

Advancing Biobanking in Europe

—

from community engagement to cross-country collaborations with Nordic biobanks

Prof. Jens K. Habermann, M.D., Ph.D.
Director General BBMRI-ERIC

History & Mission

Biobanking and Biomolecular Resources Research Infrastructure

European Research Infrastructure Consortium

European Commission Decision 2013

2006: ESFRI Roadmap

2008-2011: BBMRI-Preparatory Phase (FP7 Project)

2011-2013: Interim Phase (establishing legal entity & MS commitment)

2013-ongoing: Implementation & Operation Phase

Mission

Establish, operate, and develop a pan-European distributed research infrastructure of **biobanks** and **biomolecular resources** to facilitate the **ACCESS** to **RESOURCES** as well as **FACILITIES** and to support high-quality biomolecular and medical research.

Health & Life Science Research Infrastructure:

18 Member States

Austria
Belgium
Bulgaria
Czech Republic
Estonia
Finland
Germany
Greece
Hungary (joined 2021)
Italy
Latvia
Malta
Netherlands
Norway
Poland
Slovenia (joined 2022)
Sweden
United Kingdom



6 Observers

Cyprus
IARC/WHO
Lithuania
Spain (joined 2021)
Switzerland
Turkey

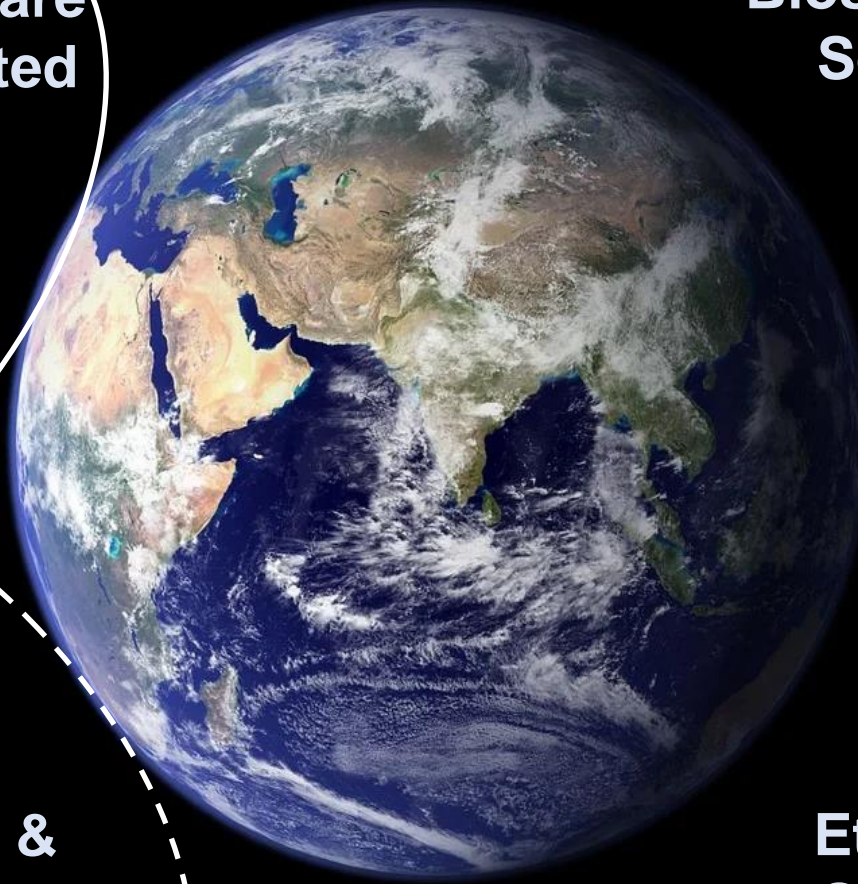
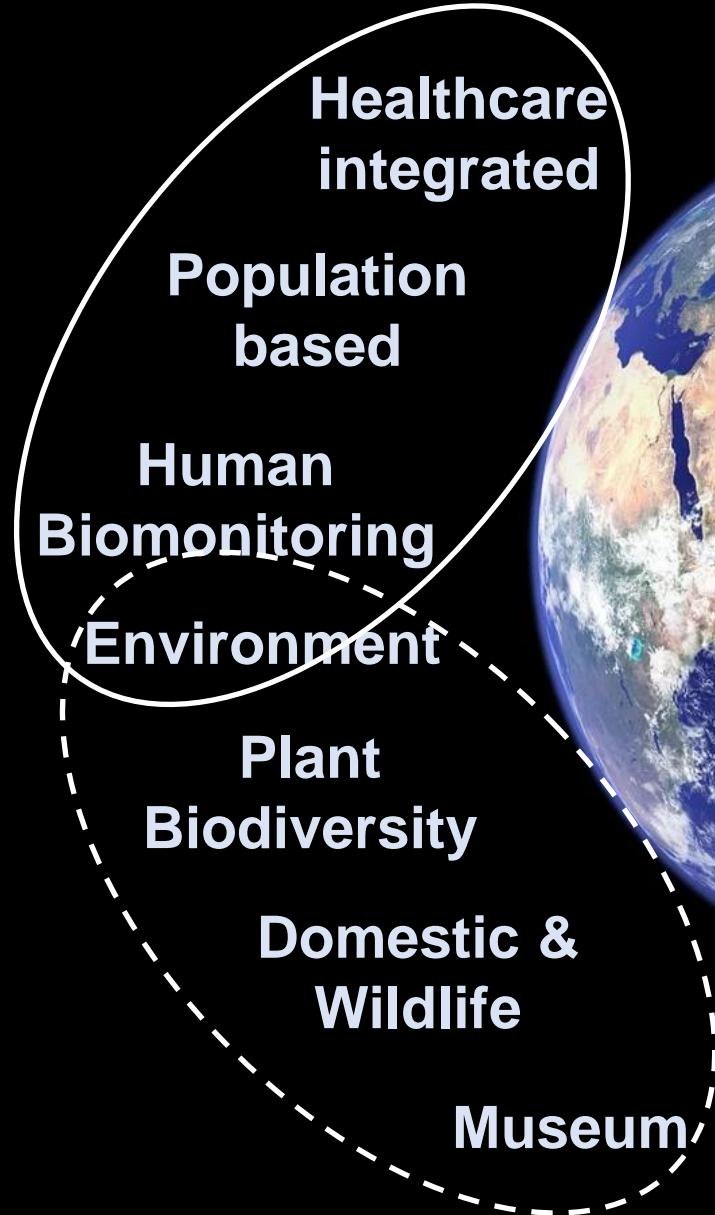
Comprising

- > 700 biobanks
- & affiliated partners
- 24 National Nodes
- 3 Expert Centres
- 1 Headquarter

