

ELSI2.0 Annual Report 2016

01 February 2017

During 2016, ELSI2.0 continued to build connections between international researchers interested in the ethical, legal and social implications of research in the life sciences. The highlight of our year was our international symposium entitled 'Exploring International Policy Development in Regenerative Medicine' which was held alongside the 13th World Congress of Bioethics, Edinburgh, 14 June 2016, and organised in conjunction with the EU FP7 project EUCellEX (<https://www.eucellex.eu/>). 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.

Publication of a thematic collection of articles relating to the meeting in BioMed Central testifies to the success of the symposium in stimulating ongoing collaboration. Citations of articles included in the thematic issue are given below. The open access collection can be viewed online at <https://www.biomedcentral.com/collections/translationalelsi>

During the latter part of the year attention was focussed towards redesign of the communities' framework for collaboration. Members are encouraged to participate in Making Connections groups, which can be set up and led by any member and provide a forum for discussion of topical ELSI research. Details of ongoing activity and how to set up a new Making Connections group are available on the Network's website: <https://elsi2workspace.tghn.org/making-connections/>

Community publications during 2016:

- Michael Morrison, Donna Dickenson, Sandra Soo-Jin Lee, 'Introduction to the article collection 'Translation in healthcare: ethical, legal and social implications. *BMC Medical Ethics* 2016 17:74
- Alessandro Blasimme and Effy Vayena, 'Becoming partners, retaining autonomy: ethical considerations on the development of precision medicine'. *BMC Medical Ethics* 2016 17:67
- 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