organization (1998) . The Ministry of Health Jalisco, in bioethics and multiculturalism, intends to apply intercultural dialogue programs through : the doctor- patient, health staff training and research. And where the person and dignity must have a vision of man from his personal being transcendent.

Abstract number: 258	PROPOSAL FOR THE ANALYSIS OF ISSUES BIOETHICAL DILEMMA
ID: 755	<u>RAFAEL RIVERA-MONTERO</u> , ANTONIO LUÉVANOS-VELÁZQUEZ, JOSÉ GILBERTO , RODRÍGUEZ-RODRÍGUEZ
oral	Mexico, COMISIÓN ESTATAL DE BIOÉTICA E INVESTIGACIÓN DE JALISCO.

Bioethical dilemma is a narrative that raises a moral conflict situation and also poses a possible solution analysis and reasoned. Although the term bioethical dilemma is considered synonymous with clinical ethical problem enunciate this issue from the point of view of deliberation , the medical act and the proposal to make the three-step method . The health worker will require certain features in your professional profile , which should not just theory. Hence the need to recover the profound sense of the reality of the human person. We propose a triangular method in which we analyze three focal points : the medical act , the anthropological significance and possible ethical problem solving . State the philosophical orientations that may influence the decision bioethics are sociobiologista naturalism , radical liberal model , utilitarian and pragmatic orientation personalist model , which will help us better understand the reasons for such decisions. We exercise the approach to a case of possible conflict of bioethical dilemma through the method of the three steps are: diagnosis, prognosis and treatment in bioethics . And finally , we report the experiences in the State of Jalisco in integrating hospital bioethics committees and the way of how we try to attain the skills , abilities and skills through comprehensive case evaluation taking into account all the objectives allow analysis of reference such as: identify, differentiate and propose possible solutions based on the need to respect patients and their families.

Abstract number: 259	Reflexiones Bioéticas sobre la Condición de Identidad en Pacientes con Trastorno de Diferenciación Sexual (TDS)
ID: 757	Ana Lilia Higuera Olivo,
oral	Mexico, Depto.Historia y Filosofía de la Medicina–Facultad de Medicina-UNAM

Taking for granted now called Disorder Sexual Differentiation (TDS) , to what was described above as intersex states -that is , the biological condition why some individuals exhibit discordance and / or ambiguity in relation to the different aspects determine the chromosomal , gonadal , genital , hormonal, and finally legal sex , much less discussed from the humanistic point of view : the existential , fundamental reason for this work. Questioned whether the definition of sexual identity in those subjects classified as different, represents a bioethical dilemma as the appointment could be made without violating their human rights, so the right to review the dispute is not discrimination in the doctor- patient relationship , while the conflict that arises from the genital - allocation - first instance , identity of the individuals in question, due to the diverse, curious pre - set parameters and historically match forms of medicalization of what is or can be classified as : illness, disease and / or failure , from medical positivist languages optical character biologically -lesional , indicating that a diagnosis should be established regarding what comes out of normal, since this condition places it as abnormal and therefore as a disease and / or condition by not responding as defined by the Anatomy and Physiology.

Abstract number: 260	Proposal four ethical and methodological aspects in research on humans
ID: 760	Rafael Bustos-Saldaña
Oral	Mexico, Universidad de Guadalajara

Introduction: Research methodology do tip but respecting the basic ethical principles in research studies especially in humans, convert the knowledge gained in a valuable contribution to the progress of humanity

Development: We propose a diagram where four facets viewing options intersection of the progress of the methodology for conducting research studies and observed ethical values exist for its realization
1.- Ethical and methodological low value: Often the researcher (mainly beginners) performs studies, despite not having sufficient knowledge in their frame of reference on the subject to study, make scans or worst manipulations without knowing what makes or ethical implications .

2.- Ethical high value and methodological low value: Characterized by the care of the rights of individuals entering the study, but has the disadvantage that is not done taking into account scientific developments suitable for obtaining results. These studies are considered work thrown away by their limited scientific value, but with great ethical value in their realization

3.- Ethical low value and Methodological high value: The research was made based arguably the greatest advance of scientific knowledge that exists at the time but with a very bad ethical basis. This activity can make us dangerous only researchers seeking knowledge regardless of the means

4.- Ethical and methodological high value: It is characterized by the care of the rights of individuals entering the study and the latest methodological advances. This type of research, are what we should really point as teachers in research and therefore should be the role models to investigate

Conclusion: Ethics should not go against the methodological progress in research studies, will then be adjusted properly understand both the advancement of scientific knowledge.

Abstract number: 261	The Role of Bioethics in the Resolution of Ethics Environmental Conflicts
ID: 761	Jaime Escobar
Oral	Colombia, Universidad El Bosque

Problem: This article establishes the bioethical criteria to be taken into account in the resolution of conflicts of an environmental nature and proposes a method of justification and analysis. Objective: To identify gaps in knowledge of critical methodologies, we call for deliberative processes that favor pluralistic and proactive participation. Thesis: Regarding problems of an environmental nature, it is necessary to understand contingent nature of life. At the foundation of environmental conflicts there exists a controversial manner to value biodiversity and the environment. We affirm that it is useful to think of biodiversity and the environment as common goods, as the wellbeing of the populations that inhabit an area is dependent on their use. Conclusions: We conclude that this approach to bioethical criteria is a work in progress. The emergence of a field that unites new knowledge and practices of Bioethics is revealed.

Abstract number: 262	Morally relevant differences in vulnerable groups of research subjects
ID: 762	<u>Karin Jongasma</u>
Oral	Netherlands, Erasmus Medical Centre

New therapies for respectively childhood diseases and dementia are highly needed. However, relatively little biomedical research is performed on children and dementia patients. Both groups are considered incompetent for making decisions about research participation and for this reason laws are restrictive with respect to the levels of risks and burdens that are found acceptable for these groups.

The young and the old have a thing in common: their incompetence is or was not a permanent condition. Under the age of eighteen, children are generally considered incompetent for deciding about participation in biomedical research. As their autonomy develops and their understanding of the purposes and risks of research grows, they become more and more capable of making their own decisions about participation. At the end of persons a life, one can become demented. In that case, the decision making capacity and understanding of the person gradually diminishes.

In some respects, the legal requirements for doing research with incompetent research subjects are largely the same for children and incapacitated adults, whereas in others they differ. One can question whether the way children are incompetent to consent to research, is in fact comparable to the way people with dementia are incompetent. There are moral differences between the groups, which ethical and legal guidelines do not take sufficiently into account. In this presentation, an overview of the regulations failing to do justice to these morally differences will be presented, and recommendations for improvement will be explored.

Abstract number: 263	The reality in bioethics
ID: 765	<u>PhD. Martha Franco Espejel</u>
Oral	

The following article is a critic to the idyllic reason of Bioethics, it is questioned the non-proximity to the essential human reality, just after we may be able to find the second cause of the creation of Bioethics as such.

Let's imagine that Philosophy is a very strong and leaf abundant tree, the core branch is the human understanding which perfects itself by using the knowledge of reality. The greatness that mankind has taken, since times before two thousand years ago, two tortuous roads just to understand and transform reality, platonic relativism and aristotelic realism. Centuries have passed and mankind continues to know and transform reality, nowadays the acceleration of near sciences and the creation of techniques and technologies, overcome, apparently the way of thinking of the order of human actions (Ethics) which is completely false, all product of particular interests in the contemporary social structure, which lacks values and virtues.

The science of Bioethics is a full proof of the disorder promoted by the platonic relativism, since that divided log, has been multi-diversified in some very convenient opinions to the systemic de-humanification in which we live, knowledge has been left behind and opinion was given a place. We have stopped to contemplate reality to invent an implanted image in the personal and collective conscience.

Reality in Bioethics, can be understood when we understand Bioethics as a discipline invented by modern ways of thinking, which discards human essence and its millennium-long entitative product. Fundamental philosophical sciences to activate the understanding of reality are befogged by opinion, Metaphysics, Ontology, Axiology, Moral Philosophy or Philosophical Science of ethics, have been degraded by the fantasy of the image, which affect the very essence of the human being and the society that is voluntarily constructed. Human rights are affected as consequence by positive unjust laws, and many times perverse, which leads to the creation of presumed moral and legal rules that are only ghosts of our times. Reality has stopped being understood.

Abstract number: 264	Reflexiones sociales y bioéticas sobre el movimiento de los Derechos Animales en Latinoamérica
ID: 710.	<u>Fabiola Leyton, Daniela Romero</u>
Iberoamerican Network oral	España, Observatori de Bioetica i Dret, Universitat de Barcelona

El movimiento por los derechos de los animales en América Latina se destaca tanto en la encrucijada entre la modernización y la postmodernidad, y en la confluencia de identidades y valores indígenas, mestizos y occidentales. Incardinados en un contexto socio-político que reivindica el valor de la naturaleza, la valoración de los animales como seres individuales y refleja la importancia de la acción política en su evaluación global; esta propuesta se basa en el enfoque de los nuevos movimientos sociales y la bioética global, para explorar y reflexionar sobre los fundamentos del movimiento de acción social y sus formas particulares de organización en el movimiento por los derechos de los

animales en América Latina. Teniendo en cuenta que los cambios en las sociedades capitalistas occidentales también se han convertido en formas de conflicto, se abren como oportunidades para la acción colectiva y la movilización social, especialmente cuando se trata de la reivindicación de los derechos animales, que ha establecido nuevos temas de discusión, abre nuevas preguntas a la bioética y explora nuevas posibilidades de acción, conceptos de ciudadanía y consumo, y abre áreas que hasta ahora habían permanecido reducidas al ámbito de lo privado, como las decisiones de consumo en la alimentación, la vestimenta, el entretenimiento, etc. El objetivo de esta ponencia es explicar algunas experiencias latinoamericanas reivindicadoras de los derechos de los animales en el actual contexto de crisis del capitalismo neoliberal, cuyo metabolismo de explotación masiva e industrializada de los animales pide responsabilidades morales, legales y políticas a los ciudadanos y la sociedad; y cuyas respuestas desde la bioética global asumen un papel de desafío para la práctica ciudadana, política, y por supuesto, para la educación en bioética.

Abstract number: 265 **Responsabilidad ética hacia los animales de compañía en situación de abandono**
ID: 711. Claudia Edwards, Islas, E., Esquivel, C
Iberoamerican Network
oral

Mexico, FMVZ, UNAM

El dilema que se presenta en este trabajo versa sobre el papel de las personas que poseen responsablemente animales de compañía y de quienes no los poseen, con respecto a los animales que se encuentran en situación de abandono o a cargo de personas de bajos recursos lo que les impide ofrecerles el bienestar que ellos necesitan. Planteamiento del dilema: Si alguien no posee un perro o un gato ¿Por qué debe de ocuparse en ayudarlos a tener una mejor calidad de vida? O si alguien tiene un perro o un gato en condiciones de alto bienestar ¿por qué habría de preocuparse por uno que es suyo? Según WSPA "Más de un 75% de los cachorros de los países en vías de desarrollo mueren en la agonía de enfermedades que incluyen la rabia y el distemper". La solución a este dilema puede fundamentarse en la ética principalista de Tom Beauchamp y James Childress, ya que éste es uno de los métodos más utilizados para la toma de decisiones. Después de realizar el análisis ético de esta corriente, se concluye que sí existe obligación moral con los animales en situación de abandono a pesar de no estar bajo la custodia de un responsable. Dado que la bioética es sinónimo de ética aplicada, este trabajo justifica la presentación de programas para mejorar la calidad de vida de los animales de compañía en situación de abandono o bajo el resguardo de personas de escasos recursos.

Abstract number: 266 **Análisis bioético del uso de presas vivas en depredadores confinados en zoológicos**
ID: 712. Lorena Jiménez Naranjo,
Iberoamerican Network
oral

Mexico, FMVZ, UNAM

En la naturaleza los organismos vivos se relacionan de diferentes formas, por ejemplo, la interacción que se presenta entre los depredadores y sus presas, de la cual no se desprende ningún cuestionamiento ético cuando se presenta de forma natural y sin intervención del ser humano. Pero a raíz del confinamiento de la fauna silvestre en zoológicos, el hombre ha manipulado y artificializado sus vidas, no permitiéndoles desarrollar comportamientos propios de ellos. En un intento por tratar de brindarles una vida "natural" y de remediar o atenuar los posibles efectos negativos inducidos por el cautiverio, dentro de los programas de enriquecimiento ambiental se ofrecen presas vivas a depredadores, no como parte de su alimentación, sino con la intención de propiciar comportamientos de exploración, acecho y cacería, bajo los argumentos de que "se debe hacer porque es algo natural", que "estimula un comportamiento propio de las especies" y que "aumenta la experiencia de los visitantes en el zoológico, pues los animales permanecen activos y visibles por más tiempo". No obstante estos razonamientos se sustentan en falacias. Por otra parte, las presas, al igual que los depredadores, son animales vertebrados con Sistema Nervioso Central que les confiere la capacidad de experimentar dolor y sufrimiento, además de poseer capacidades cognitivas que les permite darse cuenta de lo que sucede en su entorno. Por lo anterior, se sugiere incluir a las presas dentro de los criterios de consideración ética, aplicar los principios bioéticos para beneficio de ambos, y evitar incurrir en el especismo.

Abstract number: 267 ID: 713. Iberoamerican Network oral	<p>Las bibliotecas Parlamentarias como nuevos espacios de deliberación y reflexión para la toma de decisiones normativas en el ámbito de la bioética <u>Blanca Bórquez Polloni.</u> Chile, Departamento de estudios, extensión y publicaciones, de la Biblioteca del Congreso Nacional de Chile</p>
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Hoy día es ya un hecho que la disciplina Bioética, en su concepción amplia, debe ofrecer respuesta a situaciones que son ante todo problemas político-jurídicos, y es que las nuevas posibilidades que abren las tecnologías de la vida exigen respuestas que otorguen a los individuos ciertos márgenes de certeza frente a sus actuaciones. Son los Parlamentos las instancias llamadas a adoptar tales decisiones, pues es en ellos donde se plantea la conveniencia de regular normativamente o no determinadas actividades y en qué términos, definiendo cuáles serán los valores a proteger, según el modelo de sociedad que se persiga. Para el mejor desempeño de sus tareas surgen las Bibliotecas Parlamentarias como instituciones que brindan a los legisladores asesoría parlamentaria especializada y contribuyen a acercar el mundo parlamentario a la ciudadanía. De este modo, en un marco de democracia participativa pueden estas instituciones llegar a constituirse en nuevos nodos entre los distintos actores vinculados a las temáticas bioéticas, generando espacios reales de reflexión pluralista acerca de los desafíos que plantean los cambios tecnológicos, científicos, sociales y/o ambientales. El trabajo que desde un tiempo lleva desarrollando en esta línea la Biblioteca del Congreso Nacional de Chile en colaboración con el Observatori de Bioètica i Dret y la Cátedra UNESCO de Bioética de la Universitat de Barcelona, es un ejemplo del modo como las Bibliotecas Parlamentarias pueden contribuir al desarrollo de procesos deliberativos en temáticas bioéticas, que favorezcan la adopción de decisiones políticas participativas y de mayor consenso, y basadas en la protección de los derechos humanos.

Abstract number: 268 ID: 716. Iberoamerican Network oral	<p>ASPECTOS ÉTICOS DE LA INVESTIGACIÓN SOBRE VIOLENCIA DE GÉNERO Y VIOLENCIA FAMILIAR <u>María Isabel Rivera, Agueda Muñoz del Carpio Toia, Patricia Sorokin, Pollyana Magallanes, Benjamín Herreros Ruiz-Valdepeñas</u> Chile, Universidad Santiago de Chile</p>
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La Asamblea General de las Naciones Unidas en el año 2006 reconoció que la violencia contra la mujer, es una de las violaciones a los derechos humanos más sistemáticas y extendidas en el mundo y que afecta a todas las sociedades sin importar edad, estatus socio económico, educación o procedencia geográfica. La violencia que afecta a la mujer dentro de su hogar, en su trabajo y sociedad, es un problema de salud pública y de derechos que atraviesa la vida cotidiana de las familias, las comunidades y la sociedad. Cuenta con permiso social y transcurre silenciosa y silenciadamente sobre todo en los países de Latinoamérica. Este permiso y complicidad social constituye un verdadero dilema ético. Por todo ello, es que los investigadores desarrollan diversos trabajos de investigación para conocer detalles que desencadena la violencia, o las consecuencias de la violencia, entre otros. La investigación social se ocupa del tema de la violencia de género y la violencia familiar desde hace mucho tiempo, pero no se evidencia protecciones específicas para evitar algún daño dentro de la investigación con víctimas de agresión, por ello es que proponemos algunas estrategias: Las investigaciones sobre violencia de género y violencia familiar contra la mujer deben ser ejecutadas con los mayores cuidados éticos, requiere asegurar la calidad ética de la investigación, de la calidad ética de los investigadores y monitoreo ético independiente. Algunas recomendaciones en el ámbito de la bioética: Respeto de los derechos humanos de las víctimas. Trato Digno (no revictimizar a la mujer agredida ni a sus hijos). Justicia: En el caso que se sospeche dentro de una investigación sobre violencia familiar que no solo la mujer es agredida, sino alguno de los hijos menores de edad, se deberá intervenir denunciando el acto de violencia contra el menor. Beneficencia: Procurar que las investigaciones sobre violencia lleven a algún beneficio directo de las participantes víctimas de violencia tales como: Proponer servicios de atención contra la violencia hacia la mujer tengan un enfoque integral por ciclo vital, es decir proteger a la niña, adolescente, joven adulta y adulta mayor y proponer programas de terapias de rehabilitación integral. Guardar la confidencialidad de los datos. Respetar la autonomía de las víctimas. Involucrar en la investigación a todos los actores sociales. En investigaciones con niños o niñas que sufren de violencia utilizar estrategias lúdicas no directas para la toma de datos, no revictimizar a los niños/niñas. Escuchar demandas y propuestas, es decir que las investigaciones de tipo social como las de violencia de género y violencia familiar, no sólo levanten datos estadísticos, sino que brinde herramientas para la labor de intervención. Por último recomendamos divulgar los resultados de la investigación entre la sociedad civil y entre los que toman las decisiones políticas.