 MEMBERS OF BBMRI-ERIC
 OBSERVERS OF BBMRI-ERIC

... and growing interest

Distinct Biobank Types



Various Requirements

**Biospecimen
Science**

**Quality
Management**

**Cryobiology &
-technology**

**IT
Infrastructure**

**Ethical, Legal &
Societal Issues**

Equipment

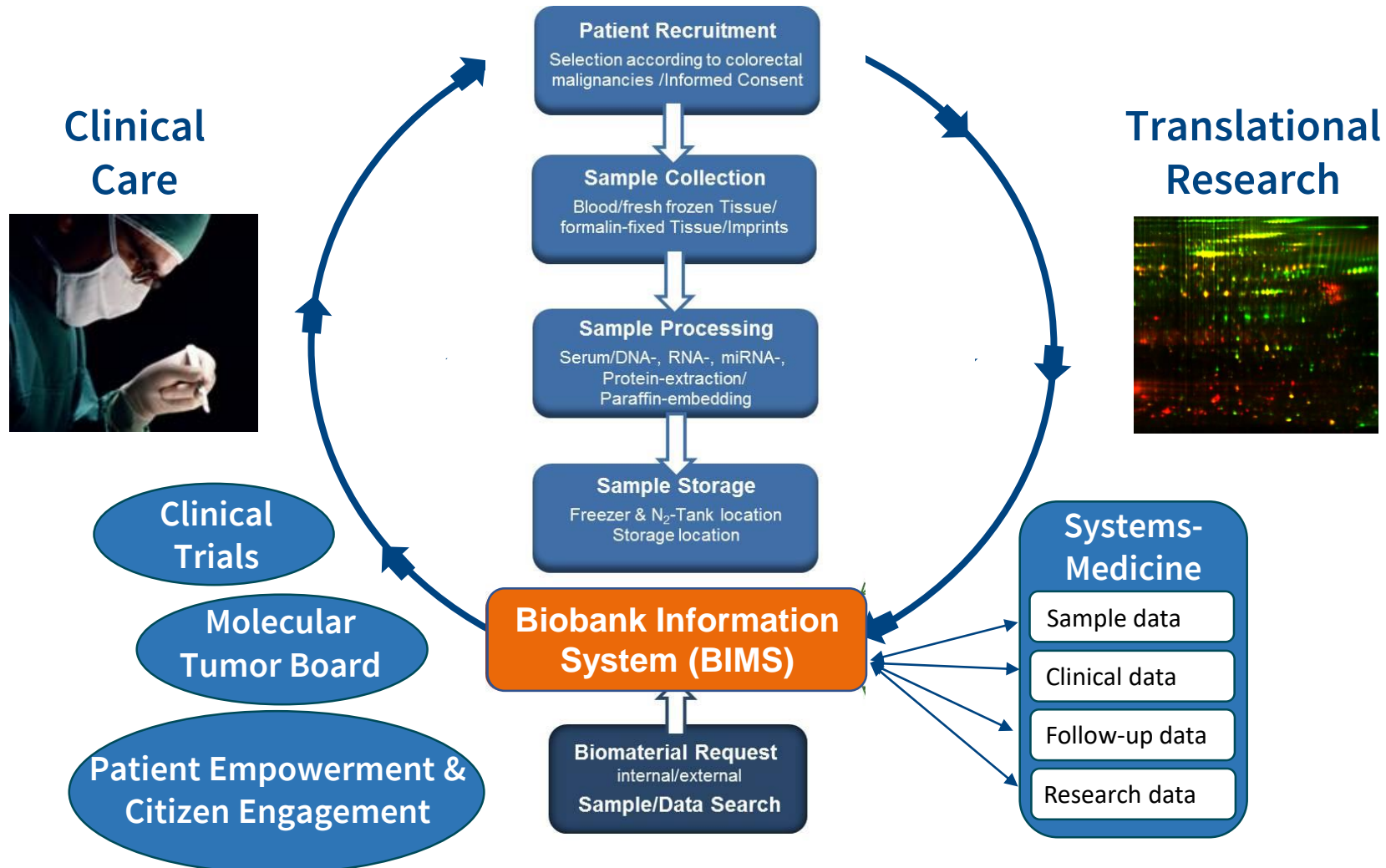
QM-Certified!



Healthcare integrated
central Biobanks

≈

„Data Integration
Centers“



BBMRI enabling personalized medicine through:

