



INDIANA UNIVERSITY
CENTER FOR BIOETHICS

Report on the ELSI 2.0 Meetings, May 5-7, 2014, Indianapolis, IN

The Indiana University Center for Bioethics and ELSI 2.0 convened meetings in Indianapolis: May 5 (ELSI 2.0 “Methodology” work group; ELSI 2.0 Steering Committee); May 6 (*The Indianapolis ELSI 2.0 Meeting*); May 7 (*“Ethics at the Crossroads: When Public Health, Genomics, Data and Translational Science Meet*). This document provides a summary of the meetings including funding, outcomes, logistical information, and preliminary evaluation results.

Funding

The cost for three days of meetings was approximately \$34,250 (final invoices still being processed) which covered: food, ground transportation, hotel accommodation for all speakers and steering committee members, air travel for many steering committee members and invited speakers, materials, signage, incidentals. We were aided greatly by direct sponsorship from several sources:

SPONSOR	CONTRIBUTION
Case Western Reserve Center for Genetics Research Ethics and Law (via P. Marshall)	\$5000
Center for Law, Ethics, and Applied Research (CLEAR) in Health Information (via F. Cate supporting May 6 reception and dinner)	~\$2000
Indiana Clinical and Translational Sciences Institute (CTSI) Workshop Grant (Meslin PI)	\$1500
Center for Health Policy, Richard Fairbanks School of Public Health (via R. Silverman)	\$750
IU Center for Bioethics (through several different grants)	~\$25,000
TOTAL	~ \$34,250

In addition to this direct sponsorship, Public Population Project in Genomics and Society (P3G) and BioShare.eu supported travel of certain members as did several Steering Committee members who used their own resources to support air travel. See Appendix A for a table of those who received support and from which source.

The Indianapolis ELSI 2.0 Meeting: May 6, 2014

The day's events were held in the main conference room and Center for Bioethics suite at the Health Information and Translational Sciences Building, 410 West 10th Street, Indianapolis, Indiana. In total, 39 participants registered and 36 attended representing eleven countries: Australia, Canada, France, Germany, Japan, Kenya, Norway, South Africa, South Korea, United Kingdom, and USA (See Appendix B for list of participants).

- ◆ After opening remarks by Eric Meslin and an overview of ELSI 2.0 by Jane Kaye, members of the ELSI 2.0 Steering Committee gave brief presentations on “**The ELSI 2.0 Toolkit**”: organizational strategy and outreach (Kaye), research methodology (Harris), informatics (Edwards/Tasse), and graduate training (Hoppe).
- ◆ Jeff Kahn and Gail Geller (Hopkins) gave an overview of their NIH CEER (Center for Excellence in ELSI Research) planning grant from on “**genomics and infectious disease**” as a case study of ELSI 2.0 research.
- ◆ Four expert-moderated groups were convened at the **ELSI 2.0 Interface** to discuss four priority areas: infectious disease and genomics (Kahn/Geller); data sharing, big data (Thomsen/Kato); genomic sovereignty (DeVries/Marshall); and ethics safe harbor (Dove/Nic Terry). Due to excessive interest and tight scheduling, only 3 of 4 round tables were possible. General discussion was facilitated by Alastair Kent and Anne Cambon-Thomsen.
- ◆ Ted Dove and Kazuto Kato gave the group an update on the latest draft of an International Code of Conduct for Genomics and Health-Related Data Sharing developed by the Regulatory and Ethics Working Group of the Global Alliance for Genomics and Health.

Outcomes from May 6:

1. Agreement on a set of Objectives for 2014-2015 presented by Jane Kaye
2. An informal list of IT tools currently used and those participants wished to use (Appendix C).
3. A memorandum of understanding to host graduate students for ELSI training developed and circulated by Nils Hoppe. Twenty signatories committed to this activity
4. Jeff Kahn presented an overview of www.Ethicshare.org and invited participants to use and provide comments
5. Meslin invited to be part of Kahn/Geller panel at ASBH San Diego Meeting 2014 (October)
6. Dove and Kato invited participants to comment on the *Code of Conduct* [circulated May 12]
7. DeVries, Subha, and Marshall developed specific aims for the genomic sovereignty project
8. Meslin and Burgess to pursue application involving “smart data governance” using a deliberation model
9. Slides from 6th are being collected and will be posted with a number of photos, contact information of ELSI 2.0 members, and other files on the IU Center for Bioethics webpage at <http://www.bioethics.iu.edu/>.

Ethics at the Crossroads: Where Public Health, Genomics, Data and Translational Science Meet, May 7, 2014

The conference was held at the IUPUI Campus Center Theater, Indianapolis. 107 people registered and 73 people attended at least some part of the conference. A list of attendees can be found in Appendix D.

- ◆ Opening addresses were given by IU's Dean of Medicine, Dr. Jay Hess, and Director of Indiana CTSI, Dr. Anantha Shekhar.
- ◆ The morning keynote address was given by Jantina de Vries of South Africa and titled, "Negotiating fairness in sharing H3Africa samples and data: a policy framework in development."
- ◆ The afternoon keynote address was given by Susan Wolf of the University of Minnesota and was titled, "Genomic Surprises: Should We Give Patients and Research participants Unexpected Findings of Clinical Importance."
- ◆ Four expert moderated panels addressed the audience on the topics of: biobanks and precision medicine; genomics and public health; big data, small data, shared data; and translational science and global governance (which became a more informal discussion with the audience (Appendix E).