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- Abstract number:** 269
ID: 719.
Iberoamerican Network
oral
- Bioética y propiedad intelectual. Debates actuales en torno a las patentes farmacéuticas: el caso de los Medicamentos de Alto Costo (MAC)**
- Maria Sol Terlizzi,
Argentina, FLACSO
- Bioética y propiedad intelectual. Debates actuales en torno a las patentes farmacéuticas: el caso de los Medicamentos de Alto Costo (MAC)**
-
- Abstract number:** 270
ID: 720.
Iberoamerican Network
oral
- LIBERDADE, DEMOCRACIA E AFETIVIDADE ÀS RELAÇÕES FAMILIARES: POR UM MODELO ABERTO DE FAMÍLIA**
- Nara Pereira Carvalho, Brunello Stancioli
Brazil,
- Instituição talvez tão antiga quanto a existência das pessoas, a família é constantemente anunciada como a base da sociedade (inclusive pelo artigo 226, caput da Constituição Brasileira e pelo Preâmbulo da Convenção Internacional sobre os Direitos da Criança, de 1989). É o local onde as pessoas tendem a desenvolver os mais profundos vínculos de convivência, que repercutirão, direta ou indiretamente, em todas as ações entre homens. Paradoxalmente, é comum falar-se na decadência da instituição. O desaparecimento da organização patriarcal; o aumento do número de mulheres que atuam no mercado de trabalho, com menos tempo para dedicarem-se exclusivamente à coesão interna do lar; a volatilidade dos relacionamentos amorosos, com consequente elevação dos casos de divórcio; a opção pela constituição familiar por formas diversas do casamento; o reconhecimento da união homoafetiva, são alguns dos fatores normalmente associados à crise da família, que estaria fadada à extinção. Não obstante, é necessário destacar o processo de profunda transformação que a família vem sofrendo.
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- Abstract number:** 271
ID: 721.
Iberoamerican Network
oral
- Transexualidad: Del derecho a la no- identidad al derecho a la salud**
- Mauro Pérez Bravo,
Mexico, Universidad Autónoma de Querétaro
- La transexualidad como tal, es un hecho relativamente contemporáneo. Hoy en día se cuenta con los avances científicos y tecnológicos que posibilitan que el cambio de sexo en un nivel físico muy concreto sea posible. El sexo como tal, además de constituirse como una característica "ya dada", ahora también se encuentra dentro del ámbito de la decisión, de la libertad, y por lo tanto, dentro de la ética, que de alguna u otra manera repercuten claramente en el ámbito concreto, y sobre todo, dentro del ámbito jurídico. Nos encontramos entonces ante el paradigma de la transexualidad como decisión para romper una constitución en la cual genéticamente fuimos constituidos. La transexualidad podría plantearse como una rebelión, como una construcción, como una alternativa, pero también como un quiebre histórico, una ruptura en nuestra forma de ver la historia del hombre, y sobre todo, la historia de la sexualidad. Un quiebre histórico, desde el planteamiento que aquí se propone, es una ruptura en la línea histórica de un evento que plantea múltiples y nuevas posibilidades. Para el caso que nos ocupa, dicho evento es la sexualidad; ésta ha dejado de ser ese rasgo del ser humano que lo organiza dentro de los esquemas de femenino o masculino. El ser humano como tal, ahora se encuentra dentro del ámbito de la decisión para proveer sobre su sexualidad, y más profundo aún, sobre su genitalidad. Es la transformación del cuerpo, es la revolución del cuerpo, es alejarse de esa dualidad en la que históricamente hemos encasillado al ser humano: hombre-mujer, masculino-femenino, varón-hembra; todo para situarse dentro del ámbito medio, o para no situarse en ningún ámbito. Para vivir en una especie de diáspora, de éter común en el que lo único que se pide es lo mínimo: respeto. En México estamos acostumbrados a regular jurídicamente todo. Creemos tristemente que las leyes son la solución a los problemas políticos y estructurales que padecemos. De aquí esa necesidad de querer "legalizar" y "sancionar" toda conducta o planteamientos social. La transexualidad, me parece, podría romper en alguna medida ese esquema dentro de la tradición jurídica mexicana: el derecho a una no-identidad, a no ser clasificado dentro de esos ordenamientos jurídicos que pretender controlar a la sociedad, a no ser ubicado dentro de unos límites, a no ser parte de una concepción tradicionalista de la sexualidad. La no-identidad significa que podemos acatar las obligaciones que todo ciudadano por ley debe cumplir, pero también exigir de la autoridad, en este caso del Estado, las condiciones mínimas para la sana convivencia, sin que por ello sea indispensable el control político y jurídico sobre la intimidad del ser humano. El derecho a la no-identidad en la transexualidad, pretende ser un reclamo a esas políticas públicas de control en el sector de la salud y de la sexualidad que deficientemente aplica el Estado y a las concepciones tradicionalistas y conservadoras que determinan la libertad del ser humano, incluso en un momento tan íntimo, personal y privado, como lo puede ser el acto sexual. Las decisiones que se puedan tomar en la transexualidad afectarán entonces no sólo las relaciones personales, sino que incluso pueden afectar y de hecho lo hacen, a las instituciones públicas de salud y sus estructuras políticas. El derecho a una no-identidad sienta las bases para exigir entonces las condiciones mínimas, específicas y sobre todo, eficientes en el sector público de la salud. No importa la identidad, importa el derecho a la salud.

La objeción de conciencia en medicina se puede definir como la decisión individual que toma un profesional de la medicina para dejar de realizar un acto médico científica y legalmente aprobado según el ars medica aduciendo la trasgresión a su libertad de pensamiento, conciencia o religión (en otras palabras, sus principios morales y creencias religiosas). Un médico puede ser que encuentre problemática una acción médica porque contraviene sus principios morales o religiosos (por ejemplo, tener que transfundir sangre a un paciente accidentado cuando su religión, la del médico, lo prohíbe). Thoreau ejerció un acto de desobediencia civil al ordenamiento de pagar sus impuestos defendiendo su postura moral pero no afectó a nadie más que a él mismo al ser encarcelado. El médico en cambio, aduciendo objeción de conciencia, trasgrede las necesidades y derechos del paciente que requiere del acto médico (por ejemplo, una transfusión por hemorragia aguda); así, el médico, al pretender defender su postura moral en contra de la exigencia que él siente le "impone" su ejercicio profesional de transfundir sangre (acción que médica, moral y legalmente es totalmente aceptada), lastima los intereses de un paciente que espera de él su mejor actuar en aras de su beneficio. Lo mismo resulta con mujeres que buscan a su médico especialista en salud reproductiva porque requieren controlar su fertilidad con objeto de no embarazarse o, al contrario, porque se quieren embarazar y no pueden; o bien, han sido víctimas de una violación y quieren protegerse para evitar quedar embarazadas o simplemente desean terminar un embarazo que no entró dentro de sus planes de vida (como legalmente ahora tienen derecho en el Distrito Federal). Y resulta que su médico aduce la figura de la objeción de conciencia para lavarse las manos (a la manera de Pilatos, no por higiene) y falsamente justificar su actitud omisa ante las necesidades de su paciente. Resulta entonces que la objeción de conciencia puede generar un conflicto de intereses con el otro; en el caso de los médicos, el otro es la contraparte de la relación primordial que da sentido al actuar médico: el paciente. Recientemente se ha aceptado la Declaración Internacional de los Derechos Humanos como válido con un rango incluso constitucional en nuestro país. Dentro de las libertades y derechos que protege dicha Declaración se encuentran el derecho a la salud (art. 25), y el derecho a la libertad de pensamiento, conciencia y religión (art. 18). Es importante hacer notar que la Declaración menciona el derecho de "libertad de pensamiento, conciencia y religión", y en ningún lado aparece un derecho a objetar; la objeción es un mecanismo de resistencia para tratar de ejercer un derecho, no constituye un derecho en sí, si bien existen muchos escritos donde se plantea la objeción como tal; incorrectamente, desde mi punto de vista (una situación similar sucede con el derecho a las condiciones necesarias para tener una vida adecuada incluyendo salud; en ningún lado se establece un "derecho a la salud" como tal). Las actividades médicas se dan siempre dentro del contexto de una relación que establece el paciente con su médico y debe pasar a través del análisis profundo de los objetivos de la medicina. Estos objetivos son: 1) preservar la salud; 2) curar, aliviar o acompañar/consolar al paciente; y 3) evitar las muertes prematuras e innecesarias. Las técnicas, procedimientos, maniobras y tratamientos que utiliza la medicina para lograr sus objetivos conforman la lex artis medica que deriva de la generación de conocimiento médico-científico, del valor humanístico que el gremio médico otorga a dicho conocimiento y de la aprobación que la sociedad le da a todo esto a través de la expedición de leyes, reglamentos y normas. Una paciente, entonces, espera recibir de su médico lo mejor de su conocimiento médico-científico, dentro de un contexto humanístico de respeto, empatía, confianza y bajo la luz aprobatoria de la ley (o, por lo menos, en ausencia de su prohibición). Cabe recordar que esta relación paradigmática, la del paciente con su médico, se ve influida de manera importante por un desbalance de poder en favor del médico quien, si no hace una reflexión profunda sobre dicha situación, puede, de manera consciente o inconsciente, abusar del mismo e indudablemente termina por afectar al paciente. Es por esto que la relación de los pacientes con sus médicos ha ido evolucionando del sistema hipocrático-paternalista clásico hacia un sistema participativo en la toma de decisiones por parte del paciente a través del respeto a su autonomía utilizando el conocimiento científico como herramienta insustituible de la práctica médica y tomando en cuenta la realidad pragmática de la economía de la sociedad y las leyes establecidas por ella misma para regularse. En otras palabras, los factores reales que determinan y le dan validez al cuidado médico son: a) Los deseos del paciente expresados voluntariamente (consentimiento informado); b) El conocimiento científico; c) La distribución justa/equitativa de recursos finitos; y d) Lo establecido por las leyes vigentes. Tomando esto en cuenta se entiende que los valores personales de un médico (o del resto del personal del sistema de salud) no establecen ni determinan el cuidado que dicho médico le debe a su paciente. Los valores particulares son relevantes exclusivamente para el individuo pero no determinan el cuidado médico que requieren los pacientes y que el médico tiene la responsabilidad de proveer. Un médico que antepone sus valores particulares por encima de las necesidades de un paciente no está cumpliendo cabalmente con el cuidado que debe proveer y no cumple tampoco con los objetivos de la medicina; comete entonces una transgresión ética. De lo anterior se desprende que la llamada objeción de conciencia es una práctica de resistencia que solo es válida cuando no implica dejar a los pacientes en estado de indefensión por no cumplir los objetivos que asumimos cuando nos convertimos en médicos. Caer en esto abunda al desbalance de poder de la relación paciente-médico.

Abstract number: 273 ID: 727. Iberoamerican Network oral	Cuestiones bioéticas pendientes en el ámbito sanitario: ¿objeción de conciencia o desobediencia civil? <u>Silvia Navarro Casado,</u> España, Observatori de Bioética i Dret
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En la actualidad debido al contexto económico, España no sólo presenta crisis en el ámbito económico, sino que en la misma también deben incluirse los derechos de los ciudadanos y el uso de los mismos. A raíz de la entrada en vigor el pasado 20 de abril de 2012 del Real Decreto 16/2012 sobre medidas urgentes para garantizar la sostenibilidad del Sistema Nacional de Salud y mejorar la calidad y seguridad de sus prestaciones, se limita la atención primaria a inmigrantes "sin papeles". Aunque posteriormente se han aceptado algunas excepciones -en concreto en los casos de enfermedades crónicas y asistencia en urgencias- la asistencia en los Centros de Atención Primaria queda prohibida. Algunos profesionales sanitarios han alzado la voz en contra de tales medidas, invocando la objeción de conciencia para que el colectivo afectado reciba la atención sanitaria necesaria, amparándose en que "la salud es un derecho universal". Pese a que esta última afirmación es indudablemente cierta, la figura ética y jurídica a la que se han acogido estos profesionales sanitarios no es la adecuada. El presente artículo pretende poner de manifiesto que lo que en la práctica ha sido presentado como objeción de conciencia es, en realidad, una manifestación de desobediencia civil.

Abstract number: 274 ID: 728 oral	Laicidad y objeción de conciencia <u>Rodolfo Vázquez Cardozo,</u> Mexico, ITAM
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Abstract number: 275 ID: 732. Iberoamerican Network oral	El diagnóstico genético pre-implantatorio (DGP) sobre embriones en la normativa y en la práctica española <u>Sergio Romeo- Malanda, Pilar Nicolás- Jiménez</u> España, Universidad del País Vasco
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La DGP o diagnóstico genético preimplantatorio (también denominado preimplantacional) es una técnica de laboratorio que permite estudiar el ADN de los óvulos (DGP-O) o de los embriones (DGP-E) para seleccionar los que cumplen determinadas características y/o descartar los que tienen determinadas alteraciones hereditarias. Las mayores controversias éticas y jurídicas se plantean cuando el objeto del DGP es el embrión, por lo que este trabajo se centrará en este caso. Esta técnica es especialmente útil cuando existen antecedentes de enfermedades genéticas o cromosómicas en la familia y se realiza dentro de programas de fecundación in vitro. Así, en el DGP-E, una vez realizada la fecundación in vitro y antes de transferir el embrión al útero, se estudia su material genético para detectar si hay alguna alteración genética concreta. Este estudio se realiza cuando los embriones se encuentran en la fase de 6-8 células, generalmente el tercer día de su desarrollo. Para estudiar su material genético se hace una biopsia de cada uno de ellos, se descartan los que tengan la enfermedad genética concreta que se esté determinando y, de este modo, se seleccionan sólo los embriones sanos que transferirán al útero. Aunque muchos países aún no permiten esta práctica, debido a los problemas bioéticos que genera la destrucción de embriones considerados no aptos para la reproducción (por ser portadores de alguna enfermedad de origen genético), esta técnica es ampliamente admitida y de práctica común en España. Y no ha suscitado excesivos problemas éticos cuando se trata de evitar el nacimiento de niños con enfermedades graves. Así, el artículo 12.1 de la Ley 14/2006, de 26 de mayo, sobre técnicas de reproducción humana asistida, autoriza el uso de las técnicas de selección embrionaria en los siguientes casos: a) La detección de enfermedades hereditarias graves, de aparición precoz y no susceptibles de tratamiento curativo posnatal con arreglo a los conocimientos científicos actuales, con objeto de llevar a cabo la selección embrionaria de los preembryones no afectos para su transferencia; y b) La detección de otras alteraciones que puedan comprometer la viabilidad del preembrión. Pero estos no son los únicos supuestos posibles. Muchos más controvertidos son los DGP-E dirigidos a la selección de embriones en otros dos supuestos: a) la selección de embriones con predisposición a ciertas enfermedades; y b) la selección de embriones sanos, pero que resulten compatibles con un familiar con vista a poder practicar un trasplante (de médula ósea). El artículo 12.2 de la Ley 14/2006, de 26 de mayo, sobre técnicas de reproducción humana asistida, deja la puerta abierta a la realización de DGP con estos fines: "La aplicación de técnicas de diagnóstico preimplantacional para cualquiera otra finalidad no comprendida en el apartado anterior, o cuando se pretendan practicar en combinación con la determinación de los antígenos de histocompatibilidad de los preembryones in vitro con fines terapéuticos para terceros, requerirá de la autorización expresa, caso a caso, de la autoridad sanitaria correspondiente, previo informe favorable de la Comisión Nacional de Reproducción Humana Asistida, que deberá evaluar las características clínicas, terapéuticas y sociales de cada caso." Pues bien, en la práctica española ya tenemos ejemplo de autorizaciones en ambos supuestos. Así, la Comisión Nacional de Reproducción Humana Asistida ha autorizado hasta el momento varios casos de selección de antígenos de histocompatibilidad. Esta misma Comisión ha autorizado también el recurso a esta técnica para evitar la mutación de predisposición al cáncer de colon hereditario no polipósico (HNPCC) o Síndrome de Lynch.

Abstract number: 277
ID: 733.
Iberoamerican Network
oral

Donación de óvulos humanos. Cuando los cimientos del consentimiento se tambalean
Pilar Nicolás Jiménez, Sergio Romeo- Malanda
España, Universidad del País Vasco

Planteamiento: El principio de respeto a la autonomía de los sujetos se ha constituido en el eje alrededor del que gira la construcción de un sistema de garantías en que se deben desenvolver las intervenciones biomédicas. La manifestación más evidente de esta premisa es la relevancia que el consentimiento del sujeto ha adquirido en las normas internacionales y nacionales, tanto de naturaleza ética como jurídica, que han regulado de manera profusa los requisitos que debe reunir. El consentimiento como acto de la voluntad, no es tal, porque no es válido, si no se presta libremente y en unas determinadas condiciones que se refieren al conocimiento y comprensión de su contenido. En el contexto biomédico la ley con frecuencia ha concretado unos parámetros en este sentido. Así, se describe el contenido de la información que el sujeto debe recibir para considerar suficiente el conocimiento sobre aquello a lo que se consiente en ámbitos particulares (investigación invasiva, ensayo clínico, donación de material biológico, cesión de datos...), y se toman algunas precauciones para evitar condicionamientos en la formación de la voluntad del sujeto que, en el caso de intervenciones que no reporten un beneficio directo debe construirse a partir de una motivación altruista para evitar abusos en situaciones de vulnerabilidad (gratuidad, asunción de que no se derivará un beneficio para la salud del sujeto...). Objetivo: en el trabajo que se presenta se pretendía estudiar si en las intervenciones para donación de óvulos pueden plantearse dudas sobre la validez del consentimiento o si es un contexto en el que existen riesgos para que se presenten vicios en la formación de la voluntad. Metodología: Con aquella finalidad se revisó la literatura sobre riesgos de la intervención y sobre regulación de donación de óvulos, y se analizaron documentos de información para donantes, sentencias, sistemas de remuneración o compensación de gastos y análisis de sistemas de llamada a la donación. Conclusión: la extracción de óvulos con fines de donación puede ser un ejemplo de intervención en la que el consentimiento de las donantes se constituye en un elemento trascendente en su regulación, a la vez que pueden plantearse dudas sobre la motivación altruista de las donantes y de su comprensión y asunción de los riesgos que representa. Que las actuaciones biomédicas se lleven a cabo únicamente cuando concurre la voluntad del sujeto es imprescindible desde la perspectiva ética y jurídica, pero no se debe sobredimensionar la eficacia de la firma del documento de consentimiento como garantía de respeto a los derechos del sujeto.

