WP3: RARE DISEASE BIOBANKS

Chiuhui Mary Wang, David van Enckevort, Heimo Müller, Roxana Merino Martinez and Lucia Monaco

WP3 main achievements
Biobank location, contents, access

Finding biobanks

Registry & Biobank Finder
Searchable by disease

http://catalogue.rd-connect.eu/
Gainotti et al, 2018

22 biobanks listed
- Quality assessment prototype
- Disease matrix
- No. of cases per disease
- Relevant documents

Searching for samples

Sample Catalogue
Shared minimum dataset

https://samples.rd-connect.eu/
van Enckevort, Wang et al, in preparation

90 diseases, 7237 samples listed
- Disease
- Type of material/diagnosis
- Sex/affected status
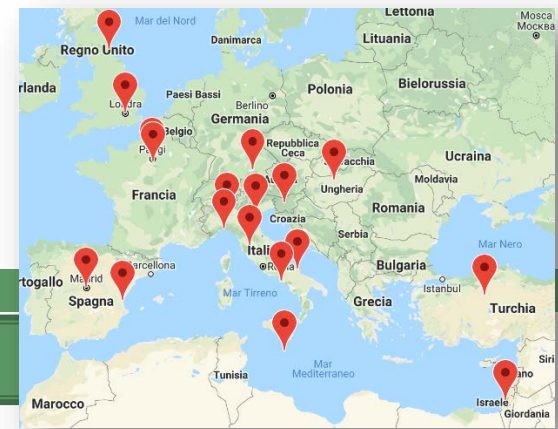- Hosting biobank/related registry

Requesting samples

Managing biobank workflow

Sample Negotiator

BIBBOX RD demo

In collaboration with BBMRI-ERIC – work in progress

RD Connect

14 May 2018

WP3 main achievements
Biobank network, users

Establishing the network

EuroBioBank

- The RD-Connect biobank network http://rd-connect.eu/organisation/eurobiobank/
- First European rare diseases biobank network http://www.eurobiobank.org/

- Member biobanks listed on the RD-Connect Registry & Biobank Finder
- Samples searchable through the RD-Connect Sample Catalogue
- Shared SOPs and ELSI documents

Expanding the network

Biobank assessment process

To ensure new biobanks meet shared quality criteria

http://rd-connect.eu/biosamples-data/biobank-assessment-process/

Panel for biobank assessment

Experts with knowledge in: biobanking; rare diseases research; IT infrastructure; ELSI

