



E-Rare Data Sharing and Harmonization Workshop

Berlin, Germany
RAMADA Hotel Berlin-Alexanderplatz
3-4 of May 2017

3rd of May 2017

18:00 - 21:00 **Poster session and Reception with RD-Connect**

4th of May 2017

8:00 - 8:15 **Setting the scene**

8:15 - 9:45 **Session 1: Application of the data sharing policies and recommendations by the researchers**

Plenary and working groups

Moderator: Bartha Knoppers

Bartha Knoppers, OECD recommendations on Health Data Governance and data sharing policies

Breakout groups: International Code of Conduct, what would you like to see in such a code?

Report back/open discussion

9:45 - 10:05 **Coffee Break**

10:05 - 12:00 **Session 2: Data sharing and harmonization tools and platforms**

Plenary

Moderator: Hanns Lochmuller

Mike Brudno, Phenome Central/MatchMakerExchange

Sergi Beltran (CNAG, Barcelona), ELIXIR

Thomas Keane, European Genome-phenome Archive

Ana Rath, Hipbi-RD

12:00 - 13:00 **Lunch**



13:00 - 14:45 **Session 3: Integrating, tools, platforms and patients participation:
what is desirable and how to get there?**

Panel discussion

Moderator: Paul Lasko

Orion Buske, RareConnect
GA4GH, (speaker TBC)
Marco Roos, RD Connect
Luca Sangiorgi, ERN, BOND
Virginie Bros-Facer, EURORDIS

14:45-15:00 Break

15:00-17:00 **Session 4: « Hands on » experience**

Breakout groups

Moderator: Marco Roos