Abstract number: 277
ID: 735.
Iberoamerican Network
oral

Bioética, aborto y políticas públicas
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Mexico, Colegio de Bioética

El aborto ha sido una realidad en el orbe en todos los tiempos, y lo es en la actualidad. La Organización Mundial de la Salud estima en 85 millones los abortos para interrumpir embarazos no deseados por mujeres gestantes de todas las edades, estado civil, situación socio-económica y creencias. De esa cifra, veintidós millones de abortos se realizan en condiciones inseguras, esto es, en la clandestinidad, a manos de personas no calificadas y/o en sitios insalubres, con lo cual las gestantes exponen su salud y su vida. La afamada revista científica *The Lancet* publicó recientemente un estudio sobre la tendencia mundial del aborto de 1995 a 2008[1]. El mapa global del aborto revela que los países que restringen esa práctica generan los niveles más altos de procedimientos inseguros y, por tanto, de morbilidad y mortalidad maternas. La problemática humana y social del aborto reta a la reflexión bioética –multi- disciplinaria por definición– a ofrecer alternativas adecuadas para su prevención y solución. El análisis ha de considerar los avances en las ciencias de la salud y en las biotecnologías, lo mismo que los modelos de políticas públicas que abordan la cuestión del aborto inseguro de manera apropiada. Asimismo, se han de identificar los principales impedimentos para que las mejores prácticas sean adoptadas en el ámbito global. De ello trata esta presentación.

Abstract number: 278
ID: 736.
Iberoamerican Network
oral

¿A quién beneficia el vacío legal alrededor de la maternidad subrogada?
Ingrid Brena Sesma,
Mexico, IIJ, UNAM

La maternidad subrogada en cualquiera de sus variantes se ha convertido en una práctica común en numerosos países a pesar del vacío legal existente en muchos de ellos. Esta situación genera una serie de escenarios que pueden catalogarse de ilícitos en distintos grados. Se detectan casos de fraudes a la ley como cuando la solicitante suplanta a la parturienta que acaba de dar a luz a fin de registrar al recién nacido como hijo suyo o casos que según las leyes penales podrían configurar el delito venta o trata de personas. El vacío legal deja en estado de incertidumbre a todos los que participan en una maternidad subrogada: a los solicitantes que pudieran ser chantajeados por la portadora que se niegue a entregar al recién nacido o exigir un mayor pago por sus servicios; la portadora podría no

recibir su pago, si así se pactó, o no ser indemnizada y cubiertos sus gastos en el caso de imprevistos derivados de la gestación o parto. Los médicos tratantes deben saber cuándo actúan lícita o cuando ilícitamente y desde luego debe existir la certeza de que el menor o los menores que nacerán estarán protegidos jurídicamente aún cuando nacieran con problemas graves de salud. ¿A quien beneficia la falta de legislaciones adecuadas? ¿A las agencias especializadas que reciben jugosas ganancias o a los grupos conservadores que se niegan a reconocer opciones para que mujeres con problemas de fertilidad puedan ejercer sus derechos reproductivos? En todo caso los Estados deben asumir su responsabilidad frente al vacío legal y cumplir con sus deberes de proteger los derechos reproductivos de las personas con problemas de fertilidad y de quienes de algún modo participan en los procedimientos de maternidad subrogada, además de garantizar el buen desarrollo y control de las técnicas de reproducción asistida.

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- Abstract number: 279
ID: 737.
Iberoamerican Network
oral
- Impacto de una Metodología Activa de Enseñanza realizada por Monitores Adultos Mayores.**
Karin Lagos, Ximena Lee, Cristian Vergara, Elizabeth Astorga, Claudia Sommariva
Chile, Universidad de Chile

INTRODUCCIÓN: La Encuesta Casen 2011 develó una creciente población de adultos mayores (AM) en el país, que nos enfrenta a desafíos, pues se requiere otorgar un sentido a esta etapa de la vida, a partir de lo que la sociedad y el entorno valoran en relación a la vejez y la autoperccepción. **OBJETIVOS:** 1) Implementar estrategia de innovación pedagógica que evidencie la participación del AM en educación de salud oral (SO). 2) Mejorar aprendizajes, traducido en la calidad de vida de ellos en sus comunidades. 3) Fomentar valores en la comunidad académica. **MATERIAL Y MÉTODO:** A 18 miembros de Casa del AM, Comuna Recoleta, se invitó al curso: Monitor en Salud Oral para AM, auspiciado por Universidad de Chile. **Características del aprendizaje:** Se distribuyó en 12 semanas, abordando aspectos: salud y enfermedad, promoción y prevención, con pausa saludable, como yoga y poesía. **Propósitos:** Manejar técnicas básicas de autocuidado (AC) orales y protésicas; Fomentar la importancia del AC pronóstico y plan de tratamiento; Evaluar acciones de AC. Para indagar las percepciones del curso, se aplicó metodología cualitativa. La recolección de datos fue empírica obtenida de entrevista semiestructurada. Se identificaron unidades de registro para categorizarlas (CAT): Lo más destacado del curso; Dificultades presentadas; Repercusiones en la calidad de vida. **RESULTADOS:** CAT1: "preocupación por la tercera edad" "enseñanza de aspectos odontológicos que sirven para educar a nuestros hijos y nietos" "claridad para explicar en las clases, disposición para responder y aclarar dudas".CAT2: "pronunciación de algunas palabras de odontología".CAT3: "disfrutar de la compañía de los demás y poder ser útil a la sociedad de algún modo" "estoy estudiando en la Universidad de Chile" **CONCLUSIONES:** La Implementación de esta estrategia pedagógica evidenció la participación del AM, traducido en mejora de la calidad de vida de ellos y sus comunidades. Fomentando valores como participación, responsabilidad social.

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- Abstract number: 280
ID: 738.
Iberoamerican Network
oral
- Donar ¿un problema bioética?**
Ángel Alonso,
Mexico, UNAM

El filósofo australiano, Peter Singer escribió un texto que se titula Salvar una vida. Cómo terminar con la pobreza, que hace referencia a los motivos que se tienen para que las personas efectúen donaciones y el deber que el ser humano tiene para ayudar a los más necesitados. En este sentido, el presente texto tiene como finalidad preguntarse acerca del problema bioético que supone que un sujeto o una institución otorguen algún tipo de donación, bajo el supuesto de ¿cuáles son los motivos éticos que a manera de imperativo categórico subyacen en el donativo? ¿Por qué ante la abismal brecha entre ricos y pobres el donativo se convierte en un paliativo de equidad social? Y ¿cuáles son las desgracias o hechos que obligan a compartir lo poco o mucho que se tiene? Para lograr esto, el texto se dividirá en dos partes, en primer lugar el presentar algunas objeciones que Singer tendría hacia la "Cruzada Nacional contra el Hambre" que se ha impuesto como meta el Gobierno Federal de México en el presente sexenio y, en segundo lugar, lo acontecido hace algunos meses en el territorio nacional con la ayuda que miles de personas brindaron a los damnificados por el huracán Ingrid y la tormenta tropical Manuel, en septiembre de 2013, en especial brindando solidaridad al pueblo de Guerrero

Abstract number: 281	Solidaridad y el derecho a la atención de la salud
ID: 739.	<u>Ricardo Paéz Moreno,</u>
Iberoamerican Network	Mexico, UNAM

oral

La atención de la salud es un derecho humano consignado en la legislación de los países democráticos, cuya concreción en la práctica tiene varias limitaciones, sobre todo en países de mediano o bajo ingreso. No obstante México pertenece a la Organización para la Cooperación y el Desarrollo Económicos, los distintos indicadores revelan que tiene uno de los niveles más bajos en la atención de la salud. La bioética ha abordado este problema principalmente desde otros principios bioéticos distintos a la justicia, más cercanos a la vida diaria de las personas, tales como el de solidaridad. Éste se ha malentendido como un sentimiento de benevolencia o empatía, o una actitud altruista hacia otros. El Nuffield Council of Bioethics ha publicado el estudio "Solidarity. Reflections on an emerging concept in bioethics" que ofrece algunas pautas operativas que pueden ser de utilidad ante las importantes carencias a la atención de la salud sufridas en México. El presente trabajo presenta un enfoque teórico y operativo del principio de solidaridad, para una mejor comprensión del mismo, que se traduzca en prácticas grupales, a favor del derecho a la atención de la salud.

Abstract number: 282	Despessoalizando a população da identidade pela falta de reconhecimento
ID: 740.	<u>Brunello Stancioli, Nara Pereira Carvalho, Daniel Mendes Ribeiro, Carolina María Nasser Cury</u>
Iberoamerican Network	Brazil,

oral

A identidade é comumente destacada como um dos elementos constitutivos da pessoa (TAYLOR, 1989; STANCIOLI, 2010). Com base em MEAD (1913) e TAYLOR (1989), afirma-se que ela não se encontra no indivíduo, mas no entorno dele, na medida em que só é possível tê-la havendo senso de pertença comunitária. A identidade pressupõe o reconhecimento, pelo próprio sujeito e pela comunidade, de um determinado status, revelado por uma série de sinais distintivos da pessoa: sua forma de falar, de agir e sua apresentação no cotidiano (GOFFMAN, 1959). Toda essa plethora de signos acaba por construir uma heurística pela qual é possível se identificar (sou único) e ser identificado (e reconhecido) na esfera pública (sou "aquele"). Entretanto, voltando-se para a população em situação de rua no Brasil, verifica-se um processo de "des-identificação", o que acaba por conduzir à própria despessoalização desses indivíduos. Através da repetição de discursos hegemônicos sobre a precariedade social e a dissimulação de questões sociais graves, naturaliza-se a invisibilidade dos em situação de rua, ante uma postura cômoda de ignorá-los. E quando esses indivíduos teimam em se fazerem visíveis, tendo sua presença considerada incômoda ou ameaçadora, o posicionamento frequente é por negarem-se-lhes direitos e a própria identidade pessoal. Frequentemente, estar na rua implica não ser reconhecido como um interlocutor, alguém igual, a ser respeitado e ouvido; um ser autônomo, capaz de elaborar projetos de vida boa. A questão agrava-se quando a falta de reconhecimento é usada para legitimar o tratamento desses indivíduos como objeto. Citem-se a retirada compulsória de pertences, o uso de violência e os desaparecimentos dos em situação de rua em Belo Horizonte, Brasil. Ao não possuir convívio familiar, domicílio, convivência com pares, carteira de identidade, certidões, CPF, mínimos pertences, verifica-se a precariedade no reconhecimento desses indivíduos enquanto pessoas. Tal fenômeno aproximar-se-ia do instituto da "morte civil", se não fossem os casos que redundam em morte física. A eliminação identitária não é apenas simbólica, formal, num alusão à morte civil. É física também.

Abstract number: 283	El debate sobre los daños en investigación en ciencias sociales
ID: 742	<u>María Florencia Santi,</u>
Iberoamerican Network	Argentina, CONICET/UBA/FLACSO

oral

El concepto de daño ha sido abordado en diversas áreas de la filosofía práctica. A través de su análisis se aspira a comprender bajo qué circunstancias un agente puede resultar dañado, y cómo puede ser reflejado esto en una determinada normativa. No obstante, definir el concepto de daño, estipular su alcance es una tarea compleja. Un concepto demasiado amplio avalaría la intervención del estado y la prohibición de numerosas actividades, entre ellas cierta clase de investigación, y un concepto demasiado laxo dejaría sin protección a muchas personas. En el ámbito de la ética de la investigación biomédica el problema de los daños ha sido debatido en numerosas publicaciones académicas y guías éticas. En cambio, en el contexto de la investigación en ciencias sociales esta problemática ha recibido menor atención. Por una parte, existe cierta reticencia a reconocer la existencia de daños en este tipo de investigaciones. Por otra parte, es frecuente recurrir al argumento de la "excepcionalidad de las ciencias sociales" según el cual los daños por participar en una investigación social son mínimos. El propósito de esta ponencia es argumentar a favor de la existencia de daño en investigación social mostrando que es posible defender un concepto amplio de daño que contemple diversos aspectos de la vida de las personas que pudieran verse afectados como consecuencia de su participación

en una investigación. Para ello, (1) examinaré críticamente distintos argumentos a favor y en contra del reconocimiento de la existencia de daño en investigación social; (2) analizaré críticamente el concepto de daño ofrecido por Joel Feinberg según el cual alguien es dañado cuando sus intereses han sido frustrados, invadidos o dejados de lado; (3) finalmente, adaptaré dicho concepto al ámbito de la investigación social de manera que permita ampliar el espectro de daños a ser considerados en estas investigaciones.

Abstract number: 284 **Vulnerabilidad y violencia hacia los animales**
ID: 744 Beatriz Vanda Cantón,
oral Mexico, UNAM

Abstract number: 285 **El uso de animales en experimentación**
ID: 745 Fabiola Villela Cortés,
oral Mexico, UNAM

Poster Presentation

Poster Presentation

Abstract number: 1 Organization and functioning of the National Bioethics Council of Colombia since a global vision.
ID: 16
Poster Víctor Márceles, Dra. Teresa Ayala; Dr. José Vicente Villalobos
Colombia, Universidad de la Costa, CUC; Universidad Rafael Belloso Chacín, URBE

This work is product of the thesis conducive to the degree of Doctor in Science, mention: Management, named "Organization and Functioning of the National Council of Bioethics of Colombia, since a global vision", performed by MSc. Víctor Márceles Guerrero at the Rafael Belloso Chacín University, Maracaibo-Venezuela.

The overall purpose of the Research was to approach the legal, epistemological, social, environmental and administrative fundamentals that underlie the organization and functioning of the National Bioethics Council of Colombia, NBC, since a global vision.

Its specific purposes were:

To study the international provisions on the establishment, organization and fuctioning of the National Bioethics Councils (Committees, Commissions).
To check the Latin American experiencies on the establishment and operation of National Bioethics Councils.
To explore the state of the art of bioethical institutions in Colombia.
To conceptualize the structure, systems and internal mechanisms of the management and operation of the NBC, from the global vision of Bioethics.
To reflect from a legal-ethical prospective on the importance of NBC of Colombia in building a science for life.

The Research is ontologically framed in the post-positivist paradigm. It fits well with the new rationality of knowledge; according to Vilar (1997) "it is complex in relation to all the complexities, internal (human) and external (society, nature)" (p. 17).

Research rigor is provided by methodological and key informants triangulation. Methodologically, for being framed in the critical postpositivism, the Research uses qualitative methods and techniques in the inquiri process, provided by the analog-iconic hermeneutic approach.
Results show among others, the need to organize the NBC of Colombia so that meet the needs of Colombian society in the era of post-conflict.

Abstract number: 2 Facing Facebook: Ethical challenges for medical professionals
ID: 82
Poster Aamir Jafarey, Roger Gill
Pakistan, Centre of Biomedical Ethics and Culture, SIUT

We are living in the age of a digital revolution where social media applications like Facebook have assumed an omnipresent role. With wider application, Facebook and similar third party social networking platforms have also created ethical concerns that are now being realized.

The objectives of this study were to assess the various trends of Facebook usage among medical students and health professionals in Pakistan with a particular focus on their knowledge and practice of privacy and content control. This study was conducted at five major healthcare institutions in three cities across Pakistan and consisted of an online survey using www.surveymonkey.com, and a quantitative arm with in depth interviews with key informants.

At the time of submission of this abstract, 735 people had responded to the survey, 55% respondents being females and 69% under 30 years of age. Eighty nine percent of respondents were using one form of social media or the other, with 98% of them were on Facebook.

The study notes a large presence of health professionals from all levels with a Facebook account. About a fifth of the respondents had never changed privacy settings, even though there was a high

level of discomfort regarding the privacy of contents that they were placing on Facebook. However this did not stop a majority of the respondents from maintaining an almost constant activity on their Facebook walls. Facebook presence was also threatening to blur traditional professional boundaries with "friending" going on across professional levels. Patient privacy and confidentiality issues were also noted to be compromised.

With the common use of facebook, institutions should have guidelines governing social media use by their employees and students so that the full potential of these modalities can be harnessed without compromising professionalism.

Abstract number: 3 Advance Research Directives in Dementia Research: What does it solve?

ID: 92 Karin Jongsma Jongsma,

Poster Netherlands, Erasmus Medical Centre

Dementia is still incurable and highly prevalent. In order to discover an effective treatment for dementia it is necessary to include dementia patients in clinical research trials. Free and informed consent is an important ethical and legal prerequisite for research participation. Patients with dementia face an increased risk to become incompetent to provide informed consent, and are characterized by the fact that, at an earlier stage of their life, they were able to give their consent to participation in research. Therefore, an interesting option is obtaining their consent in a phase when they are still competent to decide on their involvement by the use of an advance research directive (ARD). In an ARD they could describe the circumstances under which they are willing to participate in research, and to which research goals they would be willing to contribute. This would allow these patients to control authorization to research participation when they have lost the capacities to provide informed consent. It remains, however, unclear whether these ARDs form a defensible basis for participation of incompetent subjects in research and whether these can substitute the informed consent requirement. In this study we explore the possibilities of the use and pitfalls of ARDs for research in dementia. Are ARDs an appropriate means to allow dementia patient exercise greater control beyond their own incompetence?

Abstract number: 4 Medical Tourism and Bioethics

ID: 116 Pablo Villarreal,

Poster Mexico, Universidad de Monterrey

In the last few years, medical tourism has become a billion-dollar industry in several countries including Russia, India, and Mexico. The industry has grown in these countries and others, because they offer medical or surgical procedures that are unavailable in most of the developed world, often for economic, regulatory, or technological reasons. Medical tourism is not a new way of providing healthcare. Some of the health services offered include reproductive assistance techniques, organ transplantation, cosmetic and ocular surgeries, and stem cell based therapies. The bioethical issues involved in medical tourism are many including the just distribution of medical resources, informed consent of medical tourists, confidentiality of medical records, and oversight of medical procedures. This paper reviews the main bioethical topics that may be found in this growing field of healthcare delivery.

Abstract number: 5 Concept of What Constitutes a Difficult Ethical Problems in Military Medicine: Malingering

ID: 133 Fatih Namal, Eray Serdar Yurdakul

Poster Turkey, Gülhane Military Medical Academy Dept. of Medical Ethics

Diseases and disorders adversely affect the comfort of people's life, and sometimes they seen as life threatening situations. Perceptions about health and illness are affected by the individual and the environment related numerous factors. That the individual is healthy or sick may vary depending on the "internal point of view" including the person's subjective perceptions or "external point of view" including physician's knowledge and judgments. Disease and health, between the two extremes representing, there is a very large gray area which can described as "expressing illness". Due to this gray area in the military profession, which requires high physical and psychological activity, and in its extraordinary cases it is quite difficult to make a decision that the individual is healthy or sick.

In military medicine and also in general medicine, there is a kind of behavior which expressing, in fact, an illness is called as "malingering". Malingering is fabricating or exaggerating the symptoms of especially physical disorders and sometimes mental disorders for a kind of "secondary gain" motives. Malingering is not the same as somatization or factitious disorders. Overall this situation is less common in medical practice, but military physicians frequently encounter this condition.

