International Association of Bioethics (IAB) Satellite Symposium: Exploring International Policy Development Surrounding Innovative Technologies in Health

14 June 2016; Teviot Medical School, Teviot Place, Edinburgh

	Tuesday 14th June 2016				
0845- 0900	Symposium Registration Teviot Lecture Theatre, Doorway 5				
0900- 0930	WELCOME + ELSI 2.0 Introduction Prof Jane Kaye: University of Oxford Teviot Lecture Theatre, Doorway 5				
0930- 1100	PANEL I Socio-Ethical and Legal (ELSI) Implications of Genome Editing Technologies Assoc. Professor Ainsley Newson, University of Sydney, Australia Prof Kazuto Kato, Osaka University, Japan Dr Paul De Sousa, Reader, Centre for Clinical Brain Sciences, University of Edinburgh Assoc. Professor Rosario Isasi, Department of Human Genetics, University of Miami, USA Chair: Dr Sarah Chan, Usher Institute for Population Health Sciences and Informatics, University of Edinburgh Teviot Lecture Theatre, Doorway 5				
1100- 1130	Morning refreshments McMillan Room, Doorway 4, First Floor				
1130- 1300	Stem cell Research Scientists meet Ethicists Chairs: Prof. Georges Dagher and Prof. Kurt Zatloukal Prof. Christian Chabannon, Paoli Calmettes Institute, Marseille, France: 'Human Stem Cell Banking & Therapeutics' Prof. Dr Peter Schlenke, Department of Blood Group Serology and Transfusion Medicine, Graz, Austria: 'The Vision of Artificial Blood Supply' Prof. Dr James A. Adjaye, Institute for Stem Cell Research and Regenerative Medicine, University Hospital of Duesseldorf – UKD, Germany: 'Patient-derived induced pluripotent stem cell lines: applications and ethical concerns'	Digital Technologies for patients and publics Chair: Prof. Mahamadou Diakite Dr Flavio D'Abramo, Freie Universität Berlin, Germany: 'Reforming medical research: a dynamic consent approach based on formal ontologies' Dr Sandi Dheensa, University of Southampton, UK: 'The UK 100,000 Genomes Project: view, expectations and experiences of the first patients recruited' Dr Harriet Teare, University of Oxford, UK: 'The Rudy Study: Using digital technologies to enable a patient partnership'	Personhood in Genomics Chair: Prof. Eric Juengst Dr Allana Roach, University of Trinidad & Tobago: 'Are we vulnerable? — Potential sources of vulnerability associated with international collaborative genomics research conducted in CARICOM member states' Elonna Obiefuna, Institute of Human Virology, Nigeria: 'Knowledge of concepts of heritability of diseases and comprehension in Nigeria' Nchotou Ndimuangu, Research for Development International, Cameroon: 'Contribution of Africa Indigenous Knowledge System on the concept of personhood and a solution toward complexity in genetic research'		
1300- 1400	Lunch McMillan Room, Doorway 4, First Floor				









1400- 1530	MAKING CONNECTIONS (Networking Workshops)				
1550	Group 1: Prof Barbara Koenig, University of California San Francisco, USA and Prof Michael Burgess, 'The Future of Biobank Governance'				
	Group 2: Dr Sandra Soo Jin Lee, Stanford University, USA and Mr. Edward Dove, University of Edinburgh: 'The Challenges of Data Sharing'				
	Group 3: Dr Richard Sharp, Mayo Clinic, USA, Pensylvania State University, USA; Asst. Prof Jeremy Garrett, Children's Mercy Bioethics Center, Children's Mercy Hospital, USA; Prof Eric Juengst, University of North Carolina, USA: 'Interim Results from an International Initiative on Preserving Patient Rights in the Era of Genomics'				
1530- 1600	Afternoon Refreshments McMillan Room, Doorway 4, First Floor				
1600- 1700	CONCURRENT PECHA KUCHA PRESENTATIONS Slides move on automatically to keep everything on time. Fast, furious and fun!				
1700	Genomics and ELSI	New Technologies	Participant Perspectives		
	Hanzhi Yu, Tsinghua University, China: 'Institutional change of governing human genetic information' Dr Jacqueline Savard, University	Prof María Isabel Cornejo Plaza, Universidades de Chile y Diego Portales, Chile: 'Biobanks. Challenges in protecting data stored samples for biomedical research purposes. Chilean and Latinamerican Perspective'	Erica Jones, Personal Genome Project, UK: 'Exploring the open consent experience in the context of PGP-UK - the first research project in the UK and Europe to use the Open Consent protocol' Francis Masiye, University of Cape Town,		
	of Sydney, Australia: 'Security and reality in the personal genome testing journey: A view from Australia'	Giulia Cavaliere, King's College London, UK: 'An assessment of the 'Appeal to	South Africa: 'Ethical Challenges in Obtaining Informed Consent in the RHDGen Study'		
	Dr Rebekah McWhirter, University of Tasmania, Australia: 'Exclusion of indigenous peoples from genomics: when ELSI goes awry'	Eugenics' argument in the genome editing CRISPR/Cas9 debate' Emilia Niemiec, University of Bologna, Italy: 'Ethical issues of gene editing: what does popular media report?'	Dr Liza-Marie Johnson, St. Jude Children's Research Hospital, Memphis, USA: 'Cancer Predisposition Syndromes in Children with Cancer: Perspectives from Parents and Adolescents recently offered Next Generation Germline Sequencing'		
	Heidi Beate Bentzen, University of Oslo, Norway: 'Genomic Research Review in Norway – REC's Role' Prof. Mahamadou Diakite,	Dr Fruzsina Molnár-Gábor, Heidelberg Academy of Sciences and Humanities, Germany: 'The Duty of the European public sector to establish computing clouds for scientific research'	Dr Stacey Pereira, Center for Medical Ethics and Health Policy, Baylor College of Medicine, USA: 'Genetic Guilt: Parents' expectations and experiences of guilt, blame, and relief in response to genome sequencing for pediatric cancer patients'		
	University of Science, Techniques and Technologies of Bamako, Mali: 'Genomic Studies ethical clearance in Africa: experience from Mali in West Africa'	Pin Lean Lau, Central European University, Budapest, Hungary: 'Perpetuating Embryo Trafficking in South-East Asia? Thailand, the last Asian Frontier in Reproductive Tourism vis-à-vis Pre-Implantation Genetic Diagnosis'	Dr Victoria Chico, University of Sheffield, UK: 'Promoting a granular and achievable view of the informational requirements for consent to secondary uses of health data'		
1700- 1800	PANEL II Ethical, legal and social implications of CRISPR-Cas9 Dr Owen Schaefer: 'Against a blanket ban on reproductive germline modification' Dr Jasper A. Bovenberg and Prof Judit Sandor: 'Patenting Gene-Editing: let's hear the public first' Tristan McCaughey: 'Determinants of public attitudes to human genome editing: a global perspective' Teviot Lecture Theatre, Doorway 5				
1800	END OF MEETING Those attending the 13 th World Congress of Bioethics (IAB2016) are encouraged to continue their discussions with others at the IAB Opening Reception Edinburgh International Conference Centre				