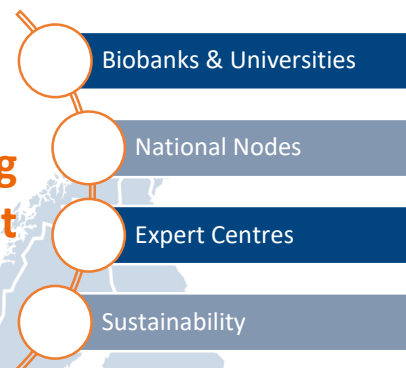


ELSI Services & Research

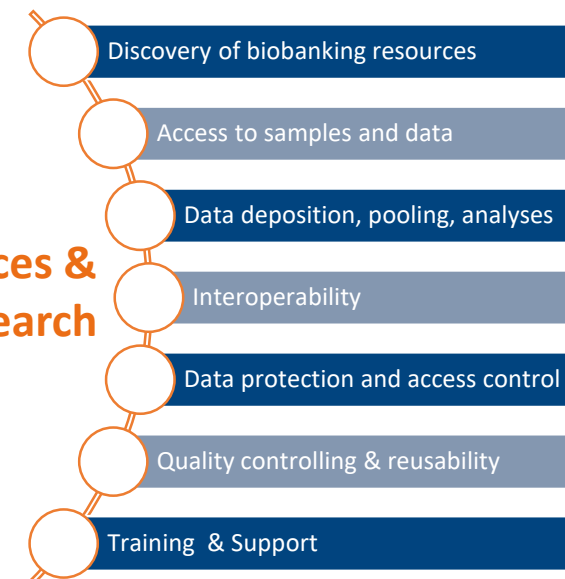
Public Affairs & Stakeholder Engagement

Biobanking Development

Outreach, Education & Communication



IT Services & Research



Quality Management Services & Research



ELSI SERVICES & RESEARCH

We support the research community by facilitating knowledge exchange, compliance with regulatory requirements, promoting best practices and ensuring guidance on ethical, legal and societal (ELSI) issues. www.bbmri-eric.eu/elsi

Key topics: Quality of Life, AI, GDPR Compliance & Code of Conduct, Incidental Findings



RESEARCH

We conduct research relating to ethical, legal and societal issues (ELSI). This is fundamental to staying up to date with and contributing knowledge to our services and training.

- > [EU Projects](#)
- > [Publications and Results](#)

Open-access resource platform that provides practical know-how for responsible research



SERVICE

We support the biobanking and life science RI communities by facilitating compliance with regulatory requirements and best practice standards.

- > [ELSI Helpdesk](#)
- > [ELSI Knowledge Base](#)
- > [Ethics Check](#)