Throughout the history of modern military medicine, this topic has been discussed as one of the main issues. Military physicians, especially in war conditions, are known to be very sensitive to malingering. In our study, we briefly summarized the issue of 'malingering' in a general perspective.

Abstract number: 7

ID: 145

Poster

Captain America: Technopressive Avenger? The problem of the superhero for the bioconservative position on enhancement

David Lawrence

United Kingdom, Institute for Science Ethics and Innovation, University of Manchester

In this day and age, it is nearly impossible to avoid the popular culture trope of the superhero. They take record amounts at the box office, they have television series, and their images are on any item capable of sporting a decal. As a society, we foster this growing popularity by voracious consumption and promotion to our children. Implicitly, we are accepting of the superhero, and the many positions they may take- frequently as an aspirational figure, a role-model, a moral ideologue. Yet, society and academia is perhaps less willing to accept the real-world human enhancement technologies which have the potential to let us achieve capacities beyond the norm, be this due to the "wisdom of repugnance" or more reasoned literature. In this paper I examine the apparent clash of behaviours and moral stances around the prospect of increasing our capacities, in order to establish whether there is a possible failure of a wider rationale within the bioconservative position on human enhancement.

In doing so, I establish that superheroes can be considered representative of various classes of enhancements- biochemical, genetic, cyber-technological, cognitive, and moral- and furthermore can embody many of the hopes and fears associated with the technology. I then use these models to study the bioconservative position, noting the growing popularity of heroes, in terms of potential inconsistency or hypocrisy of arguments particularly around the ideas of overclass, of the trivialisation of human identity, of contempt for the flesh, and of playing God.

Abstract number: 8

ID: 151

Poster

Determination the success of Informed Consent Before Surgery that Patients Undergoing Surgical Operation? An Example Of a Training Hospital

Engin KURT, Associate Professor Muharrem UÇAR; Professor Adnan ATAÇ

Turkey, Gulhane Military Medical Faculty Department of Medical Ethics and Medical History

Objectives: This study has been conducted in the clinics of surgery branches of a training hospital where the questionnaire was accepted to be participated in order to reveal the sufficiency of the disclosure to the patients by physicians and propose the solutions on the issues, if any, need to be developed.

Materials and Methods: Our study was conducted among 400 patients who underwent surgery in surgical branches. In the study, a questionnaire form consisting of two main sections and 23 items was used. Then the relationship between the items related with informed consent response of patients and patients' characteristics were discussed.

Results: In our study the 73.5% of the patients stated that the information on surgical operation was given by the physician and the 22.8% of the patients stated that no information was given regarding surgical operation; 78% of the patients stated that they already knew their diagnosis and 18.3% of them did not know their diagnosis. On the other hand 25.8 % of the patients were aware of the name of the operation, 52.3% did not know; only 12.6 % of patients were informed during surgery and 13.8% of patients were informed in post-operation period about the risky situations that may occur.

Conclusion: The scientific studies indicate that the disclosure is considered as prerequisite by patients in order to participate in the decisions that will be made for them. In clinical practise, the ethical or even legal problems occur after surgery since the patients were /could not sufficiently informed about the surgical procedure by the physicians. Therefore, it is concluded that the physicians should be careful in the stage of informing patients and should assure fully understanding of the patients in order to avoid the occurrence of ethical and legal issues.

Abstract number: 9	Neuroethics and neurosciences in (for?) developing countries
ID: 162	<u>Jorge Alberto Álvarez-Díaz.</u>
Poster	Mexico, Universidad Autónoma Metropolitana Unidad Xochimilco

It is a fact that neuroimages are something new among new technologies: they neither are nor pictures of the brain nor pictures of the mind; maybe, they could be called as "pictures of brain working", something new, and something different. However, there have been born so many "neurofields", such as neurotheology, neuromarketing, geopolitics, neuroethics, etc., and in many cases the most important support are neuroimages. It is unclear the epistemological status of neuroimaging and it should be the first issue to be clarified. Furthermore, there are some critics to do regarding these new fields: which are the social uses of neurosciences? The price of all the devices needed to have a functional magnetic resonance image is too big to derive those economic resources for neuroscientific research in developing countries. Is there an ideological use of the neurosciences to reinforce the neoliberalism? The world is turning to the right in politics, so there are many economic interest of the richest people in the world, like those ones producing and selling new neuroscientific technology. Is it possible to develop the traditional "three cultures" (natural sciences, social sciences and humanities)? Many of the "advances" have been interpreted in the same sense: neuroscience is going to give us all answers in social sciences, like in politics (by the "neuropolitics"), or in humanities (for example, in "neuroethics", "neuroepistemology", "neurophilosophy", etc.). These are some examples of issues to be analyzed in all the world, but with special emphasis in developing countries, because they need to have technology to propose specific answers to their own problems (like poverty, equity, health care, etc.), but they need also to generate their own scientific knowledge.

Abstract number: 10	Development of an instrument for early detection of psychopath behavior, based on Hare's test.
ID: 166	<u>Luz Pichardo, Fernanda Imán Carrillo</u>
Poster	Mexico, Universidad Panamericana

At present there are 900 000 psychotics in Mexico. According to the DSM-IV the psychopath is classified into antisocial personality cognitive distortion, manifestly in dangerous, strongly aggressive behaviors by the patient. It is believed that the psychopath cannot be diagnosed until age 18th. There had been almost no research that could help determine the factors that develop psychopathic personality from childhood and adolescence. But lately there have been observed in children manifestations of a psychopathic personality, which, though not decisive, may be suitable for preventing and try to reduce the influence of factors that trigger psychopath conduct and advance early treatment.

Methodology: There were applied individual interviews to experts and another to children. The data were analyzed with situational analysis and used to develop an instrument, to test children tendencies that may help to detect psychopath manifestations. It was used purposeful sampling, in five schools for children between 5 and 11 years.

Results: This instrument has shown that more studies are necessary to deepen the reactions of children and adolescents not adapted to a normal social role, not only caused by dysfunctional families, but with serious problems of the parents or other members of their surroundings, especially with examples of crime and evil attitudes. It would be important to focus efforts on clarifying what might be the causes and evolution of psychopathic personality in those stages in maladjusted children. The data confirm the thesis of Dr. Robert Hare that disorders begin to occur at a very early age because of diverse factors, mainly biological, social and emotional. The influence of the behavior of the parents or protectors, of their friends and environment, are often a determining factor in triggering the biological factor psychopathic personality.

Abstract number: 11	Construction of citizenship in health care space: between frustration and indifference
ID: 169	<u>Maria Isabel de Fátima Luengas Aguirre, Jorge Alberto Álvarez Díaz, Octavio Márquez Mendoza</u>
Poster	Mexico, Universidad Autónoma Metropolitana Unidad Xochimilco

Participatory citizenship in a democratic society is a mean to regulate power and promote human rights. Health-care spaces have specific characteristics (authoritarian, asymmetric, discriminatory) which are not the best scenarios to generate citizenship. However, ailment is an experience that allows rethinking vital goals, vis a vis gaps present in health-care institutions. If the patient or his/her relatives transcend the individual experience and transform it into a social one thought civic organization, they create citizenship. Health-care spaces should become deliberative instances where citizenship can be expressed.

Abstract number: 12	Normalcy and normativity
ID: 182	Richard Joyce
Poster	New Zealand, Victoria University of Wellington

The concept of a “normal human” plays many roles in both everyday thinking and theoretical debate. In the debate over altering individuals’ traits via biotechnological means, for example, moral intuitions often divide over the permissibility of “therapeutic” procedures versus the permissibility of “enhancement.” The former aim to bring impaired individuals up to the normal level; the latter aims to improve humans beyond that level. Moral attitudes tend to be much more comfortable with the former than the latter. The concept also plays a central role in evolutionary psychology. When evolutionary psychologists make claims about human nature (by which they mean adaptations that humans have as a result of natural selection), they eschew universality and instead speak of the traits of “normal” humans. (In the same way, a one-legged man is still a human, but humans normally have two legs.)

But is the entrenched concept of “normalcy” lying behind these intuitions a scientifically sound notion? A purely statistical understanding of normalcy is available, of course, but it is implausible that this motivates the intuitions involved. After all, even if most humans lost a leg to some bizarre disease, the notion that humans are “supposed to” have two legs would remain powerful. Moreover, a statistical understanding would lead to relativism: what is normal now was not normal a hundred years ago (in which case, today’s enhancement may be tomorrow’s therapy). This paper examines what sense can be made of a non-statistical notion of normalcy. It also investigates what relation the idea bears to normative standards, such as what a human is “supposed” be like. Should the idea of normalcy provide an ethical constraint on decision making.

Abstract number: 13	The human genome: an open door to our intimacy?
ID: 211	<u>Ana Guadalupe Olvera Arellano</u>
Poster	Mexico, Perspectiva Jurídica, A.C.

Devised as one of the most ambitious projects of the twentieth century, the Human Genome Project is just less than a science marvel: having the complete human genetic map involves advantages such as genic therapy, pharmacological therapy and preventive medicine, allowing to increase evidently the patient’s quality of life, and if applicable, even reducing mortality of certain population groups.

In spite of these benefits, genetic discrimination could happen, too. People forgot that all the information contained in a genetic map lead to identify with certainty any person. Even more, all that is described in genes happens to be so sensitive data, which could depict from our race to predisposition for developing a disease.

It’s necessary to establish certain limits, covering from ethical to legal issues, achieving this way adequate protection for this information. The dissemination and easy access that people have make us vulnerable in front of unethical behaviour. Implementation and type approval of legal criteria will shed light on management of sensitive data, which indeed will be revealed.

Is a wakeup call in safeguarding not only our intimacy, but the human species itself.

Abstract number: 14	Attitudes of geneticists and ophthalmologists regarding genetic counseling for retinoblastoma in Mexico
ID: 221	
Poster	Paula Morelos-Herrera, Dr. María de la Luz Casas, Dr. Juan Carlos Juárez-Echenique Mexico, Universidad Panamericana

Retinoblastoma is the most common intraocular tumor in childhood. In developed countries the survival rate is high, but worldwide it progresses to metastases and death in more than 50% of children. Retinoblastoma is considered a “genetic” cancer, as up to 50% of affected patients have the RB1 mutation, which makes genetic counseling key in the education of patients and their relatives regarding the risks of developing this pathology, the possibility of inheriting this disease in the future, and reproductive options. Currently there is no data about the attitudes of Mexican ophthalmologists and geneticists regarding genetic counseling in retinoblastoma patients. There are no Mexican guidelines on genetic counseling. Another interesting fact is that in Mexico genetic counseling is performed through the attending physician, whereas in USA and Europe it is performed through genetic counselors.

Objective: To assess the ethical aspects of the attitudes of ophthalmologists and geneticists regarding genetic counseling for retinoblastoma, such as neutrality during genetic counseling and respect to the autonomy of the patients and their relatives in decision making. METHODS: A prospective study

using an electronic, self-administered, multiple choice survey based on clinical cases applied to ophthalmologists and geneticists through the Mexican Society of Ophthalmology and the Mexican Society of Genetics.

Abstract number: 15

ID: 223

Poster

Community Advisory Boards: the need to expand their involvement as advisors to true partners in the design of research studies.

Alwyn Mwinga, Prof Keymanthri Moodley
Zambia, ZAMBART Project

Background: Respect for persons is one of the three principles defining ethical research. The concept of Community Based Participatory Research extends the scope of respect to include the community in which the research is taking place. The formation of Community Advisory Boards (CAB) is one of the ways through which participation of communities can be assured and this has become a pre-requisite for approval of clinical trials. In order to ensure full and equal partnership by the community in the research endeavour their participation should include their involvement in the selection of the research question and design of the study.

Approach: A retrospective survey was carried out of the processes and procedures utilized in the formation of CABs in Lusaka, Zambia. Informal individual interviews were carried out with a member of the research team and/or a member of the CAB for eight studies. Content analyses of the responses identified factors associated with the selection of the members, development of the terms of reference, methods used for community engagement, and the stage of research design and development at which the CAB was involved.

Outcomes: A total of 14 interviews were conducted with eight members of the research team and six with a member of the CAB. The CAB was mainly involved in the review of research instruments, community entry, communication between the community and the research team. No CAB was directly involved in the design stage of the research.

Recommendations: The CABs appear to be involved primarily in the procedural elements of the research with little evidence of their involvement in the substantive aspects of study design. In order to ensure true and equal partnerships research teams should ensure the involvement of the community/CAB in the early stages of the research design.

Abstract number: 16

ID: 229

Poster

Individual interests and research with no prospect benefit involving incompetent subjects

Jan Piasecki, Marcin Waligora
Poland, Jagiellonian University

Incompetent participants of non-beneficial research usually do not have any interest to participate in such research and therefore, when they do participate and since research is associated with non-zero risk, it can be said that their interests and well-being is outweighed by interests of the future patients and the development of science. It does not necessarily mean that incompetent participants involved in non-beneficial research are being exploited, but it seems to be quite obvious that their interests do not outweigh interests of the future patients and science. Nevertheless a lot of international guidelines, regulations and ethical recommendations include provisions, which in general give precedence to the individual interests over interests of society and science. Here the meaning of such provisions is analyzed. For the purposes of the argument it is assumed that non-beneficial research with incompetent subjects is morally justified and needed – it is also approved in regulations quoted later in the paper. This paper proposes that the provision of precedence of the individual over society should not refer to the best interests standard, but only to the secure participant standard. Referring to the best interest standard and putting stress on exceptionalness prevailing of individual interest over societal interests is inconsistent with acceptability of non-beneficial research and it also seems to be hypocritical and disguising the very nature of ethical balancing of individual and societal interests.

Abstract number: 17

ID: 238

Poster

Flexibilization of the norms for research: the case of Brazil

Gerson Zafalon Martins, Roberto Luiz d'Avila
Brazil, The Brazilian Federal Council of Medicine

Brazil relies on the CEP-Conep Nacional System for evaluating the research conducted in the country, laying down detailed rules for studies involving human subjects. Recently it was considered pertinent to conduct public consultation to enhance the instrument, which was attended by hundreds of ethics committees in the country. In December 2012 the new version of the document was published by the Ministry of Health website, but it was actually regulated six months later, being referred to as

CNS Resolution 466/12. It turns out that among the online version available in December and the one signed by the Minister in July, too much in the text has been changed. One of these changes is that which exempts the foreign research of submission to the CEP-Conep System if the study is conducted in cooperation with or the involvement of the "Brazilian government". Since any research in Brazil needs some support from Brazilian institutions, even if only to recruit participants, all studies inevitably involve the participation of the government. The fact that the legal framework of the country does not have the legal term "Brazilian government" contributes to an even bigger mess, giving the chance for direct negotiations to take place between researchers and any level of government for conducting researches without any ethical or technical evaluation, including the government of a local administrative area or a teaching hospital. Furthermore, the change also allows shipping biological material abroad merely upon the agreement of the participant. Such situation is not a single case. Ethicists from other South American countries and the European community report that also have been under pressure to loosen their standards of evaluation in clinical studies. This suggests the growth of the pernicious influence of the industry, a concern, especially considering the flexibilization in the Declaration of Helsinki.

Abstract number: 18

ID: 257

Poster

Ethics in scientific practice of a biobank

Pollyana Gontijo, Karine Lima; Leandro Gontijo, Ana Paula Drumond; Alberto Wainstein
Brazil, Alberto Cavalcanti Hospital/FHEMIG

The article proposes to analyze, from the critical perspective of bioethics applied, the operating routine of a biobank focused on the collection, cataloging, storage and availability of tissue samples and tumor cells for cancer research. It is considered that knowledge of the molecular pathology of tumors can provide technological advances that contribute to the healing of disease. Thus, based on the reliable experience of a biobank, this article aims to provide a subsidy for the construction of other similar institutions that promote the provision of biological resources to research ensuring, however, the rights and moral values of the research subjects. The protection and welfare of research subjects must be a priority in biobanks, established by actions based mainly in Resolution of the Ministry of Health of Brazil.

Abstract number: 19

ID: 259

Poster

Bioethics in Mexican Law

Alejandro Pacheco Gomez, Ulises Pacheco Gomez
Mexico, Comision de Bioetica del Estado de Hidalgo

Scientific progress has been vertiginous in the last years, with tremendous benefits for humanity. However, indiscriminate use of biotechnology could materially affect human rights such as dignity, life, integrity and health, basically. Because of these reasons it's extremely important that laws with bioethical principles are issued to regulate their use.

Recognising bioethics in law, makes easy to appreciate its dilemmas, and allows elaborating reference theories, rules principles and criteria. In Mexican legal order, laws based in bioethical principles have been enacted, which sheds light on their valuation in the general theory of law: within sanitary law it's emphasised medical attention and research on human subjects; within environmental law, biodiversity protection has been positivized. Additionally, Mexican State has promoted the birth of public organizations whose purpose is the study and dissemination of bioethics.

Otherwise, in order to make a multidisciplinary analysis of the dilemmas in medical practice, the existence of hospital bioethics committees is mandatory; in cases of research on human subjects, research ethics committee must exist to ensure the protection of those involved in it. Bioethics is not stranger to law, since both disciplines secure human rights.

Abstract number: 20

ID: 263

Poster

Neglected bioethics on health research of NDNP

Fernando Andrade-Narvaez, Ma. Rosario Garcia-Miss
Mexico, Universidad Autonoma de Yucatan

The WHO/TDR Program was designed in 1975 "rather as a contribution to the promotion of human welfare in the widest sense, in the context of a new international order in economic and social affairs". Nevertheless neglected diseases of neglected populations (NDNP) are largely ancient infectious diseases that have burdened humanity for centuries. NDNP affect the poorest population; most of them do not lead to epidemiologic emergencies; they are not perceived as major public health; and consequently attract little attention from the media and the public sector. Furthermore, the private sector does not necessarily consider this group of diseases as a lucrative target, a phenomenon which severely hampers spending on research and development of specific drugs, vaccines and diagnostic

tools. NDNP have received relatively little attention from the bioethicists in comparison with abortion, euthanasia, genetics, cloning, stem cell research, and so on. Possible explanations are: 1) bioethics was born as an autonomous discipline with advances in medical technology and thus has largely focused on these; 2) bioethics' birth came at a time when it was believed that NDNP would be "conquered" by medical advances; 3) NDNP are often seen as problems of "others"; 4) ethical questions about NDNP in the developing world might not appear to pose the kinds of deep philosophical questions that academic bioethicists are interested in; 5) bioethics debate has been hijacked by the church; 6) there is generally more interest in doing basic research to acquire new knowledge; 7) attention to the social, economical, and political determinants are lacked. In summary bioethics on health research of NDNP ought to be a major priority for bioethicists and not a neglected one.

