

Meeting report series

Report of the 18th Interdisciplinary Scientific Committee Meeting

Teleconference
26 June 2017

Participants

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Apologies

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Agenda

1. Welcome and introduction
2. Discussion of goals
3. Overview of technical landscape
4. Overview of consent landscape
5. Any other business

REPORT

1. Welcome and introduction

The Chair welcomed members who joined the teleconference call, and introduced the invited participants who will be involved in the work of coordination to facilitate data sharing and consent.

2. Discussion of goals

From previous discussion – the ISC should help promote data sharing; for this initiative:

- ▶ Product: core language that can be shared via IRDiRC website or through a published article
- ▶ Content: “what do we do upstream to enable downstream data sharing”, e.g. to have the right consent, data use agreement, data standards, etc.

The aim of this teleconference is to discuss how to:

- ▶ Foster data sharing by helping researchers to better contribute to and access data
- ▶ Harness experience, track record and expertise thus to promote measures that will facilitate downstream data sharing
- ▶ Promote dissemination and make visible available resources, not reinventing new ones
- ▶ Encourage funders to embrace the FAIR (Findable, Accessible, Interoperable, Reusable) principles and include relevant statements in calls for proposals and suggest data sharing tools
- ▶ Synthesise available resources into an easy-to-understand tool for researchers
- ▶ Minimise data collection by investigators without first getting relevant advice and guidance

3. Overview of technical landscape

A preliminary technical landscape analysis was started and summarised in an Excel grid circulated to all ISC members; this grid is currently incomplete.

A number of concerns were raised:

- ▶ Many different standards so harmonisation of standards is badly needed
- ▶ Unsure how/if (metadata) standards overlapped with existing efforts, e.g. NIEM, HL7, NCI
- ▶ Will a new initiative be adopted if it doesn't fit with other communication standards?
→ Proposal: landscape the standards, identify best technical standard for purpose (e.g. ISO), and recommends initiatives to fit into the standards and/or align with the protocols

Preparation of the EJP co-fund for rare diseases research

- ▶ Currently preparing to map all initiatives related to data standards, data sharing, interoperability
- ▶ Will include initiatives in Europe and beyond, some rare disease-specific, some not but address rare diseases nonetheless (e.g. BBMRI on biobanking)
→ Proposal: combine efforts in technical landscape analysis

A grid to display synthesised landscape of resources:

- ▶ Show available resources and where they can be found/accessed
- ▶ A column of principles/features offered by these resources
 - Example of concept with comparator feature grid: TopTenReviews site
 - E.g. <http://www.toptenreviews.com/software/security/best-antivirus-software/>
 - Easy to visualise which resource(s) has features that researchers want
- ▶ Multi-level display, with gradation of principles, policies, procedures and standards
 - Example with 3 levels:
 - Level 1: Specific policy, for people looking to develop things for their centres
 - Level 2: Procedural, what are the tools available and where to find them
 - Level 3: SOPs and standards already available
- ▶ Consideration of ranking resources
 - E.g. resource with more features filled will be ranked higher
 - E.g. receiving feedback from users to help weight the ranking
- ▶ Matrix could be complicated for groups that offer many resources
- ▶ Different matrices may be created in accordance to disease domains

Some obstacles:

- ▶ How to share, retrieve and analyse data – including consent and technical aspects
- ▶ How to better access information and data
- ▶ How to meet (highly variable) data sharing requirements in a global manner which have been set by stakeholders, e.g. regulators, policy makers, journals
- ▶ How to address regulations that are outdated

Initial idea behind data standards clearinghouse proposal:

- ▶ Ability to organise and promulgate data standards
- ▶ Use cases to help investigators find appropriate data standards of what they want to do
- ▶ Make sure data sharing initiatives intersect with the right stakeholders
- ▶ Potential models to look into: Bioportal of the National Center for Biomedical Ontology (NCBO), a catalogue of almost 300 ontologies, terminologies and standards

Product of this work:

- ▶ Update materials already on IRDiRC website
- ▶ Include links to relevant resources (guidelines, standards, tools)
- ▶ Restatement that funders and researchers should consider using these resources
- ▶ Summary statement that encourage the application of FAIR principle
- ▶ ADAM can be a specific, elegant solution under this principle
- ▶ Publication of an article to disseminate further this work

4. Overview of consent landscape

Preliminary consent landscape work:

- ▶ Collecting documents available on consent and links to each document

- ▶ For internal use: documents available on Dropbox
- ▶ Addition of journal manuscripts for researchers needing literature backup

→ List to be updated as consent landscape work continues

→ Collaborate with P3G/GA4GH on policy and consent work, e.g. to review the emerging grid

Summary

What IRDiRC/ISC can do now:

- ▶ Identify and catalogue data standards
- ▶ Collaborate with EJP preparation group in landscaping work
- ▶ Promote data standards through use cases
- ▶ Work with regulators/policy makers to determine data sharing criteria
- ▶ Develop a statement on what investigators should know about IRDiRC recommendations

On the next ISC call in July or August:

- ▶ To hear updates on landscaping work
- ▶ To explore if a Task Force is needed, or to set up some other collaborations
- ▶ To plan the next steps