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 addressed 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.