Abstract number: 21

ID: 279

Poster

INFORMED ASSENT IN PEDIATRIC DENTISTRY

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Children are a vulnerable group. The dentists related to pediatric population should have a clear awareness about child as a worthy individual, a self-perception holder, their needs, their situation and their surroundings, about their thought and conscience.

Informed assent (IA): Meeting process and dialogue between physician and the underage patient or between researcher and the individual participant in a research, whereby the underage expresses the affirmative acceptance to undergo a diagnostic or therapeutic procedure, as well as decide whether to participate or not in a research trial, which explains in a clear way, simple and in keeping with the child's age, the necessary information for the child or adolescent can agree freely.

An investigation was realized with 78 dentists from 20 different institutions, national and international to assess knowledge of the term IA through a previously survey validated. The 90.5% of the specialists do not know the term IA, 14% of the specialist consider not important what the child thinks to determine whether or not to perform the dental treatment. 29% consider that only in certain circumstances and depending on the age and 57% consider important what the child thinks to determine whether or not to perform the dental treatment.

The term of "Informed assent" in the area of pediatric dentistry is unknown. The dentists must be prepared not only technically and scientifically also in bioethical and legal, normative precepts, for best attention and treatment to the minor, to improve the clinical relationship, raise the ethical performance of the profession and the quality of dentistry services. The IA should be part of the routine in the clinical practice in pediatric dentistry and not only in the research.

Abstract number: 22

ID: 280

Poster

Blood donors and healthcare workers' perspectives on notification process of permanent deferral: preliminary results.

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Mexico, UNAM

Background: Donors are voluntary and healthy but may be confronted with deferral and labeled as carriers of an unexpected transmissible disease. After a while, and even though the target condition has been discarded, blood banks will keep permanently the level of "permanent deferral", preventing them any donation (tissues and organs) for life.

Objective: To examine the permanent deferral notification process from the healthcare workers' perspective, and to explore the permanent deferral experience from the donors' perspective.

Methods: Using grounded theory methods; a qualitative research study was conducted with eight healthcare workers, and eight donors who received notice of permanent deferral in three deferral categories: VIH, hepatitis C virus and syphilis. The study took place at the biggest Mexican blood bank and was approved by the research ethics committee.

Results: The healthcare workers responsible for notification are more concerned about following norms and regulations of the blood bank than about the wellbeing of the donors. The permanently deferred donors described a variety of negative emotional and behavioral responses including confusion, fear, anger, stigmatization, labeling, and loss of hope.

Conclusion: This is the first study to use qualitative research to explore the attitudes of healthcare workers and the experience of permanent deferral blood donor. And it is part of a larger, current ongoing, research work on this specific context.

Abstract number: 23
ID: 284
Poster

THE USE OF ANIMALS IN BIOLOGY SCIENCES
Elizabeth tellez, Aline S. de Aluja, Beatriz Vanda, Jorge Linares

Using animals in teaching involves conflicts of interest among students, teachers and animals themselves. Moreover, the ethical (or unethical) behavior of professionals is acquired during their studies and it is seen in their professional practice. Therefore it is important to examine those arguments used to justify harmful practices in Biology sciences. Three arguments are developed in this study as anomalies in the teaching-learning paradigm. 1) "Animals as objects rather than subjects": this anomaly analyzes the false idea that animals have no mental life or capacity of suffering, based on the Cartesian tradition indicating they are machines, as a justification to harm them in order to acquire knowledge. 2) "Hands-on learning is better than alternatives": this anomaly contrasts the traditional way of learning concerning "hands-on" in harmful practices vs. the implementation of the 3 R's as an ethical way of learning. 3) "Usefulness of alternatives" the conservative tendencies of traditional education seen as the usefulness of alternatives, perhaps due to - inertia or the ignorance of its benefits are analyzed. The ethical dilemma that should be considered in the teaching of Biology sciences is the tolerance to harm animals with the excuse to achieve a purpose (in this case, the acquisition of skills). It is therefore of greatest importance to create awareness in Biology teaching institutions of the gap between traditional harmful learning and humane education and that minimal ethical principles of nonmaleficence and minimal harm must be part of the Biology Sciences curriculum.

Abstract number: 24
ID: 285
Poster

Ethical Reflections on the Social Commitment of University Knowledge
Juan-Guillermo Figueroa-Perea
El Colegio de México and UNAM

One of the requirements for obtaining a degree from the National Autonomous University of Mexico, at either the undergraduate or the graduate level, is for students to promise to use knowledge for the good of society. It is hard to imagine anyone failing to do this when obtaining the academic degree for which they have studied, submitted a thesis and passed a professional examination depends partly on this. In some departments, the promise is extended to adhering to the ethical code of the discipline in question. There are, however, no procedures in place to monitor the social commitment of graduates of this institution. This paper proposes an analytical framework to ethically evaluate the work of persons engaged in research in light of their social and political commitments to the community that enabled them to study at a public university. It begins by systematizing certain ethical and political dimensions underlying the current models of academic assessment policies, since these criteria often tend to focus on productivity criteria while minimizing the giving back of information, even among those engaged in research. It subsequently exemplifies the ethical dilemmas associated with the mismatch between social problems and research issues within institutions that promote academic freedom. Without proposing to set limits on people's right to select their research and teaching topics, the paper presents reflections on possible omissions in academic work, problematizing individual, institutional and social responsibilities, permeated by economic models and the influence of a globalized society, while suggesting strategies to foster criticism of any process of knowledge generation.

Abstract number: 25
ID: 291
Poster

Influence of the emotional sphere on the ethical attitudes in the health care professional.
María Aurea Mendoza Olvera, José Antonio Mata Cancino
Mexico, Instituto Mexicano Del Seguro Social

Objective: To determine the relation of Emotional Sensitivity (ES) and ethical behavior (EB) on health care personnel.

Material and methods: Transversal study on 147 health professionals to whom a self-handled and structured quiz has been applied, evaluation of the ES on 3 dimensions: Negative Self-centered Sensitivity (NSS), Emotional Breach (EBR) and Positive Interpersonal Sensitivity (empathy) PIS classified as altered (ESA) and non-altered ESNA. Four skills where found in the EB: cognitive, social, ethic y emotional-affective.

Results: Average age: 37.9 ± 6.8 years. Females presented a majority 125 (83.9%) and according to the job type, more of them 88 (59%) belonged to the nurse department. 39 (27%) of the personnel scored ESA and 57 (39%) scored low EB. The ES in the whole simple was found accordingly 11% (16) with NSS, 47.65% (71) with EBR and 54. 36% (81) with PIS; depending on the PIS the low EB group was compared to the high EB group finding $P < 0.05$. The EB between different types (Physicians, nurses (N), medical assistants, social workers, nutritionists, paramedic area personnel). The N presented a higher count of low EB, according to their level of studies: college studies compared to technical-level nurses had a significant difference $p < 0.05$. Job-turn analysis got $p > 0.05$. No relation was found between ES and EB ($p > 0.05$).

Conclusions: Higher amount of PIS. There is EB distinction, between technical-level nurses and college nurses. There is no relation between ES and EB

Abstract number: 26 Ethical and Bioethical issues in Football

ID: 309 **Francisco X González Garza**

Poster Mexico, Instituto de Investigaciones en Bioética - Montessori de Monterrey

It is not necessary to carry out an extensive research to understand the amount of bruising and shock that tens, hundreds of students in American football are encourage, where the problem with the bruises and tears in tendons is not a game.

Why a student would play American football?, why if it promotes so much violence in the field is so popular?, it is unethical and it should be legal to promote in all ages? I still do not understand how a parent who is annoyed because her son scraped in a school playing football soccer does not say or do anything to see his son literally be assaulted by a dozen of players of his own age, already created many of them soccer stars.

Why so much violence?, why so many problems?, isn't American football a reasonable cause of the famous bullying that you both want to prevent in today's society?, in addition, would have to analyse and think where a minor. We have the case of a player who suffered a concussion and died, in Arizona, as well as the case in Brocton, New York, another case in Indiana that collapsed at a football training and many other published and unpublished cases.

There is a document of Loyola University suggests that American football athletes who are already retired minor cognitive injury can occur and are even more likely to develop Alzheimer's disease... It is very different that a child of 7 years go and play marbles, to swing, chess, swimming, football soccer, performing most of the sports are interesting, and are far removed from the risks to American football where the constant is the aggressiveness.

Abstract number: 27 New Family Configurations

ID: 325 **Gricelda Moreira, Adriana Ruffa, Graciela Soifer, María Laura Ferrari, Laura Andrea Massaro**

Poster Argentina, Grupo Bioética Argentina

New forms of pairing and reproduction are evident in the current configurations of families, such as stepfamilies, single-parent, adoptive, homo and trans families. Such transformations of the familiar western and Christian family model derive from socio-cultural and technological changes.

The binary male-female way of thinking must be overcome in order to think through the breakdown of woman-mother and man-father positions. Parentage is not determined by biology but by statements of intent. Motherhood and fatherhood are understood as social, and above all, symbolic concepts that transcend the biological.

On the other hand, advances in biotechnology include the possibility of human reproduction with donated sperm, eggs and embryos, surrogate motherhood, frozen embryos and pre-implantation genetic diagnoses.

What we are faced with is definitely a crossroads of bioethics, religious thinking, philosophy, legislation and psychology. Societies are making an effort to accept, name, catalog and provide a legal framework for modes of parenting. The subjective dimension, however, lies outside and future scenarios remain unpredictable.

The consecration of sexual and reproductive rights as human rights implies the right to make decisions about reproduction without suffering from discrimination, coercion or violence.

Faced with these new types of families, we may also ask whether we need to provide legal protection for these new realities to ensure that they are operational.

Perhaps these complex issues are hard to address because as men and women our perspective is determined by modernity and subjectivity as we transit through postmodernity.

Abstract number: 28 The Patient's Physically Protection of Privacy and the Responsibility of Physicians: An Assessment

ID: 336 **Reflected in the Media Through Examples**

Poster **Mesut Ersoy, Assistant Professor Engin Kurt, Associate Professor Muharrem Uçar**

Turkey, Gulhane Military Medical Faculty Department of Medical History and Ethics

Medical intervention must be exercised by the patient's privacy to be respected. The patient's medical evaluation studies regarding the state of their health, should be carried out in secrecy. Examination, diagnosis, treatment, and other operations that require direct contact with the patient a reasonable must be ensured in the privacy environment. Primary Health Care Centers are made an intensive

examination and treatment. In this place as a result of inability of physical conditions and allied health personnel, during the examinations of patient, - especially female patients - physicians and patients can be left alone. Protection of privacy and confidentiality of legally guaranteeing, bears an ethical responsibility for the management. If ideal conditions cannot be provided as a result of misunderstandings or malevolent thoughts of patients, physicians against "sexual harassment" charges are made. Although physicians in any fault, to defend themselves legally stay or suffer a loss of reputation. The physician's examination or treatment when required in order to be alone with the patient, physician is experiencing dilemmas to the responsibility to protect the privacy of the patient's physically and itself legally. How physicians should act in such cases?

Abstract number: 29 **Scientific Integrity in Brazil: analysis of the scientific literature**
ID: 356 Gabriela Cristina Cantisani, Dirce Guilhem
Poster Brazil, University of Brasília

Background-Over the years the number of scientific publications increased. The researchers are qualified according to the number of published papers they produce each year. The best way to publicize scientific knowledge is through publication of scientific papers; however, it must be considered the quality and scientific integrity practiced in the country. The number of cases of misconduct in scientific circles reported by the media has grown significantly in the last 5 years. However, the issue of scientific integrity is still underexplored in academic environments. **Central research question-**To analyze the quantity and quality of knowledge produced specifically about the theme scientific integrity in Brazil. **Methodology-**Scientometric analysis of the topic Scientifics Integrity in the following databases: SciELO (Scientific Electronic Library Online) and LILACS (Latin American and Caribbean Literature on Health Sciences) from January 1995 to September 2013. We considered articles published in Portuguese and that used the term "scientific integrity" in the subject or in the title of the paper. **Results-**Two searches, one in each database were performed using the term "Scientific Integrity". There were found 14 scientific articles published in journals related to the field of health and health care. The papers were separated into 4 thematic categories: 1-Discussion on standards and rules used by scientific journals (4 items), 2-Reflecting on the importance of scientific integrity in research practices (4 items), 3-Health practices and their relation to scientific integrity (5 items), and 4-Perception of medical students on the topic of scientific integrity (1 item).**Conclusion-**The results reflect that the subject of scientific integrity has not been a common discussion among Brazilian researchers. Increasing the production of knowledge in scientific integrity could contribute significantly to improving the quality of scientific production in the country.

Abstract number: 30 **Bioethics in physician - patient relationship and development of the medical record**
ID: 362 Adriana Mejía Estrada,
Poster Mexico, Universidad Michoacana de San Nicolás de Hidalgo

Actually we can recognize different models of medical care; relationship between patient and physician requires several attitudes: empathy, truth, will, understanding and trust, with scientific knowledge bases. All medical activity is recorded in the patient's medical history, testimony and reflection of the relationship of the physician and the patient; between users and hospital; only document valid as legal or clinical support for defense of the physician. An appropriate medical record requires all experience and professional knowledge of the physician; in the case of medical students, they require since the school, to develop their abilities and skills, theoretical content and a solid ethical education because the focus of attention is the human person; the future physician requires integrate humanists values to theoretical medical contents. Bioethics appears as a support for medical sciences, helps the search for solutions to conflicts and dilemmas that arise with the innovation of the knowledge, the technology and its impact on the lives of human beings, of all living beings and the ecosystem. With the implementation of its principles: autonomy, beneficence, and justice strengthening ethical personal and professional conduct. Bioethics helps to promote respect for life and universal values, protect the recognition of the dignity of human beings. Bioethics helps patient's rights, privacy and confidentiality of the medical record information.

Abstract number: 31	EFFECTS OF COURSE OF ETHICS IN THE DEVELOPMENT OF MORAL JUDGMENT OF NURSING STUDENTS
ID: 364	<u>Leticia Vázquez Arreola</u> , Dr. Sofía Guadalupe Medina Ortiz
Poster	Mexico, Facultad de Enfermería de la Universidad Autónoma de Nuevo León

GOAL. To determine the effects of the course on ethics and bioethics intervention program in Moral Judgment Development (DJM) of nursing students. METHODOLOGY. Design was longitudinal, time-series measurements and quasi experimental. The control group (CG) was simple random sampling, leaving a sample of 115 participants. Experimental group (EG), groups of the study population were enumerated and randomly selected via random number table leaving a sample of 23 participants. Sociomoral Problems Questionnaire (COPS) was used [DIT] Rest (1979) Spanish version, Nuevo Leon, Mexico (2010). Alpha Cronbach reliability coefficient of 0.89. In GC were three pre-intervention measurements, GE three pre-intervention and post-intervention. RESULTS. GC was significant difference in stage 3 ($Z = -3.07$, $p < 0.01$) stage 4 ($Z = -2.80$, $p < 0.01$), index D ($Z = -2.59$, $p < 0.01$). In GE Correlation of age in Post-Conventional Level III Stage 5B ($rs = 0.517$, $p < 0.01$) by sex stage 3 ($U = 484.5$, $p < 0.01$) stage 4 ($U = 494.0$, $p < 0.01$) Stage 5A ($U = 000.0$, $p < 0.01$) and sex-Conventional Level II, Stage 5A ($Z = -2.31$, $p < 0.01$). CONCLUSIONS. The DJM remained in GC and GE in stage 4, the correlation by age was high and positive in GE, to> age> schooling> DJM in level III Post-conventional stage 5B. The intervention of bioethics program shows positive effects by Increase DJM in stage 4 to stage 5B.

Abstract number: 32	EFFECT OF BIOETHICS PROGRAM IN DEVELOPING MORAL JUDGMENT OF NURSING
ID: 365	<u>Sofía Guadalupe Medina Ortiz</u> , Dra. Leticia Vázquez Arreola
Poster	Mexico, Facultad de Enfermería Universidad Autónoma de Nuevo León

Educational opportunities in bioethics include courses, conferences and seminars where the objective is to increase knowledge. However, forgets to develop the competence of moral reasoning. There is little attention to study the validity of the models used in the ethical behavior of nursing. The objective of the study was to determine the effect of an educational program on bioethics in the Moral development of the nursing staff.

The theoretical perspective is the development of Moral judgment of Kohlberg, I. & Herch, R.H (1977). Method: Design was quasi-experimental, with simple random sampling. The study population were 81 nursing professionals who held an intervention bioethics based on discussion of moral dilemmas. Results: dominates the level of conventional moral development in the participants before and after the intervention (66.82%, 65.90%).

The results of the test of Wilcoxon (Z) present significant difference in stage 3 ($Z = 569$, $p = 0.02$), stage 6 ($Z = 588$, $p = 0.03$) and in the index \"P\" morality of principles ($Z = 621$, $p = 0.05$) in the intervention group after the course of bioethics.

It is concluded that to solve moral dilemmas nurses use the Moral conventional II development level and that the continuing education program with livelihoods in the socialization and interaction of nurses through the discussion of moral dilemmas has an effect on moral development.

Abstract number: 33	Teenagers Attributes On Sociomoral Reasoning As A Building Process Of Bioethical Competences
ID: 369	<u>Martha Marcela Rodríguez Alanís</u> , Geraldina Guerrero González
Poster	Mexico, Instituto de Investigaciones en Bioética

In the globalized world bioethics education is utmost relevance. The development of educational programs framing the culture diversity gives rise to pedagogical validity research, that encourage cognitive learning and moral reasoning.

The main objective of this study was to assess the teenagers attributes and sociomoral reasoning in building of bioethical competence process in the high school level of Mexican education. Deepening in the adolescent moral reasoning from forming attributes during their educational instruction, the intrinsic structure of moral judgment (Kohlberg has described micromorality) was exposed, finding from this context extrinsic resources (macromorality) that were important components for the development of competence moral .

The moral reasoning of 312 Mexican adolescents as from Kohlberg's theory and the Piaget, Rest, Pérez-Delgado, Mestre studies were reviewed by sociomoral questionnaire in the full version (Defining Issues Test -DIT) and the effect of factors was obtained, determining as the cognitive level (ongoing semester), gender, working status (active or unactive). The sample were acceptable to meet the objectives and show a reliability for the estimation of coefficient Cronbach, the ANOVA had acceptable power, determining the P index, which represents the percentage of postconventional reasoning preferred, this point were facilitating the evaluation on effect of factors to respondent building bioethical competences process.

