

## Meeting report series

### Report of the 15th Interdisciplinary Scientific Committee Meeting

Teleconference  
13 January 2017

#### Participants

Prof Hanns Lochmüller, Newcastle, UK (Chair)  
Dr Petra Kaufmann, Bethesda, USA (Co-Chair)  
Dr Angel Carracedo, Santiago de Compostela, Spain  
Ms Gema Chicano, Murcia, Spain  
Prof Jack Goldblatt, Perth, Australia  
Dr Stephen Groft, Bethesda, USA  
Prof Bartha Maria Knoppers, Montreal, Canada  
Dr Jeffrey Krischer, Tampa, USA  
Ms Samantha Parker, Paris, France  
Prof Rumen Stefanov, Plovdiv, Bulgaria  
Dr Domenica Taruscio, Roma, Italy

Dr Lilian Lau, Scientific Secretariat, Paris, France  
Dr Anneliene Jonker, Scientific Secretariat, Paris, France

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#### Agenda

1. Updates on Task Forces
2. Planning for in-person meetings in Paris on 6-7 February 2017
3. IRDiRC goals and area of focus

## REPORT

### 1. Updates on Task Forces

#### 1.1 Privacy-Preserving Record Linkage (PPRL), formerly Participant Unique Identifiers (PUID)

A face-to-face meeting was held in Paris in December 2016, led by Bartha Knoppers, Petra Kaufmann and Dixie Baker. Two primers were prepared for discussion: one on informatics and security issues, and another on ethical-legal issues. The report of the meeting was in preparation.

After the meeting, a follow-up call to get technical clarification on a framework called EUPID<sup>1</sup> took place. Another teleconference was scheduled on 20 January for the PPRL members to go over the proposed framework and conference report.

*[Post-meeting note: Workshop report in review by Co-Chairs of PPRL Task Force.]*

#### 1.2 Automatable Discovery and Access (ADA); formerly Machine Readable Consent (MRC)

The ADA Task Force has produced a paper for consultation in autumn 2016, and further writing of the manuscript is ongoing. Presentations on how the ADA-Matrix (ADA-M) were given at GA4GH meetings in October 2016; a request would be made to present the ADA-M to IRDiRC Sci Comms in Paris. Additionally, a request would also be made for an executive summary of ADA-M, and if available, a preview of the draft manuscript.

#### 1.3 Patient Engagement in Rare Diseases Research (PEfRD)

The proposal of PEfRD was presented to IRDiRC Consortium Assembly and has been approved for action in Catania, Italy. A suggestion was also made that patient groups lead this Task Force; however, the Patient Advocates Constituent Committee is still in its infancy and therefore uncertain if ready to take on this task.

#### 1.4 Clinical Research Network for Rare Diseases (CRNfRD)

A few slides were also presented on potential new Task Force proposal on Clinical Research Network for Rare Diseases, which would also be a joint TSC-ISC Task Force. The idea was well-received, and a more detailed proposal should be prepared.

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<sup>1</sup> Nitzlnader M & Schreier G. Patient Identity Management for Secondary Use of Biomedical Research Data in a Distributed Computing Environment. e-Health 2014 – Health Informatics Meets eHealth; 198:211-218.

<http://ebooks.iospress.nl/volumearticle/36166>

## 2. Planning for in-person meetings in Paris on 6-7 February 2017

### 2.1 General information

- ▶ Travel arrangements for all members have been made
- ▶ Meeting rooms have been booked, along with catering

### 2.2 ISC Meeting on Monday, 6 February 2017

- ▶ Logistics:
  - ISC meeting will start at 2.00pm and run to 5.30pm-6.00pm
  - All members invited to join the Consortium Assembly for lunch (from 1.00pm onwards)
  - Group dinner at Au Port du Salut will take place at 8.00pm
- ▶ Items for discussion:
  - Next steps of current Task Forces
  - Brainstorming of future Task Forces
  - Brainstorming goals for IRDiRC
    - Implementation aspects (e.g. funders' actions, language of data sharing, code of conduct)
    - Program content of scientific cross-cutting issues

### 2.3 Joint Sci Comms meeting on Tuesday, 7 February 2017

Proposed for inclusion in the agenda

- ▶ Overview of Task Forces and activity time line
- ▶ ADA-M presentation
- ▶ Discussion of joint Task Forces
- ▶ Further brainstorming of new goals of IRDiRC

## 3. IRDiRC goals and area of focus

A document in draft format has been prepared that pulled together information across different committees of IRDiRC as areas important to work on. The members of the IRDiRC Conference Planning Committee have been asked to score on importance of various items in order to form hierarchy.

Additionally, feedback was also sought on IRDiRC goals for the coming years. Current IRDiRC goals have served as recognisable branding – 200 new therapies and means to diagnose most rare diseases – and these ambitious goals have energised stakeholders to get on board and work towards these goals. Next set of goals should be equally exciting in nature, and putting numbers up front could be a good way to show the Consortium's ambition to reach further.

Members of Sci Comms should give collective perspective to the Consortium Assembly and advise research funders on areas to prioritise in as well as adding missing items.

It was unclear if the mandate of the ISC would change, given independently-listing of some focus areas (e.g. data/informatics, patient engagement) that affect across diagnostics and therapeutics, therefore up to now have been largely under the remit of the ISC given their interdisciplinary nature.

The presence of both public and private funders on board in IRDiRC represents implementing power; equally important for IRDiRC member organisations to show tangible actions to achieve goals:

- ▶ How could funders integrate specific language that enforces data sharing<sup>2</sup>
- ▶ How have funders follow through policies and guidelines proposed by the Sci Comms
- ▶ How have funders integrate some of the recommendations into organisational practice
- ▶ What are the tools funders found to be most useful, what do they need in the future, and what are their policies to foster further data sharing (e.g. the recognition given to code of conduct<sup>3</sup>) given introduction of new legislations

### **Main action points**

- ▶ Complete and send PPRL workshop report to Task Force members
- ▶ Contact TB/EK for summary and draft manuscript re ADA-M
- ▶ Check with TB re: presenting ADA-M during joint Sci Comm meeting
- ▶ Contact YLC and DA re joint TSC-ISC Task Forces
- ▶ Review IRDiRC goals document, add missing items and list priorities
- ▶ Draft ISC agenda

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<sup>2</sup> The recent passing of recent 21st Century Cures Act in the USA allows NIH Directors to require data sharing from recipients of funding from the NIH, even retrospectively.

<sup>3</sup> BBMRI is looking into code of conduct and have requested for contribution from IRDiRC