

BBMRI-ERIC - A distributed RI for health research

Erik Steinfelder

November 16th, 2017



What is a biobank?





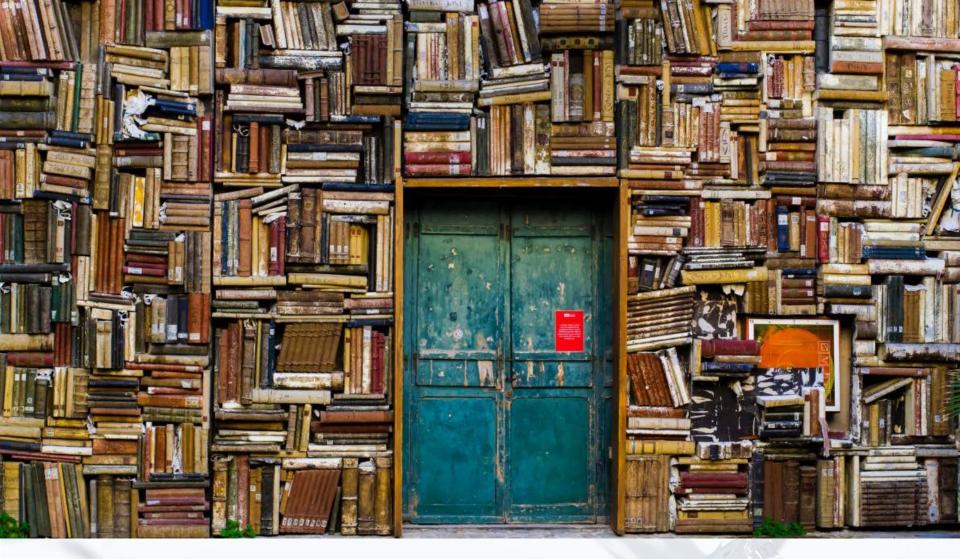
BBMRI-ERIC



"BBMRI-ERIC is a research infrastructure of biobanks and biomolecular resources that provides expertise and services in order to facilitate the use of European sample collections and its data for the benefit of human health"



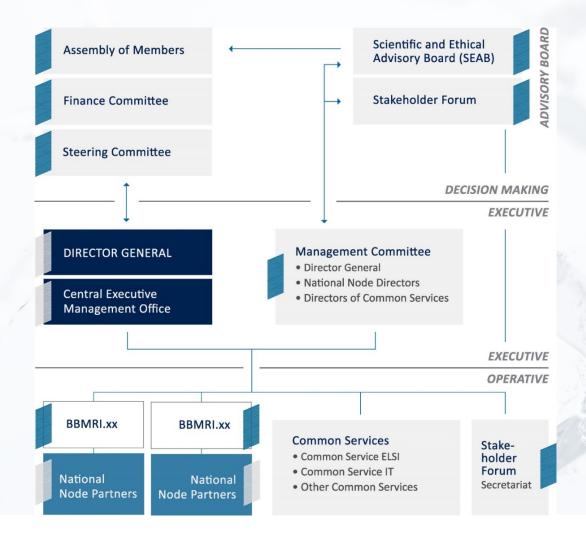




"If you think biobanking is about hoarding, you are doing something wrong" – Greg Simon, President at Biden Cancer Initiative



Governance Structure



Membership



Members of BBMRI-ERIC

Austria

Belgium

Czech Republic

Estonia

Finland

France

Germany

Greece

Italy

Latvia

Malta

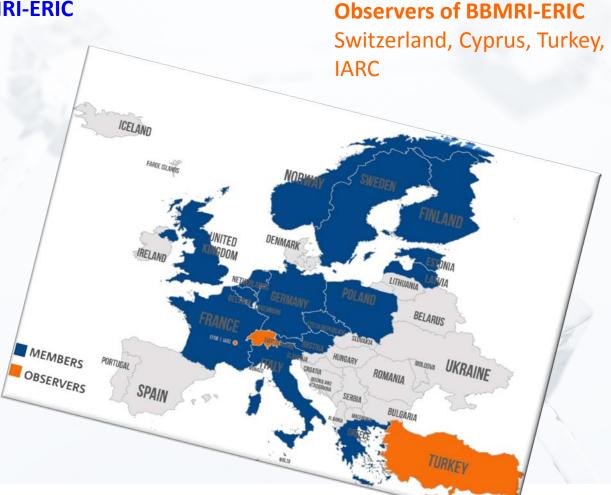
Netherlands

Norway

Poland

Sweden

United Kingdom



Who are we serving?





- Biobankers
- Researchers
- Patients
- Clinicians
- Politicians
- Industry
- Partners
-

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What do we serve?