The study results allow the knowledge about the teenagers student's moral reasoning and these attributes are integrated, so that should be taken into account as a basic component of bioethical competence.

Abstract number: 34

ID: 371

Poster

Cross-functional Analysis of Ethical Dilemmas in Palliative Care

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Objective: to identify the ethical dilemmas arisen during the care of a cancer patient at the end of life.

Materials and Methods For this purpose, two systematic reviews of the literature (PUB-MED) were carried out to know the current and historical trends in the different regions. Subsequently, it was applied a semi-structured and validated survey and a holistic method to ethical discernment on a sample of 24 medical specialists with more than a year of experience in the care of patients in palliative care.

The results were analyzed using the statistical program Atlas Ti in order to identify and classify the arisen dilemmas and the values at stake in decision-making, in addition to its axiological analysis.

Results: The arisen dilemmas were related to: a) the administered therapy (removal of hydration, food or drugs), b) communication of the prognosis, c) double effect with (powerful opiates), d) request for euthanasia, e) institutional regulations or legal problems, e) request for terminal sedation, f) to extend or not to extend life.

The axiological analysis of the participating values in decision making recurrently reported: compassion, meditation, confidence. With regard to the virtues and the roles of the palliative physician, it is advisable: justice, professional humility, introspection, self-knowledge, respect, dignity, autonomy, presence; and as an educator: competence, commitment, confidentiality, autonomy, altruism, reliability, integrity, honesty; and as a healer: self-regulation, social and professional responsibility and group work.

Conclusions: the results of this empirical research show for the first time in the history of palliative medicine, the values, roles and virtues that come into play in decision making during the ethical dilemmas arisen in the care of cancer patients at the end of life. We consider that these can serve as the basis for improving clinical practice with these vulnerable patients

Abstract number: 35

ID: 380

Poster

Discrimination that suffer Mexicans who have epilepsy in the Field of Work.

Amparo Ponce, Guillermo Cantú Quintanilla, Lilia Núñez Orozco

Mexico, Universidad Panamericana

Which and how is the discrimination that suffers Mexicans in the field of work?

The epilepsy is a disease known, defined but not accepted since the human exists. Almost all the cultures around the world relate the epilepsy with abnormal beliefs. In this moment, people assume every type of epilepsy as the same and that they are synonym of not been able to live as any other person who does not have it.

One of the most damaged areas for the people with epilepsy is the field of work. When we think which are the damages they suffer in this field; sometimes we believe it is only in the contract procedure. But is it really true?

The aim of this study is to know the work conflicts in which these people are involved, and their feelings around this issue.

There are some countries which have laws that support the rights of the people with epilepsy but in this moment Mexico have a lack of them.

The study is qualitative, phenomenology, depth interview, closed traverse survey method and documentary.

There will be made depth interview to 7 persons with epilepsy that work or had work, this for knowing the way they confronts the process.

The Questionnaire of Quality of Life in Epilepsy (QOLIE-89) adapted to Mexicans will be applied to 30 persons with epilepsy. The subjects will be between 18-60 years old, who have or not work at any time in their life. The questionnaire will be applied in four different states of Mexico.

There will be an analysis and comparison of the different laws that exists in some countries all around the world, and who the Human Rights are defended.

Abstract number: 36	Designing a public system for the research ethics consultation service in Japan
ID: 396	<u>Kuniko Aizawa</u> , Kaori Doi, Haruka Nakada, Taketoshi Okita, Kenji Matsui
Poster	Japan, National Cerebral and Cardiovascular Center

Research question: What kind of public system should be developed in Japan for the research ethics consultation service (RECS)?

Methodology: Theoretical consideration.

Background: The research ethics consultation service (RECS) is an ethical advisory service offered beyond the standard approval given by the institutional review board. The RECS has been developed at individual clinical research institutions, and the creation of a centralized service system is now under consideration in the U.S. There is a need for the same service in Japan, and a few institutions in Japan have started the RECS. However, it is still unclear how the RECS should be developed in Japan across the country.

Results: We examined the advantages and disadvantages of different RECS setups. An institutional service, such as one provided at a medical school, is usually only available for people involved in the institution. The Japan Association for Bioethics could run a public RECS, but this would depend heavily on its voluntary member consultants. The government could establish an Office for Research Ethics and a national RECS, but this would require strong leadership, and may not be easily accessible for individuals at local institutions. Implementing ten government-funded programs at core clinical research hospitals across the country would better provide the RECS and other services to a larger number of local institutions. Additionally, employing the RECS at six national advanced medical centers featuring important disease areas would also better provide the RECS for studies in the specialized areas.

Discussion: The best bases for the public RECS are core clinical research hospitals and the national advanced medical centers. The consultants at these hospitals and centers should share information in order to standardize their services.

Conclusion: A public RECS system should be developed at these institutions.

Abstract number: 37	When Ethics Committee Generate Government Revenue!
ID: 400	<u>Martin Anu Nkematabong</u> , Irene Akumbu Wibedimdom
Poster	Cameroon, National Ethics Committee, Cameroon

Good clinical practices, the general safety and dignity of research participants heavily depend on the review framework put in place by various governments and health institutions to institute and implement international guidelines and regulation prescribed by scientific committees, the Ethics Committee being the ideal structure.

Unfortunately, the government of Cameroon has remained reluctant, despite alarming prevalence rates of HIV/AIDS, malaria, sleeping sickness, meningitis, cancer and cardiovascular infections which have attracted international and local scientists who currently attempt to reverse the ailing health trends through phases II and III clinical trial programs.

The National Ethics Committee (NEC) instituted in October 1987 was, until 2009, managed by three physicians and one researcher who occupied top positions in government, but absolutely lack basic knowledge of research ethics.

In December 2009, the government stepped up the number from four (4) to 13, where I occupy the position of Community Representative. Since then, board members have remained at dagger-drawn during review sessions. Physicians and researchers, who are also top politicians in the regime, come to the board with firm instructions to approve study protocols, irrespective of their benefit-harm ratio, designed by supporters of the regime or proposed by pharmaceutical industries capable of paying substantial taxes to the State.

In September 2011, 24 participants of a sleeping sickness study died in Wabane Sub Division, South West Region of Cameroon. The critically sick patients were placed on placebo by a local researcher, who is another influential member of the National Ethics Committee, against the general decision of the board.

In such situations, where do ordinary members of Ethics Committees go to? Should we scream along the streets? Should we incite riots at the research site? Should we involve the media? Should we resign?

Abstract number: 38	The Reality of Transsexuals in Brazil
ID: 413	<u>Valéria Silva Galdino, Luiz Geraldo Do Carmo Gomes</u>
Poster	Brazil, UEM / UNICESUMAR

Human sexuality comprises the affective sexual orientation, sex and gender, which includes the expression, role and gender identity. Transsexuals have the desire to conform sex in accordance with their gender, because there is a conflict between them. The WHO defines transexuality as a gender identity disorder (ICD 10). Some transsexuals preserve their genitals, despite making all other changes and understand that sexual affective relations occur influenced by gender and not by sex. Transsexuality cannot be confused with transvestism, since it is characterized by the expression of gender. In Brazil there is no law regulating the sex reassignment surgery, but this became possible since the Resolution 1.955/2010 from the Federal Council of Medicine, but it must have a diagnosis of gender identity disorder, signed by a multidisciplinary team, also fulfilling others requirements of the Resolution. The forename is still a stage to be overcome to achieve harmony with the gender, regardless of reassignment. Many Brazilian transsexuals have obtained in court the change of their documents without any reassignment surgery. The transsexual also faces himself with a family that disqualifies him and with a justice system which depersonalized him, since there is no recognition, leaving him to the fringes of society, violating fundamental rights and personality rights. The transsexual should be protected based on the constitutional principles of human dignity, freedom and on bioethics principles, as self-determination, which ensures gender reassignment, providing the realization of his individuality, non-maleficence, which maintains the physical integrity, beneficence, which consists in providing his physical and psychological well-being and ultimately the justice that should safeguard all the rights of every citizen regardless the exercise of their sexuality.

Abstract number: 39	Bioethics education: Prospects in medical education of Bangladesh
ID: 432	<u>Fariha Haseen, Prof. Syed Shariful Islam</u>
Poster	Bangladesh, Bangabandhu Sheikh Mujib Medical University

Bioethics, as a discipline, helps health care professionals identify and respond to moral dilemmas in their work (Begum, 2010). In the 32nd UNESCO General Conference (UNESCO, 2003), the need to initiate and support teaching programs in ethics, bioethics and in all scientific and professional education was stressed by Member States, because of this, UNESCO initiated the ethics education program in 2004. There is a growing interest on bioethics among health professionals including academics and researchers of Bangladesh. They have started to raise awareness on bioethics among health professionals (Hossain, 2010). The issues are mainly focused on intellectual property rights (Ali, 2010), ethics in clinical research and human subjects (Fakruddin et al., 2012), pharmaceutical research (Faroque, 2011), institutional ethical review board (Talukder et al., 2011). Even the researchers also focus on stem cell research and ethics (Ullah et al., 2010). However, a study found that there is a huge gap of bioethics education in medical science of Bangladesh. Increasing awareness, sensitivity, research and practice of bioethics in various disciplines of medical science is required. Bioethics education is essential in Bangladesh.

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Abstract number: 40	Opinion of university students on management of genetic information
ID: 439	<u>Berenice Perez-Cavazos, Vanessa Flores</u>
Poster	Mexico, Universidad de Monterrey

Background: Research regarding the human and other species genomes are every day more common on a global scale, as well as those studies offered in the market. Until now, there are not studies about public opinion on these new technologies and management of genetic information in Mexico. The objective of this study, is to know the opinion of university freshman students on genetic testing and information gathered in that process, topic which continuously involves ethical dilemmas.

Methods: A questionnaire, designed by the Human Genetics Commission, was applied to assess

the knowledge and attitude towards genetic information. Inclusion criteria: Students who entered Universidad de Monterrey in 2013 and are less than 25 years old. It was anonymous and answered voluntarily.

Preliminary Results: Up until November 30th, 2013, 221 freshman students were surveyed. They showed various and varied opinions and thoughts. On particular, they have shown a firm opinion on the way genetic information can be handled and how it should be used in the future. Preliminary results tend to show that university freshman students consider beneficial the advances in the genetic field, for example, disease prevention, make understandable who is at greater risk of common diseases, develop treatments to genetic diseases and identify or eliminate possible delinquents in police investigations. There is a clear tendency in students to think that genetic information should not be used by parents to decide if offspring with genetic malformations should be aborted and that knowledge acquired in public and private research centers should be of public domain and available for any use without a cost.

Conclusions: This information could be helpful for the scientific community as a tool to reflect upon what could be used confidently by the population in the future.

Abstract number: 41

ID: 445

Poster

Conscientious objection in the medical migration context: cultural interference

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Medical migration is a particular case of migration within which the aspects of conscientious objection (CO) generates a framework of analysis which does not seem to be sufficiently homogeneous nor heterogeneous enough to encourage a different approach to common problems of medical practice. OC remain very challenged in the medical field: in the analysis of the medical act on the relationship between physician autonomy and the supposed benefit of the patient, some authors believe that the OC diminish the moral conscience of doctors, while others have suggested that physicians must be able to define the scope of their practice using their conscientious judgments (Brown NJ, 2010). OC evaluation depends on the legal, social, cultural factors, specific to the national context, associates a set of the ethical values (autonomy, respect and dignity).

Central ethical problem: contradiction between the patient's request for certain health care and principles (cultural, religious, moral) of the medical staff reflected in the OC.

Approach / methods / arguments: First, we extract the main ethical issues which OC involve them in healthcare. Then we will show how these problems reflect or not OC practice in national context. For a realistic picture of the local situation we will conduct interviews with physicians and medical students who have experience or intend to experience migration in UE and non-UE countries. All aspects of the empirical work will be reported to the literature, legal framework and jurisprudence.

Conclusions: We will underline the existence of those situations where doctor due to OC may refuse to grant certain medical services. We will identify the reasons of conscience (religious, cultural, moral) that may underlie this refusal and we will identify, present and motivate health care that can not be refused on grounds of OC.

Abstract number: 42

ID: 453

Poster

To profile adolescents and women who underwent legal termination of pregnancy in Brasília.

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Brazil, Universidade de Brasília

Legal abortion: women and teenagers' profile in a Brazilian healthcare service

Background: Brazil has 441 care services for women who were victims of sexual violence, 63 performing abortion allowed by law. This service consists of a multidisciplinary team that bio psychosocially cares women who seek this service when they are victims of sexual violence and opt for legal abortion. The number of interrupts represented is from 2007 until the second half of 2013.

Central research question

To profile adolescents and women who underwent legal termination of pregnancy in Brasília.

Methodology: Descriptive study to document the delimitation of women and adolescents at a referral service provided by law profile. Gathering retrospectively performed of official records of the abortion program provided by law between 2007 until October of 2013. The following aspects were analyzed: age, gestational age at pregnancy termination, place of residence, religion, color self-reported, the police report registry, view the public prosecutor, reason for termination of pregnancy in case of violence: victim's relationship with the offender, method used for termination of pregnancy.

Results: 81 were assisted by the program; 37% of them were composed of adolescents and young adult women, 74% reside in DF, 43% were protestant, 54.3% self-determined brownish color, 50% of the participants were on the twelfth month of pregnancy. 64.7% of the aggressions were extra familial. The main ground for the termination of pregnancy were: intra and extra-familial sexual violence and

risk of maternal death.

Conclusion: Direct the practices in service; enable the multidisciplinary team that provides care: humanization, awareness of women regarding bio psychosocial follow up after abortion; contribute to the reshaping of public policies. Service quality; respect, dignity and adoption of human rights.

Abstract number: 43
ID: 464
Poster

Memory project: history, research and ethics
Dirce Guilhem, Patricia Sorokin
Brazil, University of Brasilia

Background: A weak border separates ethics in science and violations committed against volunteers included in the studies. Many researchers have surpassed this frontier to achieve discoveries for the humanity's benefits. Nazism was a perverse milestone for the research ethics debate, allowing atrocities against vulnerable groups carried out in name of science. Promoted great debate and reflection on the science limits, scientific freedom and conducts adopted by scientists.

Central research question. Rescue scenarios, speeches, moments, documents and images related to the research ethics history which could contribute to the adoption of good ethical practices in the scientific context.

Methodology. Socio-historical research performed with Salomón Feldberg, survivor of a Nazi concentration camp, who as a child was included in a study on hepatitis conducted by Josef Mengele. Four interviews were carried out by trained researchers. A health professional team (physician, geriatrician, psychiatrist), was responsible for monitoring the process with the objective to prevent that "Sali" could be re-traumatized remembering extremely painful facts. The most relevant moments were accompanied by a filmmaker and a photographer who captured the images and performed the documentary's edition. The ethical requirements were rigorously followed. In addition to the informed consent was obtained the authorization for use of image and voice.

Results. Twenty hours of interviews and video records originated a testimonial documentary, nonprofit, titled Childhood test (Infancia a prueba), produced in Spanish and in translation process into English, French, Hebrew and Portuguese.

Conclusion. The documentary was created to be used as educational material in different scenarios. Key actors, their memories and experiences can contribute to make visible conflicting situations encountered in the past that echoes in the present, could be modified and avoided. Also contributes to fostering a culture of respect for human rights in scientific practice.

Abstract number: 44
ID: 498
Poster

Does Bioethics need or not to accept a foundation of human rights?
José Pedro García Scougall,
Mexico, Universidad Panamericana

An argumentation based on contemporary thought and the classic, which seeks to contribute to the Bioethicist personal reflection on whether due or not theoretically based his interpretation of human rights. This concerns the philosophical and historical origin of their current decoder key, showing that by its origins, there are paid almost exclusively to the principle of autonomy, to the detriment of other bioethical principles. Currently in deliberation bioethics concerning health and human life human rights, as invoked in the discussion items, tend to provide, in the best of cases, some additional nuance to intelligence that provide positive legal systems to the understanding of the clinical problems and medical research that are studied.

The analysis shows the different alternatives that have historically been proposed to substantiate human rights becoming a reality that concerns the political and legal level, but, also, of the ethics, which is the main Avenue by which must reach the territory of bioethics, and which makes them liable for the Bioethicist knowledge. With the same aim of clarifying the theory of the non Foundation of human rights, proposed by Norberto Bobbio is exposed.

And with respect to both positions demonstrates the problems that present in the practice of ethics and bioethics. For example: how to get that human rights do not become declinations of the narrative that is could substantiate them, breaking the flexibility of bioethical deliberation?

Conclusions: a single or official Foundation of human rights is not required, but you are really based on the mind and the conscience of each Bioethicist

Abstract number: 45 ID: 502 Poster	From object to subject: The Adolescent as actor of his health care <u>Blanca Bórquez.</u>
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Spain, Observatory of Bioethics and Law, UNESCO Chair on Bioethics (OBD) University of Barcelona The Convention on the Rights of the Child of 1989 meant a paradigmatic change about the role that children and adolescents play in society. This new conception supposed important modifications in the regulations, law and public policies from tutelary system to an integrated protection system. However, these transformations are still insufficient in the health space because that the real acceptance of adolescent as a subject of rights and as the principal actor of his health care, required not only a new social culture that estimates the adolescent as a citizen with rights and duties, but too it needs a law system in the same way. Give access to adolescent to the health care without obstacle with a leading role in the decision making is the challenge, and the Bioethics should contribute to this goal.

Abstract number: 46 ID: 503 Poster	Building a list of the basic functionings for transgender people Cristiane Maria Amorim Costa, Marilena Cordeiro Dias Villela Corrêa; Carlos Dimas Martins Ribeiro. Brazil, Universidade do Estado do Rio de Janeiro.
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In 2007, was established in Brazil a public policy called "Processo Transexualizador", based in diagnosis, gender identity disorder and reassignment surgery, which has been reformulated and expanded in 2013. Among its guidelines , it includes Comprehensive health care for transsexuals , which aims at meeting the demands and needs of transgender people. This guideline , based on the principle of justice, would promote basic functionings , defined as the various things a person can do or be considered valuable, and the achievement of the life project of those people. This study aimed to build a list of the basic functionings for transgender people to serve as the guidance to realize a bioethics evaluation, by the principle of justice, to the "Processo Transexualizador". To meet the goal, we performed an integrative review whose research question was: which functionings have been appointed in publications related to transsexuality? The study was comprised of 80 national and international studies, by means of a survey conducted online in the databases Scileyo , Lilacs and Medline. From the analysis of the studies, the list of the basic functionings for transgender people should consist of the following functionings: 1 - Health - affordable and appropriate treatment, free of discrimination. Access to hormone treatment and body modification; 2 - Source income for a decent living; 3 - Personal Relationships; 4 - Free exercise of sexuality and Autonomy of Gender Identity; 5 - Formal Education; 6 - Life - living conditions appropriate to a dignified life- shelter, nutrition, sanitation, leisure, reproductive and sexual satisfaction, religion; 7 - Right to decide on legal issues such as change of name and sex , marriage , adoption; 8 - bodily integrity - able to move anywhere you want , without running the risk of suffering any transphobic attitudes.