http://rd-connect.eu/biobank-assessment-panel/

Process successfully implemented for the two latest biobank additions

Training users

2 training courses

Within the RD-Connect annual meetings

1 training course

Within an international RD meeting

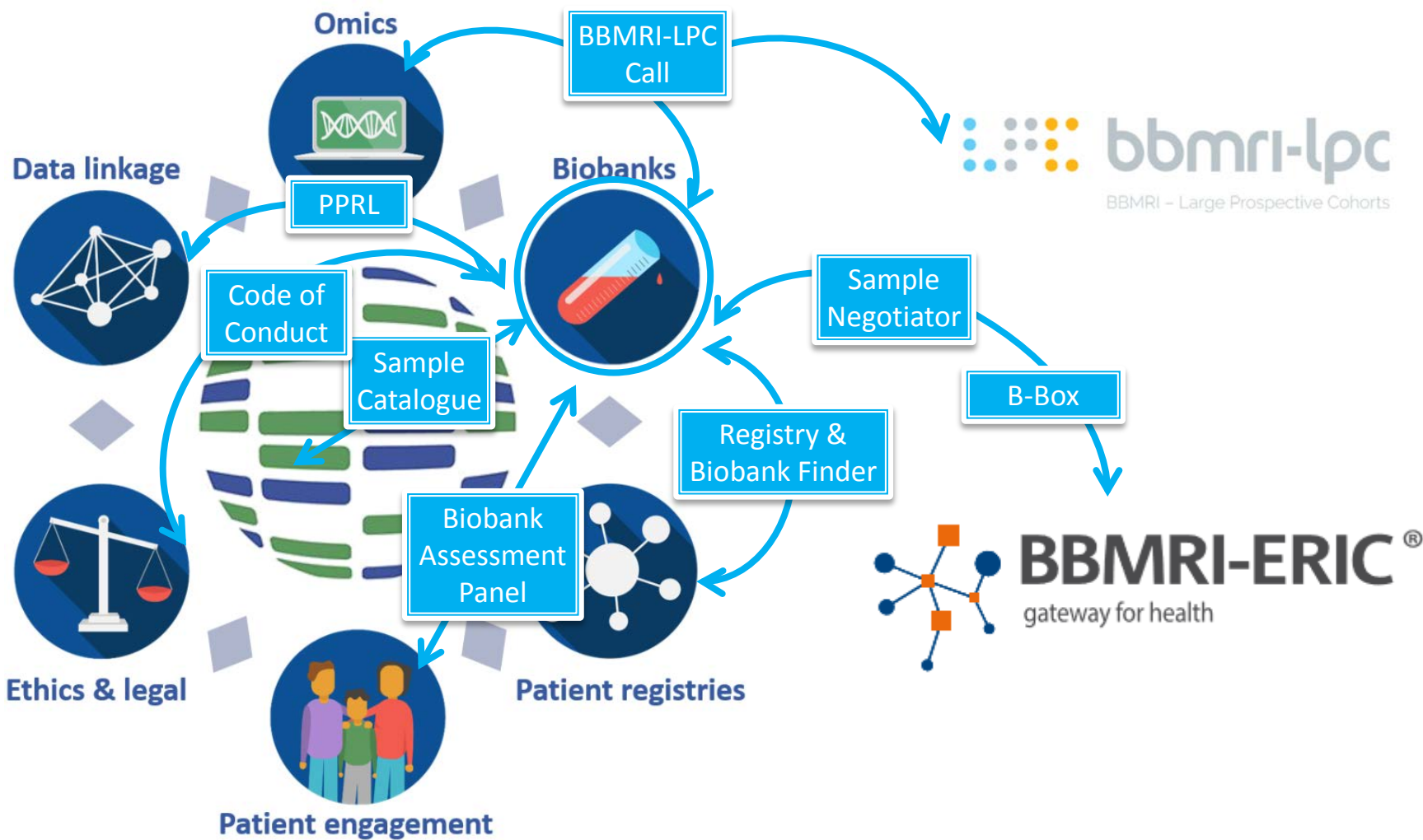**2 webinars**

For biobank managers

RD Connect

EuroBioBank

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WP3 challenges

Next six months

- ☐ **Jun: 100k samples in the catalogue**
  - ▪ 65k ISCIII, 25k TNGB,
  - ▪ 6k NCL, 4k Other biobanks)

- ☐ **Apr – Jun: Implementation of Sample level Negotiator**
  - ▪ And add support for the Negotiator to the catalogue (with BBMRI-ERIC)

- ☐ **May – Aug: EUPID pilot with biobanks**
  - ▪ With some of the biobanks that participated in the BBMRI-LPC call

- ☐ **Jul - Aug: User interface improvements & Simplify upload for biobanks**
  - ▪ Based on feedback from users
  - ▪ Based on experience from this year

- ☐ **May - Aug: Implementation of the F2Share federation tool**
  - ▪ Create federation of RD-Connect biobanks
  - ▪ Integrate with sample catalogue

Obstacles & Risks

- → Loading data still difficult for biobanks to do on their own
- → Harmonization of data takes a lot of time

- → Significant changes are needed to Negotiator

- → Linkage data might not be available for samples

- → Depends on backend improvements that we're still working on

- → Limited resources to complete this task

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WP3 prospect

- **EuroBioBank** continues to be involved – to express their needs, to provide use cases, to implement software, validate data models, to guide sample and data sharing among researchers, ERNs, and biobanks

- **BBMRI-ERIC** to fully support the **Sample Catalogue** – transfer to BBMRI-ERIC CS-IT for sustainable hosting

- **Sample Catalogue** is an integral part of the **EJP Rare Diseases** proposal – budget for further innovation & support of the biobanks

- **PPRL** is part of the **EJP Rare Diseases** proposal – integration of support in the Sample Catalogue & platform would go a long way to solve the issues around patient identifiers

- **Training & outreach**
  - Training for biobank data management is envisaged in the **EJP Rare Diseases**
  - Training session at the **Groningen Biobank summer school** 2018

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