Ethical, Legal and Societal issue support

- IT Tools and expertise

Quality ManagementService

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Common Service ELSI



- Operational since the end of 2015
- All BBMRI-ERIC Members and Observers nominated participating experts (important for national sensitivities)
- Offers practical interpretation on new legislation (e.g. FAQs GDPR)
- Monitors relevant ethical and legal frameworks in development (joint statement on the Council of Europe recommendations).
- Test runs a federated custom-based Helpdesk (providing 1:1 guidance)
- Develops ELSI guidelines for researchers (e.g. How-to-Engage with the patient organisations).



Mats Hanson (SE)



Marialuisa Lavitrano (IT)



Jasper Bobenberg (NL)



Michaela Th. Mayrhofer

GDPR - 25th May 2018



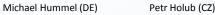


Common Service IT



- Operational since beginning 2016
- All BBMRI-ERIC Members are contributing
- Delivered core IT services:
 - Directory, Negotiator, BIBBOX, HelpDesk, CCDC, AAI
- Development of upcoming IT services:
 - Locator, data harmonization services







Quality Management Service



"Pre-analytical errors still account for nearly 60% - 70% of all problems occurring in laboratory diagnostics, most of them attributable to mishandling procedures during collection, handling, preparing or storing the specimens".



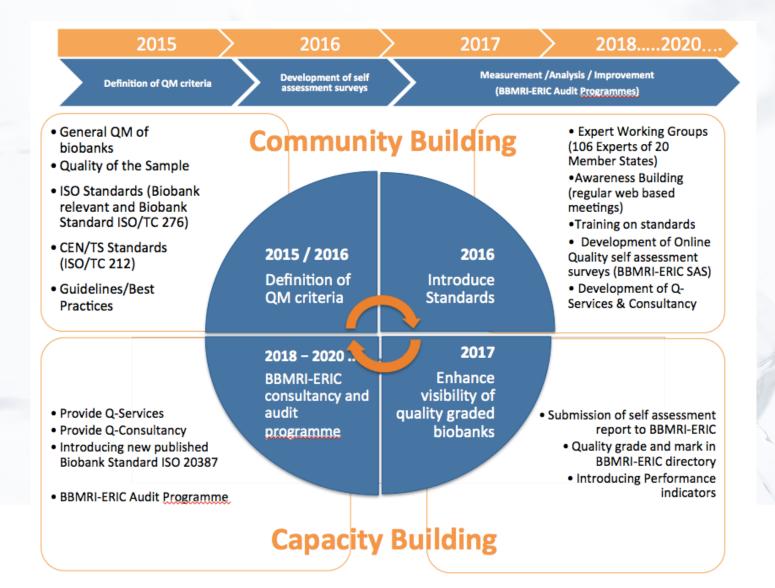
Andrea Wutte, BBMRI-ERIC

Lippi G. *et al.* Pre-analytical quality improvement: from dream to reality. Clin Chem Lab Med. **2011** Jul; 49(7):1113-26.



Quality Management

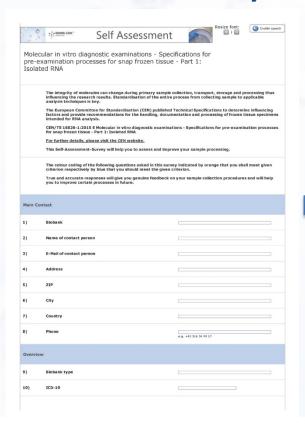




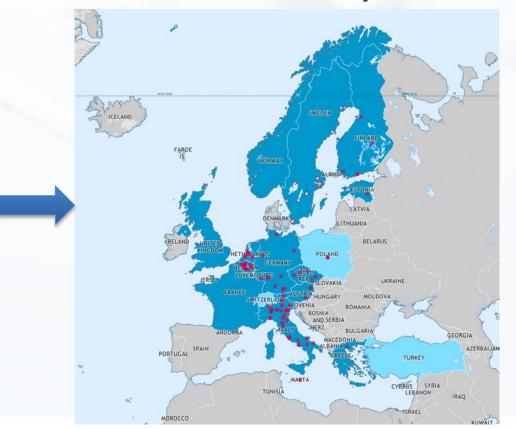
Enhance visibility of biobanks and sample collections



Self-Assessment Survey



BBMRI-ERIC Directory



ADOPT BBMRI-ERIC





- Key focus on providing a gateway access to European biobanks:
 - European map of biobanks visibility and findability (currently for 520 biobanks and 1396 collections)
 - IT tools to facilitate access and negotiate with biobanks
 - Tools for quality improvements implementation of QM requirements and assessing the quality in biobanks
 - 10 000 colorectal cancer datasets pooling together the **biobank resources** (currently 30 biobanks involved)

Thank you for your attention!



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