Meeting report series

Report of the 24th Interdisciplinary Scientific Committee Meeting

Teleconference
November 13, 2018

Participants

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Dr Dixie Baker, Martin, Blanck and Associates, USA – Vice Chair
Mr David van Enkevort, University of Groningen, The Netherlands
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Apologies

Dr Angel Carracedo, University of Santiago de Compostela, Spain
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Agenda

1. ISC Nominations
2. Review of Activity D proposal
3. Work Plan 2019-2020: What does the ISC want to work on in the next years?
1. ISC Nominations

- A Scientific Committee has typically around 12-15 members
  - There are currently 13 members in the Interdisciplinary Scientific Committee (ISC)
  - 4 positions are opening up, with possibility to add another couple of extra members
    - 3 members will reach the end of their second/final mandate in February 2019
    - 1 member recently resigned due to personal reason
  - 2 other members will reach the end of their first mandate in October 2019

- A recent call for ISC nominations has resulted in the collection of a list of potential future members, some nominated by IRDiRC members and some self-nominations
  - Once ISC members agree on the candidates to invite, the Scientific Secretariat (Sci Sec) will contact and ask them to provide a letter of motivation along with their CV
  - The candidacy will be passed on to the Consortium Assembly (CA) for vote

- A few criteria to bear in mind when selecting potential future members
  - Alignment with the mission and different activities carried out by the ISC
  - Balanced geographical and gender distribution
  - Expertise that complements those currently already on the ISC

- The ISC previously identified the following expertise areas for the call of nominations
  - Health technology assessment (HTA) and its related fields
  - Payers and insurers across different jurisdictions
  - Ethical, legal and social implications of research
  - Psychiatrists, psychologists
  - Sociologists

- Considering the activities currently led by the ISC, the following expertise areas are also essential
  - Natural histories and registries
  - Ethics and legal expertise
  - Patient advocacy

- Question was also posed on the current expertise already present in the ISC
  - A wholistic review of the strengths and gaps of expertise is needed prior to decision making regarding new members

- A broad discussion of the nominations to date took place without a consensus being reached on the shortlist of candidates; moreover, new nominations are being added
  - Sci Sec will create an updated list of nominations with short bios
    - ISC members are invited to submit new names of experts for missing expertise
  - ISC members will evaluate candidates on the updated list and indicate their preference
    - [Post-meeting note: this can be done with a survey form]

2. Review of Activity D proposal

- The scope of the Activity is very wide with objectives in several different directions
  - All objectives listed on the proposal are good and strong, but realistically, the Activity should harbor one focused and precise objective
Based on current form, it is also unclear if focus will be on technology or standards
  ▪ There are existing standards already adopted; one prevailing standard for representing data for interoperable exchange and is used internationally, in particular for electronic health records: Fast Healthcare Interoperability Resources (FHIR)
  ▪ There may not be a lot of mapping to do
  ▪ PPRL is also unlikely to be applicable to this Activity

ISC members want to see a more focused approach and precise outputs

This is a cross-committee initiative
  ▪ It aims to satisfy all committees involved in this Activity, however this is also a contributing factor to the lack of focus of the Activity
  ▪ Potentially three separate action areas could come out from the current proposal, hence the need for refinement and re-focusing of scope

The Activity proposal could benefit from a stronger regulatory emphasis
  ▪ This helps move towards the goal of having 1,000 therapeutics available to patients
  ▪ The collection of natural history and registry data should meet regulatory requirements, i.e. “fit for purpose” and not just end up in a public publication
  ▪ To make sure the standards also lend to data collection suitable for regulatory purposes

Also, the number of participants to this Activity might need revision, as smaller groups are efficient in comparison to a larger audience

3. Work Plan 2019-2020: What does the ISC want to work on in the next years?

From January 2019, the Sci Sec will be integrated within the European Joint Programme for Rare Disease (EJP-RD)
  ▪ Work plan and budget allocation of the EJP-RD is decided on a yearly basis
  ▪ E.g., for an activity planned for 2020, a final form of proposal needs to be submitted for approval by May/June 2019 in order to be integrated into EJP-RD annual plan for 2020
  ▪ Failing to anticipate in advance could lead to a delay of at least a year; as such, members need to think ahead and anticipate this new organization

For 2019:
  ▪ Activity G on Clinical Research Network has been previously approved and should commence work shortly
  ▪ Activity D will be presented to the CA for approval in December 2018, therefore the work will also take place in 2019

For 2020:
  ▪ ISC members are invited to start considering the issues they want the ISC to address in 2020 and come up with a 1-2 pager to describe the potential activity
  ▪ Suggested work timeline:
    ▪ Send the suggestion document to the Sci Sec
    ▪ Sci Sec to compile the documents and circulate among members
    ▪ Organization of a teleconference to take place in January 2019 to discuss and identify the issue(s) to prioritize in 2020, so preparatory work on the proposal could commence
- Further discussions and concretization of prioritized issue(s) for 2020 in February-April 2019
- Finalization of activity proposal for 2020 by May 2018 (likely the time when the ISC meets face-to-face)

**Main deliverables**

- Send names of further candidates to approach
- Update list of candidates to approach
- Evaluate and list preference of candidates to approach
- Prepare and send activity ideas to address in 2020 to the Sci Sec
- Organize the next ISC teleconference in January 2019