RDA Health Data Interest Group First TC Agenda

22 Dec. 2016, 4pm (CET)

Objectives

- What we would like to discuss in the forthcoming TC is which priorities stated in the Group Charter (see next slides) to address first and put in our **Agenda for P9 in Barcelona** *(topic of the session).*

- Furthermore, we would like to discuss the type of **activities** that we could initiate on these topics

Topics (1)
The focus of HDIG includes the following areas (see Charter):

- *Privacy and Security in Health Data*: sharing best practices on pseudonymisation, anonymisation, differential privacy, homomorphic encryption, secure multi-party computation, and dedicated blockchain applications; developing models for dynamic consent that protect patients while enabling research; providing a forum for discussing, explaining and responding to data protection regulatory issues.

- *Data based Healthcare for Personalised Medicine*: analytics applied to highly sensitive health data; disease signature identification and stratification of patient groups; patient-specific simulation and prediction; exploring the potential of health data usage in in-silico drug development and clinical trials.

- *Health Data Organisations environment*: defining a list of organisations dealing with Health Data to cluster with; disseminating HDIG results within other relevant Health Data organisations.

Topics (2)
Topics adressed in previous sessions:

- Data access and protection

- Data-based healthcare for precision medicine

- Data literacy in health care

- Patient data repositories

- In-silico drug development and clinical trials

- Policy makings

- Health Data Privacy & Security issues

- Data driven medicine

- Furthermore, interventions were also made by **GeoHealth**, i.e. the geospatial dimension in health data and related analyses; Population data base - project **HIVE**, i.e. building a repository for the Gold coast region in Queensland starting from hospital data to link to citizen data; Human stress management and monitoring – **MindFlow; Clinical data publication guidelines - Nature - Scientific Data**.

Activities (1):

- Having **thematic (physical or web) meetings** on ongoing projects with experts in the relevant fields, to be promoted also through the RDA website (newsletters/articles and events),

- or inviting them to our session in Barcelona

E.g.:

- *Data Protection in Health*, a comparison between EU GDPR and US HIPAA (Legal Firm, NCTM)

- *Open Data in Health* (Jonathan Tedds, co-chair of Publishing Data IG, Editor in Chief of Open Health Data journal)

- ePouta IaaS (*Infrastructure as a Service*): Finnish cloud computing environment (Leif Laaksonen, also former Project Director for the RDA Europe project)

- *Data based Healthcare for Personalised Medicine: analytics applied to highly sensitive health data, the case of BRAIN CUTS DATASETS* (Morris Riedel, co-chair Big Data IG)

- …. (others)

Activities (2):

- Defining **user scenarios** with other stakeholders and representatives from Health Data Organisations who might be involved in the next meeting

E.g.:

- Avicenna in silico clinical trial (http://avicenna-isct.org/)

- HIMSS (http://www.himss.org/)

- IMI (http://www.imi.europa.eu/)

- National Association of Health Data Organizations – NAHDO: https://www.nahdo.org/

- PerMed (http://www.permed2020.eu/)

- VPH Institute: http://www.vph-institute.org/member-list.html

- WHO (World Health Organization)

- ….. (others)

Activities (3):

- Having **joint meetings** with related IGs/WGs in Barcelona

E.g.:

- *RDA/NISO Privacy Implications of Research Data Sets IG* (Todd Carpenter): for a joint session, or a topic for a general, informational session at RDA which has a privacy angle
- *Big Data IG* (Morris Riedel): for a joint session on Data based Healthcare for Personalised Medicine: analytics applied to highly sensitive health data, the case of BRAIN CUTS DATASETS
- *Publishing Data IG* (Jonathan Tedds): for a joint session on Open Data in Health

Related WGs/IGs:

- Active Data Management Plans
- Big Data
- ELIXIR Bridging Force
- Ethics and Social Aspects of Data
- Long tail of research data
- RDA/CODATA Legal Interoperability
- Structural Biology
- bioSharing registry
- Data Security and Trust Working Group
- RDA/NISO Privacy Implications of Research Data Sets WG
- ….. (others)

Activities (4):

- Possibly establishing a particular WG on a more specific topic (e.g., **Blockchain**)

- To discuss it during our session in Barcelona or to start now?

During the TC we would like to also engage in the following:

1. Have all of us **sharing our experiences in relevant projects** that might be presented in Barcelona or during other thematic meetings

2. Inform the HDIG about **relevant Health Organizations** we should liaise with

3. Make suggestions for the **agenda of the next HDIGTC**, to be held in January or February 2017