

ELSI2.0 Annual Report 2015

19 January 2016

During 2015, ELSI2.0 continued to strengthen its network of international researchers interested in the ethical, legal and social implications of research in the life sciences. The highlight of our year was our first international ELSI2.0 conference, entitled '*Translation in Healthcare: Exploring the Impact of Emerging Technologies*'. With 135 delegates from over 20 countries the event was a huge success and a valuable opportunity to showcase our achievements. The conference also hosted the official launch of our ELSI2.0 website and online platform. A Special Issue in BMC Medical Ethics will collect papers emanating from discussions held during the conference and the collaborations they stimulated.

Three years on from the launch of our Network, we took time to reflect back on our achievements and consider effective strategies for the next 3 years. 6 new members have been recruited to our steering committee both to replace those who have stood down and increase membership. We thank Dr. Kelly Edwards (University of Washington, USA) Alastair Kent (Genetic Alliance, UK) Jantina de Vries (University of Cape Town, South Africa) for their service and dedication. Whilst the focus to date has been on growing our membership, 2016 will see the launch of our new 'Making Connections' activity groups - pop-up forums and networked groups to support collaborative endeavours or identified research synergies. A strategic committee comprised of the leaders of several pilot Making Connections groups will produce guidance to assist those interested in establishing their own groups – further details of how to do so will be released in the spring, accompanied by information on existing groups.

We look forward to an exciting and invigorating year of collaboration and knowledge exchange!!!

Selected activities supported by the network during 2015 are shown in the table below.

Partners/Lead organisation/Location	Title/dates	Description
Collaborations		
Dep. of Biomedical Ethics and Public Policy, Graduate School of Medicine, Osaka University and Centre for Health, Law and Emerging Technologies, University of Oxford	Development of a framework for medical research governance involving patients and citizens	Providing 3 years of support for members of the participating institutions to visit one another and share expertise around the governance of medical research and participant engagement
Meetings		
Centre for Health, Law and Emerging Technologies, University of Oxford	Translation in Healthcare: Exploring the Impact of Emerging Technologies, 23-25 June 2015, Oxford	This interactive and stimulating conference explored the broad theme of Translation in Healthcare. The event celebrated 5 years of research at HeLEX, and hosted the official launch of the ELSI2.0 Workspace. A friendly and supportive atmosphere sparked numerous new collaborations, and delegates will continue to work together to prepare publications for a special issue of BMC Medical Ethics.
Inserm and University Toulouse III Paul Sabatier joint Unit 1027, Genomics and public health	Sharing science, sharing values: the challenge of diversity, 03 December 2015, Toulouse	Colloquium addressing the values at stake in technological developments in genomics and their applications to the health sector, in the international context. The event celebrated 18 years of research in the group on Genomics and public health at Inserm and University Toulouse III Paul Sabatier joint Unit 1027, and marked an end of an era and the launch of a new venture as Anne Cambon-Thomsen adopted emeritus status and handed over leadership of the team to her distinguished colleague Emmanuelle Rial-Sebbag.
Other presentations		
Publications		
Centre for Health, Law and Emerging Technologies, University of Oxford together with ELSI2.0 Early Career Research Network	Challenges and Opportunities for ELSI Early Career Researchers	Paper describing contemporary challenges and opportunities identified by ELSI ESRs and discussed during a workshop held in Oxford during November 2014
Centre for Health, Law and Emerging Technologies, University of Oxford together with ELSI2.0 Steering Committee	A learned society founded in the digital era: designing a network infrastructure for ELSI 2.0	This manuscript reflects on the first 3 years of ELSI2.0 activity, outlining our achievements to date in the creation of an international collaboratory for ELSI researchers. Ongoing challenges

		are described in the context of our development during an evolving digital age.
University of North Carolina-Chapel Hill, Center for Bioethics and Centre for Health, Law, and Emerging Technologies, Oxford	Citizen Science or Scientific Citizenship? Disentangling the Uses of Public Engagement Rhetoric in National Research Initiatives	Paper comparing national strategies to biomedical data collection and distribution in the US and UK
University of North Carolina-Chapel Hill Center for Bioethics and Indiana University Center for Bioethics	Hearing Voices: Who Should Have a Say in the Governance of International Genome Research?	Paper comparing moral claims to control over the research uses of human DNA samples by individuals, families, researchers, research institutions, communities and nations