

# ELSI2.0 Periodic Report, Autumn 2016

19 September 2016

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On 14 June 2016 ELSI2.0 joined forces with the EU FP7 project EUCeLLEX (<https://www.eucellex.eu/>) to host a joint Symposium 'Exploring International Policy Development in Regenerative Medicine' alongside the [13th World Congress of Bioethics](#).

Highlights included a Panel session considering 'Socio-Ethical and Legal (ELSI) Implications of Genome Editing Technologies', Chaired by Dr Sarah Chan, Usher Institute for Population Health Sciences and Informatics, University of Edinburgh. Panellists were:

- Associate Professor Ainsley Newson, University of Sydney, Australia
- Professor Kazuto Kato, Osaka University, Japan
- Associate Professor Rosario Isasi, Department of Human Genetics, University of Miami, USA
- Dr Paul De Sousa, Centre for Clinical Brain Sciences, University of Edinburgh

A second Panel comprising Stem Cell Research Scientists together with Ethicists also stimulated a lively debate.

In addition ELSI2.0 was a proud supporter of the IAB meeting, with the event attracting a number of new members, and enabling existing members an opportunity to meet and discuss their research.

We are excitedly watching the publication of a thematic collection published through BioMed Central, which collates those articles submitted off the back of our June 2015 international ELSI2.0 conference entitled '*Translation in Healthcare: Exploring the Impact of Emerging Technologies*'. The thematic collection is available at the following URL:

<https://www.biomedcentral.com/collections/translationelsi>

Citations of articles included in the thematic issue are given below:

- Kieran C. O'Doherty, Emily Christofides, Jeffery Yen, Heidi Beate Bentzen, Wylie Burke, Nina Hallowell, Barbara A. Koenig and Donald J. Willison, 'If you build it, they will come: unintended future uses of organised health data collections'. *BMC Medical Ethics* 2016 17:54
- Ainsley J. Newson, Samantha J. Leonard, Alison Hall and Clara L. Gaff, 'Known unknowns: building an ethics of uncertainty into genomic medicine'. *BMC Medical Genomics* 2016 9:57
- Victoria Coathup, Harriet J. A. Teare, Jusaku Minari, Go Yoshizawa, Jane Kaye, Masanori P. Takahashi and Kazuto Kato, 'Using digital technologies to engage with medical research: views of myotonic dystrophy patients in Japan'. *BMC Medical Ethics* 2016 17:51
- Gabrielle Bertier, Martin Héту and Yann Joly, 'Unsolved challenges of clinical whole-exome sequencing: a systematic literature review of end-users' views'. *BMC Medical Genomics* 2016 9:52

- Don Chalmers, Dianne Nicol, Jane Kaye, Jessica Bell, Alastair V. Campbell, Calvin W. L. Ho, Kazuto Kato, Jusaku Minari, Chih-hsing Ho, Colin Mitchell, Fruzsina Molnár-Gábor, Margaret Otlowski, Daniel Thiel, Stephanie M. Fullerton and Tess Whitton, 'Has the biobank bubble burst? Withstanding the challenges for sustainable biobanking in the digital era'. *BMC Medical Ethics* 2016 17:39
- Jessica Bell, Mirko Ancillotti, Victoria Coathup, Sarah Coy, Tessel Rigter, Travis Tatum, Jasjote Grewal, Faruk Berat Akcesme, Jovana Brkić, Anida Causevic-Ramosevac, Goran Milovanovic, Marianna Nobile, Cristiana Pavlidis, Teresa Finlay and Jane Kaye, 'Challenges and opportunities for ELSI early career researchers'. *BMC Medical Ethics* 2016 17:37
- J. Patrick Woolley, Michelle L. McGowan, Harriet J. A. Teare, Victoria Coathup, Jennifer R. Fishman, Richard A. Settersten, Sigrid Sterckx, Jane Kaye and Eric T. Juengst, 'Citizen science or scientific citizenship? Disentangling the uses of public engagement rhetoric in national research initiatives'. *BMC Medical Ethics* 2016 17:33
- Stuart G. Nicholls, Holly Etchegary, June C. Carroll, David Castle, Louise Lemyre, Beth K. Potter, Samantha Craigie and Brenda J. Wilson, 'Attitudes to incorporating genomic risk assessments into population screening programs: the importance of purpose, context and deliberation'. *BMC Medical Genomics* 2016 9:25
- T. Fischer, K.B. Brothers, P. Erdmann and M. Langanke, 'Clinical decision-making and secondary findings in systems medicine'. *BMC Medical Ethics* 2016 17:32
- Louise M. Bezuidenhout and Michael Morrison, 'Between Scylla and Charybdis: reconciling competing data management demands in the life sciences'. *BMC Medical Ethics* 2016 17:29
- Isabelle Budin-Ljøsne and Jennifer R. Harris, 'Patient and interest organizations' views on personalized medicine: a qualitative study'. *BMC Medical Ethics* 2016 17:28

The next focus for ELSI2.0 is the establishment of Making Connections groups, created and managed by members to share ideas and work together on specific issues.