Experts answer your specific questions

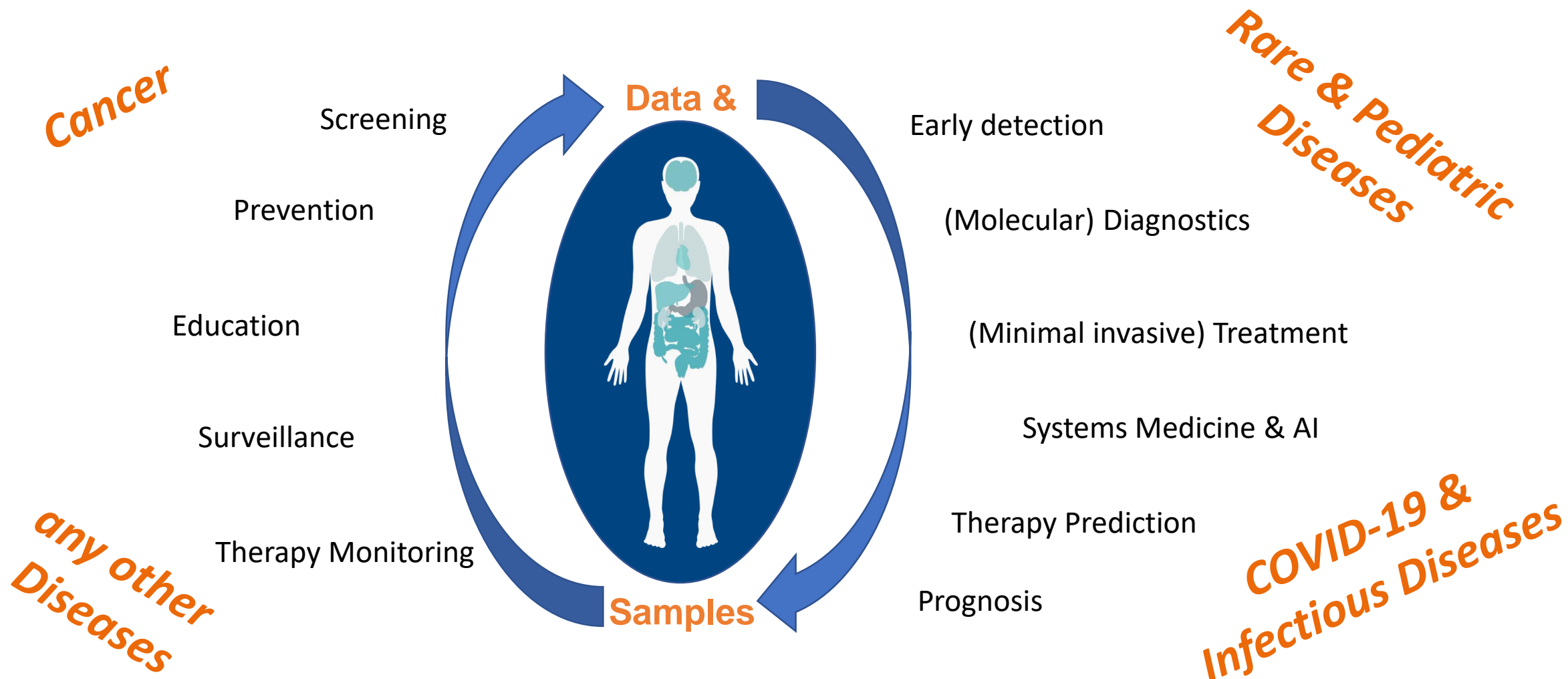


TRAINING

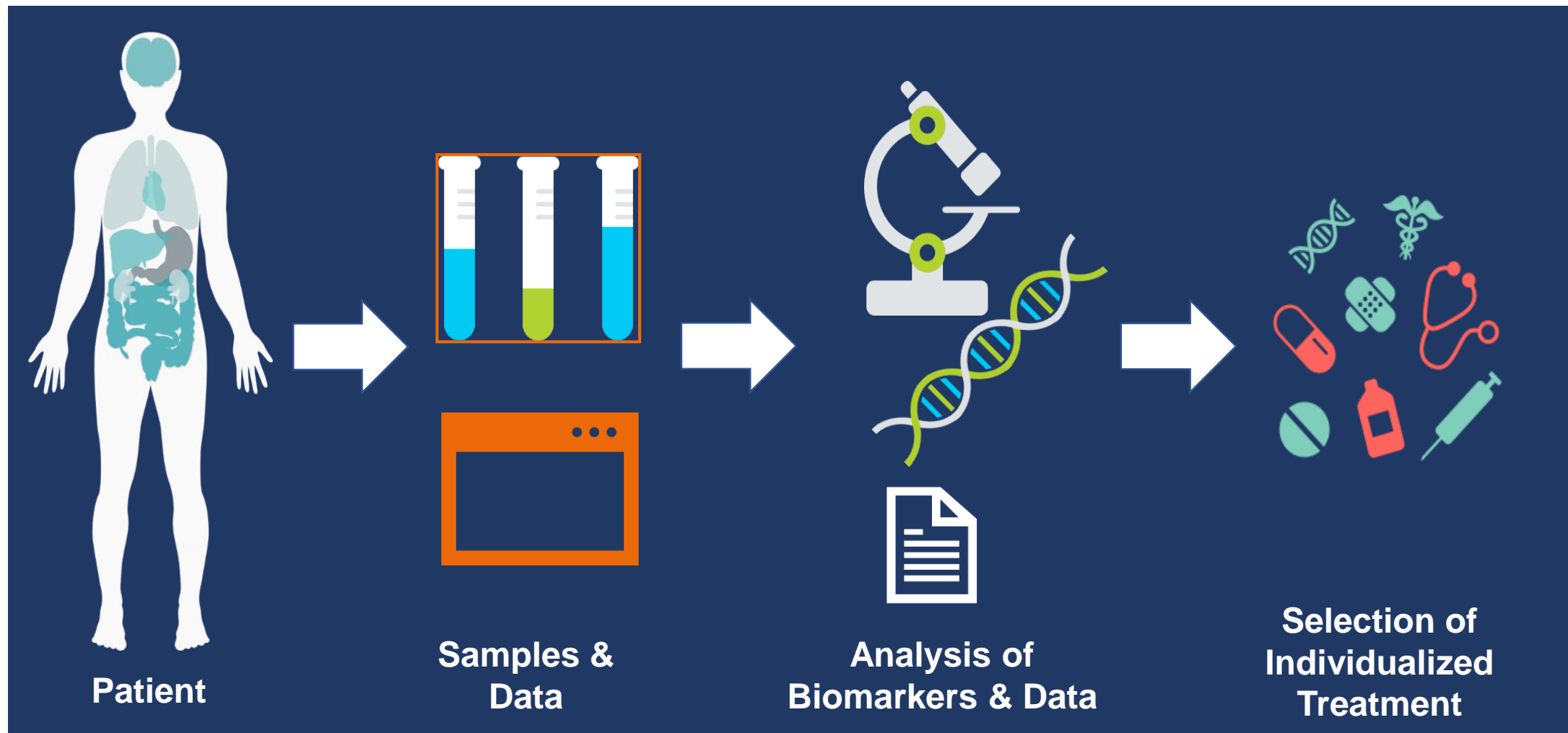
We provide training and workshops on ELSI issues such as Data Protection Impact Assessment (DPIA), ethical compliance and social engagement, among others.

