



Health Data Interest Group @P9

Meaningful Health Data for Research and for Industry

6 April 2017, 14:00-15:30

Edwin Morley-Fletcher

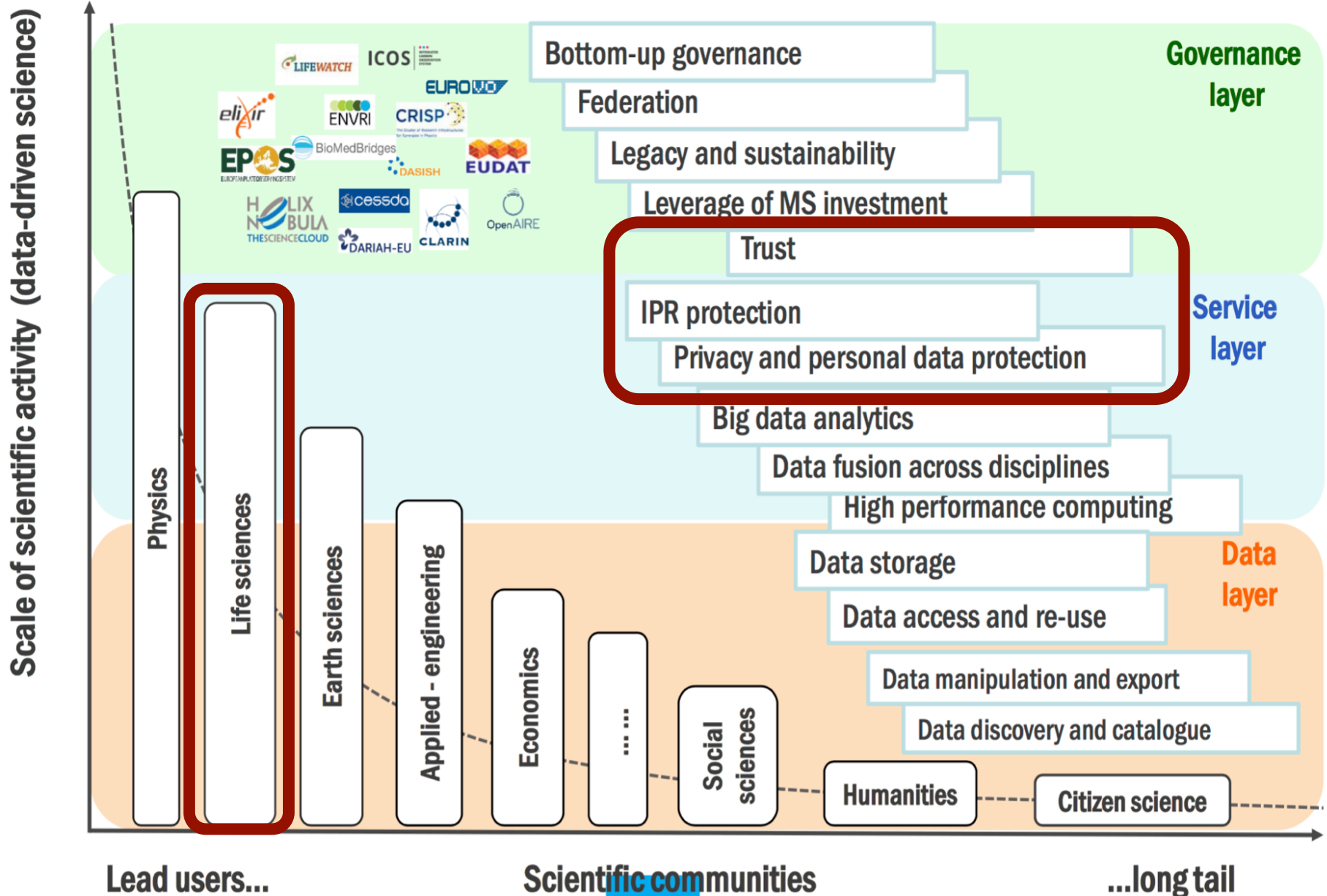
research data sharing without barriers
rd-alliance.org

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']

- **Charter / IG approved – growing number of members on the website**
- IG idea rooted in EU projects in biomedical informatics
 - Health-e-Child www.health-e-child.org
 - Sim-e-Child www.sim-e-child.org
 - Cardioproof <http://www.cardioproof.eu>
 - MD-Paedigree www.md-paedigree.eu
 - p-medicine www.p-medicine.eu
 - Avicenna www.avicenna-isct.org
 - MyHealthMyData 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



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
- ...