

Meeting report series

Report of the 11th Interdisciplinary Scientific Committee Meeting

Teleconference
January 6, 2016

Participants

Prof Hanns Lochmüller, Newcastle, UK (Chair)
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 Lilian Lau, Scientific Secretariat, Paris, France
Dr Anneliene Jonker, Scientific Secretariat, Paris, France
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Apologies

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Agenda

1. Update from the Executive Committee and Operating Committee
2. Task Force on Participant Unique Identifier
3. Recruitment of additional ISC member(s)
4. Feedback from ISC members on priorities for the next year
5. Planning of the Lyon meeting

REPORT

Update from the Executive Committee and Operating Committee

The Executive Committee (Exec Comm) met twice since Glasgow: a teleconference call on August 4 and a face-to-face meeting on September 11 in Montreal, Canada. The next Exec Comm teleconference will take place on January 11, 2016. The Chair of the Interdisciplinary Sci Comm (ISC) also attended 3 teleconferences of the Operating Committee (Op Comm), composed of IRDiRC Exec Comm Chair and Vice Chair, Chairs of Scientific Committees (Sci Comms), and the Scientific Secretariat (Sci Sec). The next Op Comm teleconference will take place on January 14, 2016.

IRDiRC Conference

The Exec Comm has been discussing the possibility of organizing the next IRDiRC conference. No concrete plans have been determined so far.

“IRDiRC Recommended”

The process of “IRDiRC Recommended” is in place. Applications received have been reviewed by Sci Comm members, with final decisions for approval or rejection taken at the Op Comm by the Chairs of the Sci Comms. An evaluation of the process will take place at the next Exec Comm face-to-face meeting. If Sci Comm members have additional insights or wish to be more involved in the decision making, the process may be re-discussed and amended accordingly.

Update on Task Forces

Several Task Forces (TFs) are operational and various Sci Comms members are involved in them. One of the TFs that ISC has been involved with is the Automatable Discovery and Access Task Team (ADA TT) (formerly Machine Readable Consent), which workshop was held in Paris on November 9-10. The report of this workshop will be circulated to all ISC members once approval is obtained from the co-leads of the ADA TT [*Post meeting note: report has been distributed*]. This TT is expected to produce a tool as its final product, i.e. the ADA matrix (ADAM).

Changes at IRDiRC

An election took place in late 2015 and Dr Christopher Austin was elected as the new Chair of the Exec Comm. At the Sci Sec, Dr Ségolène Aymé has stepped down as its Project Coordinator. Nonetheless members were assured that work will be carried out as usual and the transition with as little disruption as possible. This was confirmed by Dr Ana Rath who leads the INSERM Service Unit 14, which is contracted by the European Commission to run the secretariat. Additionally, the Administrative Assistant of the Sci Sec has left the team and a replacement is being actively sought.

IRDiRC Governance was clarified: a Chair is not automatically renewed but could be put forward for re-election; a Vice Chair is not automatically Chair Elect but eligible to run as candidate for election of Chair.

Task Force on Participant Unique Identifier

Participant unique identifier (PUID) should be coordinated to facilitate and advance rare diseases research while alleviating privacy concern by data sharing that is detached from personally identifiable information. This topic is of interest not only for the rare disease community but also for a larger scope. This Task Force will be set up in collaboration with the Global Alliance for Genomics and Health (GA4GH).

This proposal has previously been discussed by ISC members at Glasgow, and subsequently at the Exec Comm in Montreal. Positive comments were received, while two comments raised have been addressed in the updated proposal:

- ▶ Involvement of data protection expert: data protection expert has been suggested
- ▶ Identify resources to co-fund this TF: RD-Connect, US NIH, other Canadian project, etc

Accessibility and interoperability are essential elements for the successful development and acceptance of the PUID. The accessibility factor has been overlooked in this proposal and will be brought to prominence. This proposal will be discussed at the Exec Comm teleconference on January 11 and is expected to be approved.

Once given the green light, a discussion of its next steps will be organized via teleconference with the key people listed. Members were encouraged to put forward additional TF expert suggestions (e.g. an expert from the European Platform for Rare Disease Registries) and send these names of the Chair of the ISC and the Sci Sec. This proposal will also be forwarded to the GA4GH's Regulatory and Ethics Working Group (REWG) to solicit interested experts. If there is a large expression of interest to participate in this TF, different ways to provide input will be identified.

Recruitment of additional ISC member(s)

The ISC is interested in recruiting patient representative to replace Alastair Kent. Three nominations will be voted in order of preference, so the candidate can be approached for interest in joining the ISC and be suggested to the Exec Comm for approval.

Additional member(s) could be recruited to the ISC. Inclusion of health technology assessment expertise will make this committee truly interdisciplinary. A paragraph on required expertise to complement the current ISC composition will be written up, reviewed by the Chair of the ISC, and submitted to the Exec Comm for approval.

Feedback from ISC members on priorities for the next year

Members are invited to identify priorities for the ISC and IRDiRC for 2016 and submit their feedback to the Chair of the ISC. The compiled feedback will be discussed at the next teleconference of the ISC.

Planning of the Lyon meeting

The meetings of the IRDiRC Sci Comms will take place in Lyon at the Palais des Congrès. All Sci Comms will meet as individual committees on the morning of March 14, and jointly with the Exec Comm in the afternoon. The ISC could present its priorities of the year to the Exec Comm during this joint meeting. The agenda of the Lyon meeting will be discussed at the next Op Comm teleconference.

Main action points

- ▶ Provide report of ADA TT to ISC members
- ▶ Send names of experts for PUID TF to the Chair of ISC
- ▶ Contact REWG of GA4GH for interested experts in PUID
- ▶ Write short paragraph on additional expertise needs in the ISC
- ▶ Identify priorities for the ISC and IRDiRC for the next year
- ▶ New ISC member candidate preference voting
- ▶ Organize ISC teleconference in February
- ▶ Agendas for Lyon meetings