- > [ELSI Webinars](#)
- > [ELSI Training Courses](#)

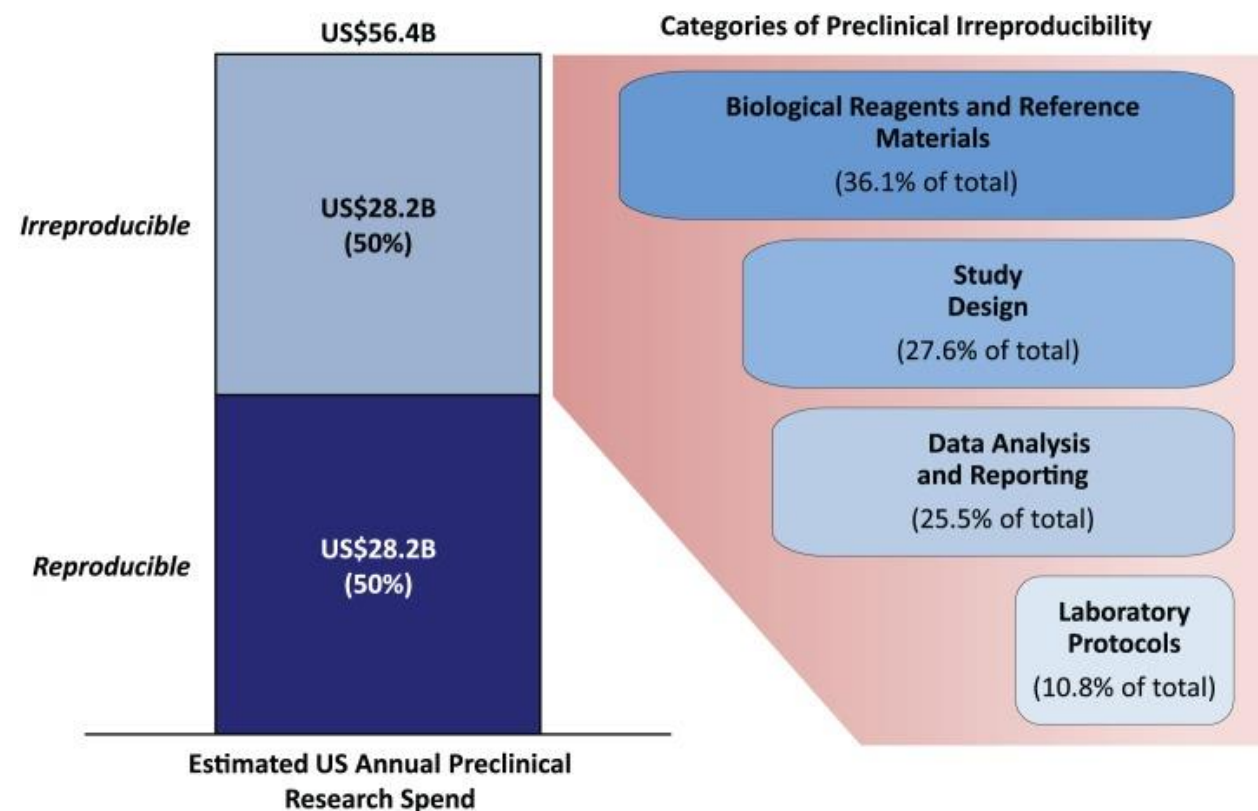
Advancing & Implementing *Personalized Medicine*