Abstract number: 47 ID: 505 Poster	Moral education about the students of odontology in FESI UNAM and their conduct code <u>Jorge Alberto Calderón Martínez</u> , Elba Ruiz Bautista & Roberto Gómez García Mexico, Universidad Nacional Autónoma de México
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The context of a globalized society that imposes a need to be pluralistic moral, requires addressing in a critical way the moral education of students. In this work, which has as aim that students of dentistry of the FESI UNAM will generate a document that will guide their conduct in the school and promote a civic morality consensual using the method dialogic with the groups from first to fourth year. The result obtained was a code of conduct for students in the career of surgeon dentist of the FESI, which consists of thirteen fundamental points that guides them in their moral preparation and deontology. Taken in the framework of participatory democracy and radical of the students, as well as by the critical view of the authorities of this institution in front of the social, political and cultural context that determines the conditions of the moral training of the students, is very slow its insertion curriculum, although the students that know about it applied in a good manner.

Abstract number: 48 ID: 507 Poster	Identifying dilemmas in pediatric cancer patients and their admission to intensive care units. <u>Sandra Luz Lizarraga-Lopez</u> , Diaz-Garcia Luisa, Altamirano-Bustamante Myriam Mexico, Instituto Nacional de Pediatría, UNAM.
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Cancer treatment has changed in recent decades with the introduction of new protocols for intensive treatment; improving the prognosis and survival, it has also increased the complications that sometimes patients are considered "non-recoverable" limiting their admission to intensive care units, these dilemmas are presented in everyday clinical practice. Aim: Identify the most common bioethical dilemmas that arise in clinical practice in a pediatric intensive care unit in patients with cancer. Method: Participants physicians working in pediatric intensive care unit, who identified dilemmas in assessing

children with cancer for admission. Results: Three patients were identified dilemmas, classified as: doctor patient relationship and therapeutic utility, limitation of treatment, quality of life and end of life. We note that the attitude of doctors who reported most frequently were aimed at medical care, life care, the utility of treatment, the ability to discern between situations of gravity and consequences of established treatments, as well as the identification of the risk of imminent death was most frequently expressed in each case. In one patient counselor role was missing deepen the role of educator, and this attitude is not detected in the participating physicians. In one patient counselor role was missing deepen the role of educator, and this attitude is not detected in the participating physicians. The values identified in each discussion were: non-discrimination, respect, autonomy, justice, compassion, the principle of non-maleficence was identified in all cases. In conclusion this is a close approximation to the values that influence the identification, discussion of dilemmas, encouraging critical and systematic reflection on the treatment of critically ill patients, developing the skills of health staff

Abstract number: 49
ID: 508
Poster

Constitutional responsibility , individual and group of bioethics in the promotion and quality health
Gabino Yescas Buendía, González Sanchez Judith
Mexico, Instituto Nacional de Perinatología ,Instituto Nacional Ciencias Médicas y de Nutrición

In the Federal Legislation of each country and the Constitution of Mexico is established that health is protected by the state and is dependent on the health institutions and health personnel. Government authorities must provide and reasonably distribute, according to the epidemiological status of each region and institution's need, the budget for the administrative operations, research and medical care. The training of medical and paramedical staff should be through a continuous program in which the authorities in each medical area train, on a scheduled basis, each member of its workforce in the main themes of disease, in order to provide adequate diagnostic process and therapy for each individual patient or individual demanding service. This objective should be based in health programs targeting each sector (rural and urban population), inclusive of indigenous groups and people in poverty, as well as the physician-patient relationship that allows for proper human interaction in the process of health-illness, leading to high quality medical care.

From support groups to quality health care in all its facets, medical and administrative supervision of hospital bioethics groups (multidisciplinary and interdisciplinary) must be independent to each institution and the government sector to meet its goals of supervision, recommendation and performance of the functions of the members of the health sector in each medical institution: monitoring proper diagnosis, timely treatment, compliance with health programs, diagnostic and ancillary services, and provide rational, appropriate and timely distribution of economic budget to assist in the reduction of morbidity and mortality. There must be a relationship between local and regional committees, in order to work for the health of the individual at all times and without conflicts of interest.

Abstract number: 50
ID: 514
Poster

Identification of values toward work, in medical staff of a unit pediatric intensive care
Maria Luisa Diaz García, LIZARRAGA-LOPEZ SANDRA LUZ, ALTAMIRANO BUSTAMANTE MYRIAM
Mexico, INSTITUTO NACIONAL DE PEDIATRIA

In the passage of time, societies have a set of moral principles and qualities that guide and regulate the actions of an individual or a professional group. Medical care has an essential dimension axiological, which convey meaning and substance to the profession. The importance of values, according to S. Schwartz is related to individual priorities, social structure, which is considered the age, gender, education and occupation. The importance of values, according to S. Schwartz is related to individual priorities and social structure, which is considered the age, gender, education and occupation. Aim: Identify of values toward work in medical staff of a unit pediatric intensive care. Methodology: We conducted, the EVAT survey, with 16 items, this questionnaire assesses four dimensions: personal interest, promote the welfare of others, motivation of individuals to pursue their own intellectual and emotional interests, preservation of the status quo and stability in relationships with people and institutions. Results: Involved 20 pediatricians, 60% female and 40% male. Multidimensional scaling was performed, observing the highest scores in the area of self-transcending: benevolence, universalism, openness to change and stimulation. The main result of health is identified as related to the protection and preservation of the welfare of the people, which is related to the medical profession. This work is one of the first approaches to the identification of values in health personnel who work in a pediatric intensive care unit.

Abstract number: 51	Experts' Legal Knowledge on Personalized and Genomic Medicine and Its Ethical Implication in South Korea
ID: 518	Sungkyoung choi, Hannah Kim, Ilhak Lee, So Yoon Kim
Poster	Korea, Republic of (South Korea), Center for ELSI Research, Asian Institute for Bioethics and Health Law, Yonsei University

South Korea is special in there is legislation on bioethics, as the Bioethics and Safety Act. Ethical components are presented only as a guideline in foreign countries. But in Korea, it has a legal effect. As the technology of whole genome sequencing rapidly develops, Gene-related health care costs decrease and it makes possible to realize genomic medicine in the health care system. On Feb. 2013, as the Bioethics and Safety Act was wholly revised, regulations are applied to whole human participating researches including genome research. This means genome research has become more common in South Korea. The objective of this article is to explore the legal and ethical knowledge of the physicians who conduct genomics research in tertiary hospital. The survey responses were collected from 99 people who conduct genomics research in tertiary hospital. They participated in an online or interview survey. Experts' legal knowledge was assessed using the structured questionnaire. The questionnaire was categorized into the general knowledge, Institutional Review Board, informed consent, gene therapy and etc. The result was analyzed by SPSS. (ver.19) 84.8% of respondents knew that the legal discipline extended to whole human and human specimens research as the Bioethics and Safety Act was wholly revised. Otherwise, most of respondents didn't have the accurate knowledge regarding the review committee. Two-thirds of respondents were clueless as to how to protect personal genome information in commercial genetic testing and if when identifiable personal information is deleted, genomic dataset can be disclosed. And only half knew that collected human specimens before 2005 could be used without consent. The results showed that most of the physicians who conduct genomics research are vulnerable legal knowledge on personalized and genomic medicine (Study in Progress).

Abstract number: 52	The national survey of the Medical Decision-making Process in the End-of-Life care in the Republic of Korea
ID: 523	<u>Yeon Ho Lee</u> , Yeon Ho Lee, Hannah Moon, Eunyoung Lee, So Yoon Kim, Ilhak Lee(corresponding), SOHN Myongsei
Poster	Korea, Republic of (South Korea), Yonsei University

The End of life decision making is to improve the patient's quality of life before the death, to protect their self-determination and to secure them a death with dignity.

In the Republic of Korea, through the case of grandmother Kim in 2009, the court defined the meaning of the medical End of life decision making and permitted the interruption for maintenance of medical treatment. Medical organizations including the Korean Medical Association developed a guideline which is reflected by the case, but the recognition of the guideline was not high in the medical field. In addition, attempts for the legislation steadily continued, but it was not enacted.

This is because the decision on how to euthanize patients has not come to a consensus. Therefore the legislation or systemization of medical End of life decision making is one of the hot issues in the Republic of Korea.

This study is to identify the experiences and expectations of the patients and the patients' family on medical decision-making for life-sustaining treatments through a questionnaire.

Abstract number: 53	Informed Assent. Minors as Research Subjects
ID: 525	<u>Eloy Cardenas-Estrada</u> , Guadalupe Lopez-Cabrera, Maria de los Angeles Castro-Corona, Roberto Cantu-Lazo, Gustavo Leal-Isla-Sanchez, Ana Karen Gutierrez-Martinez, Carlos Medina-De-La-Garza
Poster	Mexico, Centro de Investigación y Desarrollo en Ciencias de la Salud, Universidad Autónoma de Nuevo León

In the modern era the informed consent stems from the Nuremberg Code of 1947 and also present in the so-called Declaration of Helsinki since its first version to the latest (1964-2013). Belmont Report (1979). The term informed assent in minors is similar to the term of the process of Informed consent in adults.

Background of Informed Assent in USA (FDA) , refer to the decade of the seventies. It can also be seen in the European Union legislation on the obligation to seek Informed Consent from the parents and Informed Assent of minors.

In Mexico, the General Health Law (Ley General de Salud), in article 100 and also in the regulations of this law in the field of research (1986) Article 14 and specifically article 37, states that must also be obtained Informed Consent from parents and acceptance of the child, after an explanation of what is intended to do (Informed Assent).

Acceptance is also conditional on the mental and psychological state of the child and that the Ethics

Commission may waive compliance with these requirements for good cause. For the National Bioethics Commission in Mexico, informed consent is a process that consists of two parts: Information and Freedom of Choice.

Although it is an imperative need the informed Assent, among other issues, there is the need to establishing consensus on the age in which it is requested and to establish procedures for ethical solution of controversial opinions between the child and his parents.

Abstract number: 54
ID: 531
Poster

End of life decisions in the Perinatal Medical Care

Patricia Grether, Asunción Álvarez del Río, Rubén Lisker, Alvar Loria
Mexico, Instituto Nacional de Perinatología

This study explored the views of members of the perinatal health team about decisions related to late termination of pregnancy and newborns presenting life-threatening anomalies. We analyzed anonymous surveys for 22 social workers, 29 nurses and 82 physicians (31 Geneticists, 22 Pediatrician and 29 Obstetricians).

Important findings include that 17% favored feticide and 40% considered neonatal euthanasia acceptable.

Ninety-five percent will comply with parents' management requests, suggesting high respect for patients' parents' autonomy. However, those who favored use of all therapeutic resources to prolong life as long as possible (12%), and those who favored feticide (17%) considered attending physicians' convictions important or very important in their choice (80% and 70%, respectively). This suggests that even though most people recognize parents' autonomy, attending physicians' convictions have a great weight in the main decisions regarding fetal/newborn life.

Interestingly, baby suffering and poor quality of life, were fundamental in the decisions of all those who would use all therapeutic resources to prolong life, as well as 90% of those who favor feticide. This suggests, paradoxically, that opposite decisions can be taken based on the same reasons. However, when analyzing why they choose intensive care versus palliative care, those considering baby and parent suffering, opted for palliative care while those who defend life sanctity decided intensive care. Social Workers considered family disruption as the most important factor in decision making whereas it was the suffering of the baby for Physicians

Obstetricians were more inclined than Pediatricians to give intensive care, while Pediatricians and Geneticists were more amenable than Obstetricians to interrupt pregnancy with or without feticide. The study also showed a poor knowledge about the legislation that regulates these decisions.

Abstract number: 55
ID: 538
Poster

Perceptions of justice in health care: a theoretical and empirical analysis

Yareni Monteón, Elisa Calleja & Jorge Jiménez
Mexico, Universidad Nacional Autónoma de México

In this paper we discuss two issues concerning justice: 1) We start with a theoretical discussion on the concept of justice from a capabilities approach. The discussion mainly takes into consideration the work of Sen, Nussbaum and Anderson. 2) Afterward, we carry on an empirical analysis of the perceptions of justice that the healthcare personnel have. This analysis is done using a qualitative methods of research to go through extensive interviews and several ethical dilemmas.

Justice understood from the capabilities approach will enable a broader outlook and it may respond better to ethical problems in which classical notions are at an impasse. Justice from the capabilities approach is concerned with the institutions, as well as with the actions and decisions of the physicians; moreover the interests and desires of those who do not belong to the institutions have to be boldly taken in consideration. Patients, family and care-givers as parts of society and its different groups are to be taken in consideration to effectively offer just health care.

From this perspective we were able to observe how healthcare personnel behaves depending on their own conception of justice and the role this conception takes at the workplace, from the point of view of their discursive practices. Being able to know the perception of justice that healthcare personnel has, gives us access to a clear vision on how to influence medical education in order to understand justice as fairness and in relation to the human capabilities that are necessary to reach a flourishing life. This implies expanding the solutions offered by the classical notions of justice offered in bioethics.

Abstract number: 56	Exploring research participants` perceptions and comprehension of the informed consent process in a pre-exposure HIV prevention study in Zimbabwe: A case study
ID: 549	Sitembile Ruzariro, Dr.Theresa Rossuw and Mr W. Mavhu
Poster	Zimbabwe, Meidcal Resaerch Council of Zimbabwe

Background: Ensuring informed consent is a complicated component of clinical trials particularly so with HIV prevention trials conducted in resource-limited settings. An inherent challenge characteristic of the informed consent process for HIV prevention studies conducted in these settings is making sure that trial participants understand that their participation does not increase their exposure to HIV. Participants also need to comprehend that partaking in such trials does not necessarily protect them from HIV. It is therefore intrinsically important to continuously monitor the informed consent process.

Methods: Between June and September 2011, gender-specific in-depth interviews (n=20) were held with interviewees who had been purposively selected from female participants who had exited a vaginal HIV prevention study in Harare, Zimbabwe. An interview guide was used to elicit views around the informed consent process. Discussions were conducted in Shona, the participants' language and audio-recorded. Audio-recorded data were transcribed, translated verbatim into English, coded using NVivo 8 and analysed using grounded theory principles.

Results: Discussions suggested that key information about the study had been given to research participants as they articulated study aims well. However, it also appeared that the informed consent process had been rushed and some participants had not had enough time to decide. Moreover, some participants reported that due to both excitement and anxiety, they had felt pressured to sign consent forms before comprehending some aspects of the study. Some mentioned that they had found it difficult to ask questions about the study. Additionally, data suggested that both the study procedure and duration had not been fully explained. There were mixed feelings on importance of male partner involvement in decision-making around study participation

Conclusions: This study elicited some of the issues that characterize the informed consent process for clinical trials conducted in resource-limited settings.

Abstract number: 57	Complaints about health services
ID: 562	Amparo Ibañez, Sandra Flores, Edith Sánchez, Rosa Sandoval, Jorge Soto, Edwin Vásquez, Fredy Canchihuamán
Poster	

Health care institutions must offer free, accessible and confidential services for complaints about health care services. The total number of user's complaints in an institution is considered as a proxy measure to assess the quality of institutional health care. Peruvian regulations on this issue consider complaints and transparent procedures and ombudsman offices.

Objective: The aim of this study was to describe the characteristic of the compliant services provided by health care institutions.

Methods: We assess the system of complaints of hospitals and national institutes located in Lima, the capital of Peru.

Results: The data indicate that 63% of hospitals and specialized national institutes have offices to present complaints and 93% of these health organizations have "complaint books", where patients can writes complaints. Although, all hospitals and institutes have Internet web sites, information available about complaint is only present in 60% of them. Of these organizations, 46% track the status of a complaint via telephone and 40% via internet.

Conclusion: Despite of the existing regulations, access to complaint services still remain challenging in hospital and specialized institutes in Lima. Better complaint services are urgently needed.

Abstract number: 58	Pulmonary diseases and ethics issues
ID: 582	Jose Luis Sandoval Gutierrez, Jaime Villalba Caloca
Poster	Mexico, Instituto Nacional de Enfermedades Respiratorias

In 2020 according to the data by the World health Organization, Chronic Obstructive Pulmonary Disease (COPD) will be the third leading cause of death in the global health, this combined with the pneumonia, tuberculosis (TB) and lung cancer, places the lung diseases as the leading cause of death in the world, so far there are not a sufficient number of pulmonary medicine physicians, as well as areas of intensive care medicine units nor the knowledge necessary in the areas of emergency services for the optimal care from the ethic and thanatology point of view for patients and their relatives.

