

Workshop Report: The Governance of International Consortia – Establishing a Proof of Principle for ELSI 2.0

03-05 May 2014

Summary:

The aim of this workshop was to explore some of the challenges that face the current governance frameworks of international research consortia when global data sharing is envisaged. It brought together experts who have been working in this field to prepare a publication to identify key issues and initiate a debate about this issue. This workshop resulted in:

- 1) Discussion of the limitations of current governance structures
- 2) Identification of the ways that we can improve global sharing
- 4) A draft paper based on our discussions

To optimise the benefit of having so many experts in the room the workshop consisted of formal information sharing sessions as well as less structured breakout groups and writing sessions. Using a series of post- stick sessions to enable ideas and concepts to be organised. These formed the basis for the paper. Much of the thinking was done for this paper at Brocher to maximise the deep conversations permissible because of the face to face opportunity. To continue this discussion, the newly established ELSI 2.0 e-workspace will use this topic as a one of its pilot Activity Zones topics. This has only been possible because of the Brocher Fondation meeting that enabled this initial discussion.

Major disciplines represented:

Law; Bioethics - Medical ethics; Biology; Science and technology studies; Sociology

Overview:

A 2.5 day workshop was hosted from June 03-05, 2014 which included 24 scholars from Europe, the USA, Canada, Africa, Japan and Australia. All participants presented conclusions and recommendations based on their prior empirical and theoretical analysis of consortia governance and data sharing. The meeting included extensive discussion of the issues at hand, conducted as a workshop in which different groups came together to brainstorm requirements and considerations that need to be taken into account when designing a governance structure. The group considered data sharing issues faced by today's research community, and elements that could/should be improved. The format of our deliberations, in which thoughts were summated in a few words on a post-it note before being shared

with the group, proved a particularly amenable for encouraging the participation of those delegates with less confidence in their English language skills, whilst breaking out into small working groups encouraged the interaction of junior researchers with more established academics. The thoughts that came out of these discussions were summarized into short paragraphs and fed back to the wider group for discussion, enabling all delegates to discuss a wide remit of issues and innovative ideas. A complete set of narrative notes from the meeting has been assembled, and is being formulated into a group publication.

Setting the Workshop Objectives

These were defined as:

- 1- *Articulate the limitations of current governance structures*
- 2- *To describe the meta-governance structures that should be developed to enable global sharing between consortia*
- 3- *To identify how we can accelerate our solutions into policy making*
- 4- *To write a paper based on our discussions*

In preparation for the following discussions, the group identified the following components of a governance structure:

Break out groups round 1: What are the challenges, and how do current governance structures fail large scale consortia with data sharing needs?

Challenges identified:

- 1- *Infrastructure and resources to ensure effective implementation*
- 2- *Cultural divides*
- 3- *Safeguarding data quality*
- 4- *Global communication*
- 5- *Devolved governance*
- 6- *Stakeholder engagement*
- 7- *Ownership and accountability*
- 8- *Ethical and legal agreement*

Break out groups round 2: What are the solutions? What do we need to enable data sharing between consortia

The group's deliberations identified the following themes that need to be addressed to develop an effective framework for data sharing:

- 1- *The tensions between the individual and the collective*
- 2- *Governance and sanction mechanisms*
- 3- *Thinking Globally versus acting locally*
- 4- *The socio-technical landscape for data sharing*
- 5- *Human stakeholders*
- 6- *Data sharing processes*
- 7- *Values*
- 8- *Quality assurance and usability of data*

These considerations can broadly be collated into 3 key themes: globalization, people and capital.

Group discussion: How do we get our solutions implemented, and what are the next steps?

Outcomes:

A complete set of narrative notes from the meeting has been assembled, and is being formulated into a group publication. The publication is in the process of being formulated, using the ELSI 2.0 workspace and Omnijoin webconferencing. The title has yet to be formulated but it will be about the issues that need to be considered with data sharing and we anticipate that it will be published in early 2015.

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