

Meeting report series

Report of the 24th Interdisciplinary Scientific Committee Meeting

Teleconference
November 13, 2018

Participants

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Apologies

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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?

REPORT

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
 - PPRIL 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