Abstract number: 59 ID: 585 Poster	<p>Spanish regulatory approach for Biobanking <u>M^a Concepción Martín-Arribas, Javier Arias-Díaz, Javier García del Pozo and Carlos Alonso Spain, Instituto de Salud Carlos III (ISCIII)</u></p> <p>The Spanish regulatory framework for storage of samples for research responds to most issues raised by both researchers and society regarding biobanking. The Spanish regulation currently foresees three possible ways in which these samples are to be handled: (a) gathering for use in a specific project, (b) storage in a collection, and (c) storage in a Biobank. Samples incorporated into a 'collection' can only be used by the investigator who requested them and cannot be transferred to third parties or used in research projects outside the particular research line foreseen in the original consent. On the other hand, the legal entity 'Biobank' refers not only to a set of physical facilities but to the management of the samples stored under that label, and particularly to the requirements for their cession. An approach based on putting most of the regulatory weight on the biobank side has been chosen in order to guarantee the rights of the donors as well as to ease the task of the researchers.</p> <p>A Biobank requires both to be authorized and to be registered in a public Registry. The Spanish regulation endows the Biobanks with a defined structure to ensure compliance with the quality, legal, and ethical requirements. Accordingly, a Biobank should have two committees of external experts, a scientist one and an ethical one.</p> <p>The requirements are quite stringent, allowing for the consent to be given as 'broad' in scope without implying being 'blank.' In this regard, for Biobanks to justify the taking on of some of the donors' rights, a key requirement is to have an external ethics committee supervising the adequacy of samples cession and use, notwithstanding the need for a previous bioethical supervision of the target protocol.</p>
Abstract number: 60 ID: 601 Poster	<p>IMPLEMENTING NORMATIVE AND REGULATIVE DOCUMENTS FOR ETHICAL CONTROL IN RESEARCH AT CAMPECHE, MEXICO. <u>Eduardo Garcia-Solis, Mexico, Secretaría de Salud, Campeche, México</u></p> <p>Ethics in research, its regulation and normative for an ethical control of its activities, is a palpable demand in several scenarios where research is done in humans in Campeche. The activities related to research are performed by physicians, nurses, social workers and other health related workers with no adequate regulation of its ethical aspects. This situation can affect the rights of the patients, causing injustice that can be avoided.</p> <p>It is undeniable that human research is useful in the development of the scientific knowledge and that this advances are beneficial to humanity. But this research must always be done taking care of the dignity and justice to those involved in it, specially considering the most vulnerable populations. We must note that on occasion, the ethical criteria that should be intrinsic to the researcher's activity, is not met.</p> <p>In Campeche, research is done in human beings, whether they are on the coast, on the mountain or in the rivers. It is important to create ethical and legal parameters in the fields of research where humans are involved. This is fundamental to impulse the respect to human rights and dignity.</p> <p>Objective: To establish that the health workers involved in research projects must know the ethical documents regulating this kind of research.</p> <p>Design: Implementing a course-workshop in psychiatric, general and third level hospitals to spread the documents that norm the research.</p> <p>Conclusion: The staff doing human research should apply correctly the documents that govern the ethical aspects of this type of work.</p>
Abstract number: 61 ID: 621 Poster	<p>Re-identification risk from Genome Wide Association Studies (GWAS). <u>Carlos Alonso Bedate, Teresa Pámpols, M^a Concepción Martín, Javier Arias, Pilar Nicolás Spain, Instituto de Salud Carlos III</u></p> <p>Every REC must balance the potential benefits of research and the risks it could pose to the participants, evaluating if the benefits justify the risks. The protection of patients' rights (including their identity) without hampering research is a central issue in genomic research.</p> <p>When the Research Ethics Committee at the Institute of Health Carlos III received a project managing extensive genomic information it raised a debate on the risks of re-identification of the donors.</p> <p>Genomic tests involve certain risks to the participant. The main risk would be the breach of confidentiality, which could imply social stigmatization or discrimination risk (with implication to health insurance, access to employment,...). Additionally, it is necessary to consider re-identification risk, derived from combining the project's database with other data from different sources.</p> <p>It has been argued that it is impossible to guarantee the confidentiality of genomic information</p>

when the data are included in genomic databases. According to this, the Committee decided to authorize the project requesting additional measures to guarantee confidentiality, and so allowing research without disregarding donor's rights. These additional measures are based on a number of recommendations to the researcher found in the literature: restrict data access; establish long-term protection measures; update the promises of confidentiality made to participants in consent forms, including a warning that it is impossible to guarantee confidentiality without exception, an estimation of the risk of re identification and the possible harms derived from it.

Abstract number: 62

ID: 625

Poster

THE NETWORK OF HUMAN RESEARCH ETHICS COMMITTEES IN CALI, COLOMBIA: PROTECTING HUMAN SUBJECTS

Gloria I. PALMA, Jackeline BRAVO

Colombia, CIDEIM-- Centro Internacional de Entrenamiento e Investigaciones Médicas

Attendees to the Fogarty International Center/NIH funded invitational workshop that was carried out in Cali, Colombia in May 2011 to introduce and discuss Human Research Protection Program (HRPP) models, expressed their concern regarding the lack of national guidelines for research ethics committees in Colombia. In response to this need, the Network of Human Research Ethics Committees (Red de Comités de Ética en Investigación con Humanos, RECEIH) was created in October 2011. The objectives of this local network include providing general support and counseling to institutional ethics committees for handling ethical issues in research; training activities in research ethics for the academic and scientific communities and members of research ethics committees; and the dissemination of information relevant to bioethics particularly to research ethics. The research ethics committees currently in RECEIH come from 14 institutions in Cali that are carrying out clinical, biomedical or social sciences research. Its members share their knowledge, experience and efforts to advocate the creation of a culture of respect and awareness of the rights and welfare of research participants, develop the implementation of creative approaches in institutions to facilitate the mission of protecting research participants, promote scientific integrity and ethical responsibility in the researchers, and support the generation of research ethics policies in Colombia based on national developments and experiences.

During its two years of existence RECEIH has organized two international workshops to discuss research ethics issues such as protection of research participants, research misconduct and peer review. More than 120 researchers, members of research ethics committees and institutional administrative staff from 35 research institutions from different parts of Colombia have been trained through this approach.

Abstract number: 63

ID: 643

Poster

Privacy and trust in Biobanks for research – the Portuguese context

Cíntia Aguas Pereira,

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In an age of information technology, large amounts of data can be stored, analyzed and crossed with various other information. Genetic and clinical data rank among the most highly sensitive information, as they lay out a diary on our current and future health which, if disclosed, may be damaging and render us vulnerable. Therefore, it stands to reason that the setup of biobanks and associated databases working at a national and international level may be perceived by the public as a threat to individual privacy. Moreover, individuals seem to have little control over their personal information. In order to make autonomous choices, thus giving an informed genuine consent, one needs to be informed in a clear and adequate way. Sincere trust in scientific research can be undermined if the responsible parties do not favor transparency and refuse to engage in socially responsible science.

When one agrees to donate a biological sample, how can one be sure such sensitive information will be securely stored and will not be misused, and how can researchers and other stakeholders be trusted to act responsibly regarding the respect for privacy and the protection of personal data, as laid out in articles 7 and 8 of the Charter of Fundamental Rights of the European Union? In Portugal, biobanks are regulated by the provisions of decree law no. 12/2005, of the 26th of January, concerning personal genetic information and health information. Biological information can only be collected with the approval of an ethics committee, under the supervision of the Portuguese Data Protection Authority. The present work aims at highlighting the Portuguese legal and ethical context with reference to the protection of individual privacy, as well as debating public awareness regarding biobanks and associated genetic databases for research.

Abstract number: 64	Discussion about ethics of the placebo use in clinical trials for chronic pain
ID: 64	Daniela Caputo DORTA, ESTEVAO, Rosane Figueiredo
Poster	Brazil, WCT - World Clinical Trials

The placebo reveal such a high level of efficacy in clinical conditions like pain that could be interpreted as a true therapeutic effect until 35 % of the cases. The placebo effect is due to psychological mechanism and it is higher in pain conditions, so, the placebo use in clinical trials for proof of new drugs efficacy is scientifically essential to develop a new drug, especially as indicated in chronic pain, where it provides a high placebo response. However, the ethics of placebo use in patients in pain should be discussed once the used clinical methodology (patient randomization into two groups: one group receives placebo and the other one receives active treatment) is ethically questionable. According to the Declaration of Helsinki, updated in October 2013, the use of placebo is accepted when no proven intervention exist, where for compelling and scientifically methodological reasons the use of placebo, or no intervention is necessary to determine the efficacy or safety of an intervention, besides that the Declaration of Helsinki reinforces the need to use this option with extreme caution. Despite the patient's consent to participate in this type of study through the Informed Consent, we must remember that the main principle of ethics in human research: to ensure that the patient well-being, will be safeguarded during these studies, which can't be guaranteed in some cases. The placebo use in chronic pain patients should always be discussed on a case by case basis considering the ethical values, the benefits for the subject, avoiding its use whenever it's possible to establish other ways of proving the efficacy.

Abstract number: 65	The contribution of movies to bioethical reflections
ID: 647	Rosane Figueiredo ESTEVAO, Daniela Caputo
Poster	Brazil, CLION

The movie, besides being a form of entertainment, can also constitute in a great strategy used for teaching of Bioethics.

Thus the movies can be used as an instrument to generate debate and bioethical reflections on teaching -learning process. And so should stimulate an expanded and complex thought on various issues related to bioethics.

This helps to make value judgments and reflections to understanding and conflict resolution. Through data collection on the web and using the keywords "bioethics" and "films", we selected some movies that can be used as a teaching resource for the teaching of bioethics. The creation of a table with title, director, country, year, synopsis and bioethics topics facilitate choosing topics by the teacher.

To view the movie and after open to discussion can be used as problem-solving pedagogical tool, capable of instigating reflections about bioethical issues. We hope to contribute to building a more just and fraternal society.

Abstract number: 66	Biobank research and (potential) duties of researchers'. On beneficence, research-care distinction and therapeutic misconception in era of incidental findings
ID: 649	<u>Kristi Louk</u>
Poster	Estonia, University of Tartu, Centre for Ethics

There seems to be a move towards providing at least some feedback, information about incidental findings and/or individual research results to persons who have donated their biological material to biobanks.

The potential duty to inform participants about findings and results can be grounded based on different ethical concepts – respect for persons/autonomy, avoidance of harm and also the principle of beneficence.

Mostly it has been argued that the person has the right to know information about him or herself in order to make his/her life choices or it would be in the interests of the person to know this kind of information in order to become the manager of his/her own health.

In my presentation I focus on the principle of beneficence and have a closer look at it in context of researchers' roles and possible duties. Therefore the differences between (biobank) research and clinical care are looked at and elaborated on the usefulness of the research-treatment distinction and about the applicability of this distinction at biobank research context.

After that the concept of therapeutic misconception is analyzed in biobank research context. It will be shown how alluding to the (possible) disclosure of findings may nurture therapeutic misconception in biobank context and that the occurrence of therapeutic misconception depends also on how we understand beneficence and the duties of researchers' in biobank research context.

Realizing the interconnectedness has implications both at theoretical and practical level –whose duty it is to provide feedback and what should be seen as the duties of researchers' in biobank context.

Abstract number: 67	The field concept in contemporary and "subjective processes" of the person: reflections from the thought Reyes Mate and Giorgio Agamben
ID: 655	
Poster	<u>CAROLINA VELASCO</u> Brazil, PONTIFÍCIA UNIVERSIDADE CATÓLICA DO RIO DE JANEIRO (PUC-RIO)

By electing Giorgio Agamben and Reyes Mate as analysis parameter, is intended to foster reflection of the contemporary field concept .

We suggest a hermeneutical effort to transcend the understanding of the field that had to Auschwitz: the notion of field - in which one sees the permanent state of exception - generated effects that bulge in time and make connections with contemporary society. The hermeneutical process mentioned is the attempt to explain and identify the current context of field, which acquires different formats of Auschwitz, including furniture contours (marginalized communities, ghettos, refugee camps, and for that matter the places that keep women contracted to gestate children custom for couples willing to pay a fee for this service provision?). Both the concentration camp as these examples a real dismissal of the human status occurs. Agamben portrays this issue when distinguishes the moral life (perceived with dignity in all its aspects) of biological life (in which delineates the loss of dignity of the individual). Just like in Auschwitz, new conceptions of the field for the dehumanization of the individual, which moves the ideal extolled by the concepts of citizenship and democracy.

Thus, the permanent state of exception is identified in the case of pregnancy by replacing the extent that it appears to produce a collective victim in this case is the result of biotechnological developments coupled with individual autonomy. The consent is not conceived by legitimate, since it appears to impose financial conditions for the realization of the contract.

Agamben argues that the birth of the field appears in the current context "as an event that marks a decisive way the political space of modernity itself".

Abstract number: 68	Non-Invasive Prenatal Testing: an "option" to test or a "pressure" to test?
ID: 669	<u>Hazar Haidar</u> , Vardit Ravitsky
Poster	Canada, University of Montreal

Non-invasive prenatal testing (NIPT), a new reproductive technology that uses cell free fetal DNA from maternal blood, could be performed as early as 8-10 weeks gestation in order to detect fetal aneuploidies. The clinical benefit of NIPT is clear as it eliminates the risk of miscarriage associated with invasive diagnostic tests (amniocentesis). NIPT's ease and absence of risk eliminate the anxiety associated with the procedure itself and with the miscarriage risk. Therefore, it allows women to focus on the results rather than the procedure and its associated risks. NIPT's features are meant to enhance women's reproductive autonomy. Paradoxically, the ease and safety of the test may contribute to women feeling pressured to use it, thus creating a potential threat to autonomous decision-making. In the context of invasive testing, women's choice not to test could be "justified" by the presence of a miscarriage risk. Removing this risk, modifies the decision-making context, by increasing the pressure to test that may arise from the woman's internal sense of being a "responsible mother" and her moral obligations towards the unborn child, her partner and her family, the society's increased expectation that she contributes to public health by having "perfect baby" and the potential stigmatization when deciding to bring to term an affected baby. NIPT is a revolutionary technology. However, to truly promote reproductive autonomy it must remain an "option" not an "obligation". Women must know that they may refuse the test and should be protected from external influences by several tools such as appropriate counselling by a prenatal care provider, by creating support systems and by keeping research and funding aiming for treatment of children with Down Syndrome in order to support those women who choose to bring to term an affected pregnancy.

Abstract number: 69	Fining the Flab: Should Weight Loss be Mandatory for the Obese?
ID: 701	<u>Sophie Joury</u> ,
Poster	United Kingdom, University of Birmingham

Obesity is a tremendously important public health and primary care challenge. It is associated with severely debilitating, fatal co-morbidities, psychological distress, and discrimination at work, socially and interpersonally. It is also financially expensive for the wider economy, and is emotionally taxing for friends and relatives who must watch and care for suffering loved ones. Compounded with this, lack of effective treatment options has allowed obesity to rise. More restrictive intervention is thus needed to reduce obesity. Mandatory weight loss classes for obese adults, with monetary fines for non-attendance, might be more effective in reducing obesity than the interventions in place today. Primary health care providers, such as GPs, are best placed to decide which patients should be targeted. Fines will limit the liberty of those subject to them. Obesity, however, is harmful to others, both financially and emotionally. Liberty-limiting fines may thus be justifiable in order to reduce harm to others. Additionally, obese individuals might not have adequate autonomy over their unhealthy decisions due to our obesogenic environment, which encourages unhealthy behavior. Limiting the

liberty of obese individuals may thus facilitate their autonomy. Using principles of soft paternalism, fines may thus be justifiable in order to reduce the harm that obesity causes sufferers themselves. Harm reduction arguments, both to other people, and to self, may thus be used to justify fines. Although reduction of harm is important, fines might be a disproportionate response to obesity. There are combinations of less restrictive options that have not yet been adopted by relevant government bodies that might be able to target the actual causes of obesity. Examples include reducing portion sizes, changing food advertising, banning high fat or sugar products. If these measures are ineffective, however, there might one day be a place for fines in our society.

Abstract number: 70	Differences in perception of the acquisition of ethical values in College students in a Mexican Campus
ID: 749	
Poster	Sandra Anguiano Serrano, Aguilar, Eva; Coffin, Norma; Jiménez, María de Lourdes. México, UNAM

In an age that is characterized by change, and that seems to be aimed to globalization, it is important to educate people who can meet their needs, not only actively but ethically, since it seems that is the most difficult to do, for it lies in teachers and college responsible for making this possible guiding students on the path of professional ethics. The present study aimed to find perceptions of college students on the acquisition and transmission of ethical values by their teachers. To achieve this goal, it was applied to 192 Psychology (127) and Medicine (65) students, a questionnaire of 55 items ($\alpha = 0.9660$), which addressed the issue of professional ethics. Responses were analyzed (SPSS, 19.0), finding that both careers reported as "Important" ethical values, such as Responsibility, Respect, Deliver the best service offered to a client, Moral principles and Professional values (94% to 98%); "Transmitting my own values through my professional practice" showed significant differences between careers, being less important to Medicine students. Empathy seemed to be less important for Psychology students; although students consider that most of their teachers act ethically, their perception is that almost a third of them show unethical conduct, reaching to the point of harassment and discrimination in its various forms. Based on other variables, concerning to ethical competences, significant differences were found between both careers. Different ways of coping with problems, according the professional exercise in both careers can explain this. Medicine students cope with ethical dilemmas, due the distance between theoretical concepts and practical evidence. "Success and recognition", among Psychology students is valuable. This study shows how transmission of ethical values in professional training is not perceived by college students, the way we teachers figure them out. It is a process to develop ethical values in our students, and teachers must accept our responsibility as models, and as formers of worthy professionals.

Abstract number: 71	Ethical analysis of proposed human research at a university in western Mexico. 2008-2012
ID: 759	
Poster	Eduardo Ramírez-Soltero, Rafael Bustos-Saldaña México, Universidad de Guadalajara

Objective: To analyze the ethical components of protocols conducted on humans at the University South Center (CUSUR) in University of Guadalajara during the period from 2008 to 2012.

Material and Methods: Descriptive cross sectional study in all protocols performed in humans and which were approved by the Research Committee CUSUR since 2008 to 2012. Variables studied: Presence of ethical, ethics committee approval, risk assessment in subjects, informed consent, quality of informed consent, etc. Procedure: The research protocols were approved by the research committee during the study period was reviewed. Statistical analysis: Descriptive statistics were performed to describe the variables. Ethical issues: The protocol was approved by the Bioethics Committee of the Department of Health and Welfare CUSUR

Results: 42 protocols were examined, all were approved by the Research Committee and Ethics CUSUR, of which 10 had implicit risk studied, 29 of them were released from the institution where they take place, 27 had informed consent, all as comprehensive. Only 6 ethics mentioned principles of human research: 5 beneficence, non-maleficence, justice 6 and 2 in autonomy.

Conclusion: Although all protocols had some writing in the chapter on ethical issues, most of them have significant deficiencies in their components.

Abstract: Stigma and discrimination in patients with rare diseases are a serious problem in many care settings, since that undermine the delivery of health care and prevention programs.

In our hands we have tools to identify real needs of patients to help us improve the quality of services. Based on the perception and expectation, considering that the needs are dynamic and depend on a set of internal and external factors that indicate certain dimensions in which we must work.

Professional ethics for decades has been inefficient, new perspectives and ethical standards of professional as total quality and excellence and are beginning to bear new fruit, the parameters of the law playing a major role in the Ecuadorian state ethical public policy to comply with the fundamental duty to ensure comprehensive health based on equality, solidarity, and the application of bioethical principles.

At national development, both medical ethics, then, bioethics, and public health have come to a meeting. This process results in energization of the founding principles of bioethics, due to contradictions between the individual and the social , where the focus of apparent contradictions , are represented in public health in health actions based on social concepts of solidarity, responsibility and intercultural , where rules, regulations , and actions set in terms of public policies to protect vulnerable groups.



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