

Meeting report series

Report of the 6th Interdisciplinary Scientific Committee (ISC) Meeting

Teleconference
28 March 2014

Participants

Dr Hanns Lochmüller, Newcastle, UK (Chair)

Dr Angel Carracedo, Santiago de Compostela, Spain

Dr Jack Goldblatt, Perth, Australia

Dr Petra Kaufmann, Bethesda, USA

Dr Bartha Maria Knoppers, Montreal, Canada

Dr Jeffrey Krischer, Tampa, USA

Mrs Samantha Parker, Paris, France

Dr Rumen Stefanov, Plovdiv, Bulgaria

Dr Domenica Taruscio, Roma, Italy

Dr Barbara Cagniard, IRDiRC Scientific Secretariat, France

Ms Roseline Favresse, IRDiRC Scientific Secretariat, France

Apologies

Dr Jamel Chelly, Paris, France

Mr Alastair Kent, London, UK

Agenda

1:30-2:30 pm

- ▶ ISC meeting in Berlin, May 8th 2014
- ▶ Consolidation of ISC roadmap
- ▶ WG teleconferences

REPORT

Before starting the discussion, the chair of the Committee thanked, in the name of all the members, Ms Roseline Favresse, from the Rare Disease Foundation, for her good work for the past 2 years. The Rare Disease Foundation recently became an IRDiRC member and is thus withdrawing from the Scientific Secretariat (Support-IRDiRC project) at the end of March 2014.

ISC meeting in Berlin

The next face-to-face meeting of the ISC will be held on Thursday May 8th, 2014, from 3:00 pm to 6:30 pm, followed by a dinner. The venue of the meeting will be confirmed at the beginning of next week. Members of the DSC and TSC present in Berlin at that time for the ECRD meeting will be invited to join the meeting.

Note post-teleconference: the meeting will be held at Charité Campus Virchow-Klinikum (Föhrerstr. 15, 13353 Berlin)

Consolidation of ISC roadmap

The 3 Scientific Committees (SC) will present a common roadmap at the next Executive Committee meeting to be held in Berlin in May 7-8.

To facilitate the integration of the different roadmaps, a diagram presenting some of the recommendations of the ISC was prepared with an organization similar to the DSC diagram (organization by WG, same timeline).

Discussion on the diagram focused on the following:

- ▶ There is not much overlap between DSC and ISC roadmaps.
- ▶ The purpose of the ISC is also to point out gaps and needs in relation to the functioning of the 2 other SCs, and helps them by developing tools they will need. This necessitates a review of the DSC and TSC (when available) roadmaps and to determine how to fit in there and how to respond to their needs.
- ▶ Some deliverables of the ISC may overlap with the Global Alliance for Genomics and Health.
- ▶ A mission statement of the Committee is missing in the ISC roadmap. A single sentence such as “to advance and facilitate/enhance policies that will enable the DSC and TSC to reach their goals, through the development of ethical, registries and biobanks tools” could be sufficient to describe the ISC goals.
- ▶ The possibility of publishing a series of commentaries related to IRDiRC SC and WG’s plans and outcomes should be discussed between the 3 chairs of the SCs.
- ▶ A part on ‘Patient involvement and societal outreach’ was integrated on the diagram as it is a transversal area, which thus depends on ISC although fundamental for the 2 other SCs.
- ▶ The diagram does not necessarily represent work to be done by WGs, but the research needs and solution as identified by the WGs and the ISC to be proposed to the Exec Com.

- ▶ Some tools will require significant support and resources to be successful (e.g. full version of the Clearing House) whereas other tools could be developed rapidly with seed money (consent form templates for example) and developed within one of the members' research institution.
- ▶ Once the diagram is consolidated, it will be circulated to the DSC and TSC.

WG teleconferences

While organizing the WGs next teleconference, the ISC will finalize a definitive plan and approval of the roadmap, an idea on how to achieve it and how WGs can contribute. It will then be time to restart the discussion with WGs, to give them a feedback on the roadmap (what was included from their recommendations and why) and to discuss the WGs next steps.

Deliverables

- ▶ Send comments on the DSC roadmap
- ▶ Send comments on content of diagram by April 11th
- ▶ Send the link of the European Conference for Rare diseases & Orphan Products