Health Data Interest Group @P9
Meaningful Health Data for Research and for Industry
6 April 2017, 14:00-15:30

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research data sharing without barriers
rd-alliance.org
AGENDA

- Short introduction recalling the precursor sessions (P6, P7, P8) and issues description [10’]
- **Part I - How to define anonymisation and pseudonymisation of Health Data and requirements of Open Science:**
  Rocco Panetta (Head of the Panetta&Co. Legal Firm) and Becca Wilson, Bristol University, UK) [30’]
- **Part II - Further in-depth themes sprouting from Health Data:**
  1. **Data provenance, data comparability and data traceability in biotechnology:**
     Joerg Geiger, Manager Systems Biology and Biobanking at the University of Wuerzburg [15’]
  2. **Mapping ongoing initiatives in the Health Data domain:**
     Leslie D. McIntosh, Professor of Health Informatics at Washington University School of Medicine [15’]
- General discussion and wrap-up [20’]
Background

- Charter / IG approved – growing number of members on the website

- IG idea rooted in EU projects in biomedical informatics
  - Cardioproof [http://www.cardioproof.eu](http://www.cardioproof.eu)
  - MD-Paedigree [www.md-paedigree.eu](http://www.md-paedigree.eu)
  - p-medicine [www.p-medicine.eu](http://www.p-medicine.eu)
  - Avicenna [www.avicenna-isct.org](http://www.avicenna-isct.org)
  - MyHealthMyData [www.myhealthmydata.eu](http://www.myhealthmydata.eu)

- After successful BoFs at RDA P6 (Paris), P7 (Tokyo)
  - Each attended by over 35 researchers and professionals from diverse backgrounds who expressed interest in IG formation

- First IG meeting at RDA P8 (Denver)
Scientific Activities Relevant to IG

- Bottom-up governance
- Federation
- Legacy and sustainability
- Leverage of MS investment
- Trust
  - IPR protection
  - Privacy and personal data protection
- Big data analytics
- Data fusion across disciplines
- High performance computing
- Data storage
- Data access and re-use
- Data manipulation and export
- Data discovery and catalogue

Layers:
- Governance layer
- Service layer
- Data layer

Scale of scientific activity (data-driven science)

- Physics
- Life sciences
- Earth sciences
- Applied engineering
- Economics
- Social sciences
- Humanities
- Citizen science

Lead users... Scientific communities... long tail
Health Data IG:
User scenarios/focus areas

- Emphasis on
  - Privacy, security, ethical (not only technical) issues
  - Related data management and processing issues
- Data access and protection
  - BOF on Blockchain in Healthcare tomorrow morning
- Data-based healthcare for personalized medicine
- Data literacy in Health care
- Patient data repositories
- In-silico device and drug development & clinical trials
- Policy making
- …