Outcomes from May 7

1. Video recordings and slides from this meeting are currently being collected and archived and will be placed in perpetuity on the IU Center for Bioethics website at www.bioethics.iu.edu.

Evaluation

Electronic surveys were sent to all registered participants using Survey Monkey. An initial set of responses have been received (see: <https://www.surveymonkey.com/results/SM-RT66NRF/>). This will be updated when more responses are received.

Appendix A

Name	Hotel Paid By	Airfare Paid By
Clement Adebamowo*	IUCB	IUCB
Anina Saetre Bjornhaug	BioShare	BioShare
Isabelle Budin-Ljosne	BioShare	BioShare
Michael Burgess	IUCB	IUCB
Anne Cambon-Thomsen	IUCB	Inserm
Tim Caulfield*	IUCB	IUCB
Subhashini Chadraskekaren	IUCB	UNC
Jantina De Vries	IUCB	IUCB
Edward Dove	IUCB	P3G
Kelly Edwards	IUCB	IUCB
Gail Geller	IUCB	IUCB
Alison Hall	IUCB	IUCB
Jennifer Harris	BioShare	BioShare
Nils Hoppe	IUCB	IUCB
Jeff Kahn	IUCB	IUCB
Jane Kaye	IUCB	HeLex
Alastair Kent	IUCB	IUCB
Kazuto Kato	IUCB	Osaka
Patty Marshall	IUCB	Case Western
Dianne Nicol	IUCB	U of Tasmania
Anne Marie Tasse	IUCB	P3G
Christine Wasunna	IUCB	IUCB
Susan Wolf	IUCB	IUCB
Ron Zimmern	IUCB	PHG Foundation

*Unable to attend

MAY 6 ELSI 2.0 Meeting			
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Appendix B

Appendix C

ELSI 2.0 Status Quo and Wishlist

Tools we use and tools we want

I use...

Tool (Box 1)		Tool (Box 2)	
Dropbox	20	iCloud	2
Skype	16	Video conference	2
E-Mail	15	basecamp	2
Google Docs	12	Omnijoin	3
Twitter	6	invivo, forums,	1
Teleconference	6	blogs, legal	
Facebook	4	databases,	
F2F	3	evernote, ms word,	
GoogleChat	2	wiki, youtube,	
Webpages	3	researchgate, EM	
Onedrive	2	desk, facetime,	
Phone	2	sente, sharepoint,	
LinkedIn	2	hyperoffice, pep	
		ph resonance, doodle,	
		skydrive, mobile	
		messengers	

I want...

Things I Want:

- Shareable archives of unpublished data, notes
- Idea
- Idea development
- Sitting people in the room (policy makers, public)
- Technology that gives the feeling of face-to-face meetings
- Helpdesk, chat and overview of experts in filed globally
- Archive of existing work
- Combine “tools I already use”
- Group skype
- Tools that allow remote work that don't require being online
- Tools that have been tested worldwide and work with any equipment
- Don't need new updates
- Don't need to download things all the time
- Are compatible
- Don't need tools that use more of my time than it saves
- Research sharing
- Quality screens for publications
- Reliable up to date access to breaking news/issues—consolidated, curated, grey literature
- Software that allows groups of people to analyze data together
- Primary group of researchers that own a project, and then ELSI 2.0 allows other, tertiary researchers to get involved in components of the research project
- Constructive discussion on topics pertinent to the research context
- Secure connection for F2F conferencing
- Quick messaging to colleagues
- Secure and safe documents that can be edited and exchanged
- Ways to connect to people
- Everything I need I can access easily on one dashboard
- New papers that are coming out
- One sign-in to everything
- Regular updates and Gossip (who is moving, what new things are happening)
- Track whats happening
- To use Youtube and clips to talk about my work
- Project management and other shared workspace tools used in business
- Ways to overcome time differences
- Free-flowing, face to face meeting
- Way to reach general public who read news media and are not on social media
- Motivate people to care about ethics of genetics/genomics
- Memorialization/recording archiving of technologically-mediated meetings
- Translation of international resources
- Guidance towards and access to appropriate international resources
- Accessing new stakeholder groups
- Ways of linking tools between different silos
- Identifying incentives that are relevant recognizing that this may be different for research/accelerator phases
- Tools that are able to be used when there are limitations to computers access and in developing countries
- Google doc
- Documentree
- Centralized repository of past ELSI projects across the lifespan from grant application to methodology to reports and raw data. A tool to aggregate knowledge (break down silos, get contact info) and preserve sustainability
- Engagement tools—listening to what people (whom we cannot readily reach or who do not know they need to be reached) think are important ELSI, and then tools that can collate that feedback and transform that feedback into useful information and eventual policy and practice
- Language tools
- Ethics review limits access
- Platform compatibility for analysis of data'
- Ways to find interested and committed people
- Open access to publications when copyright bars access
- One stop shop for: group communication, one on one communication, communication types (written, visual), editing publications, research planning, seeking information and disseminating information, relationship building, developing strategies, policies, guidelines, grant writing
- Tools for knowing what others are doing now
- Tools for knowing what others are trying to publish or have not published but are relevant
- Tools for knowing what conversations occur in meetings that I don't attend
- Tools for knowing how to initiate, build, and maintain collaborative relationships when I cannot attend all the relevant meetings
- Tools for knowing how to use and be more efficient with platforms
- I want something that combines
- Bi-rectional process
- Sustainability
- Governance
- Leadership
- Reaches out to others that are unaware they need to be reached

Appendix D

May 7 - Ethics at the Crossroads			
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