

Meeting report series

Report of the 2nd ISC Working Group on Registries and Natural History teleconference

2 October 2013

Organization

Organized by: IRDiRC Scientific Secretariat
Teleconference

Participants

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Apologies

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REPORT

The discussions of the WG dealt around two documents circulated earlier by the WG Chair:

- ▶ A summary of the **Global Unique Identifiers (GUID) developments**: this document has been prepared as a specific activity of RD-Connect project to be circulated among participants of the IRDiRC Working Group "Working Group on Registries and Natural History"
- ▶ A **document analysing the gaps in the field of the WG and subsequent recommendations**: this document was drafted within a short time, at the request of the Chair of the Interdisciplinary Scientific Committee, and is a first basis for the WG future work.

Global Unique Identifiers (GUID) document

- ▶ A document elaborated by 3 members of the WG in the framework of this EU project about the GUID (Global Unique Identifier), which is also a RD-CONNECT issue, was circulated to WG members prior to the teleconference.
- ▶ The GUID relies on the observation that different datasets are used for the same patient in different institutions.
- ▶ The concept of GUID is to develop identifiers that would be similar at all places for the same patients. With the GUID, data are collected (different variables can be collected), coded and de-identified through. Many advantages results from the use of the existing GUID.
- ▶ As the Registries and Natural History WG composition is wider than the one of the RD-CONNECT project, a discussion is needed on whether the use of GUID is relevant within IRDiRC.
- ▶ In answer to concerns expressed by some WG members, it was specified that the GUID is only an identification tool and that no data sharing is related to its use. Wherever the location of the data and software are, there is no access to the data themselves. It is not possible to identify the person.
- ▶ With regard to the confidentiality of the data, ethics committees can be involved and data can remain stored in Europe. Those points should be included in the document in order to increase the level of confidence in terms of data sharing.
- ▶ The document circulated to the WG members belongs to RD-CONNECT, which is linked to IRDiRC (as an EU-funded project). RD-CONNECT already agreed to use this system but IRDiRC should elaborate its point of view independently.
- ▶ A first draft recommendation related to the use of GUID could be done.
- ▶ The CDEs that NIH has been using to develop the GUID are based on information not likely to be changed.
- ▶ This is stressed that any new tool should be developed with the idea of going forward, not backward in order to share data for years to come. How data and systems already established would be incorporated will be addressed.
- ▶ Additional recommendations from the WG are welcomed.

WG gap analysis document

A gap analysis document was prepared by the chair and the co-chair of the WG prior to the IRDiRC Executive Committee meeting in Miami based on the previous exchanges held within the WG. The objective of this gap analysis document is to collect additional recommendations and to identify additional gaps from WG members in order to share this output with the ISC members on the occasion of the Montreal meeting (17-18 October). This later one will inform the Executive Committee.

Comments from the WG members:

- ▶ With regard to grant applications: reviewers seem critical about the participation of support groups. Would it be possible to include a recommendation on the need to involve support groups as real partners? Better standing should be given to support groups. In that perspective, EURORDIS already recommended enrolling disease-specific organisations.
- ▶ Best practices could be flashed out in a clearer way.

General and/or specific comments are welcomed from WG members after the teleconference.

Other issues

No other issues underlined.