Advancing & Implementing *Personalized Medicine*



Pre-analytic impact on research & healthcare



Pre-analytical phase accounts for 46 – 68% of clinical laboratory errors

Medical Laboratory Observer, May 2014

Irreproducible preclinical research exceeds 50%, US 28B / year spent on preclinical research that is not reproducible – in the US
Freedman LP, Cockburn IM, Simcoe TS (2015) PLoS Biol 13(6)



#BBMRI_QM
@BBMRIERIC

BBMRI-ERIC QUALITY MANAGEMENT SERVICES FOR BASIC AND APPLIED RESEARCH

CME accredited **BBMRI Academy** courses



KNOWLEDGE HUB

Find everything you need to know about quality management in biobanking and biomedical research in one place: The BBMRI.QM Knowledge Hub consists of a pool of experts that can help you with any of the following:

- BBMRI-ERIC liaisons with international standardization organizations
- International standards relevant for biobanking and biomedical research
- Quality management tasks in EU projects
- Biobanking in times of COVID-19
Recordings available!



TRAINING & SUPPORT

Whether you are looking for training opportunities or practical support with your quality management – quality experts can provide you with a solution tailored to your needs.

Within the BBMRI.QM network, we offer in-house and online training, university courses, summer schools, short courses, workshops, and consulting services covering different quality management systems:

BBMRI.QM Training & Education Programmes:

- Training series about molecular in vitro diagnostic examinations – specifications for pre-examination processes **NEW**
- Training series about the biobanking standard ISO 20387:2018 **Recordings available!**



AUDITING

If you run a non-certified biobank and/or you want to know if the samples stored fulfill certain quality requirements, get the support of BBMRI.QM. We offer peer-review-style audits on request. Take the next QM improvement step together with us!

Step 1: Assess your processes with the BBMRI-ERIC Self-Assessment Survey (BBMRI-ERIC SAS).

- What is the BBMRI-ERIC SAS?
- Short explanation about access principles to the BBMRI-ERIC SAS
- Request the BBMRI-ERIC SAS

Step 2: Request a BBMRI-ERIC audit

- BBMRI-ERIC Audit

Step 3: A positive audit will lead to a quality mark in the Directory

- Q-mark in the BBMRI-ERIC Directory



QUALITY ASSURANCE

Task Force to define and provide biomarkers (intrinsic/extrinsic) that allow for standardized assessment of sample quality with a focus on liquid biopsies) through biospecimen research.

RESEARCH
Biospecimen
Biomarker
Sample quality

QUALITY ASSESSMENT
Q-mark for
biobanks and
collections

CONTRIBUTE
international
standard
developments

PROJECT
partner
providing QM
Services

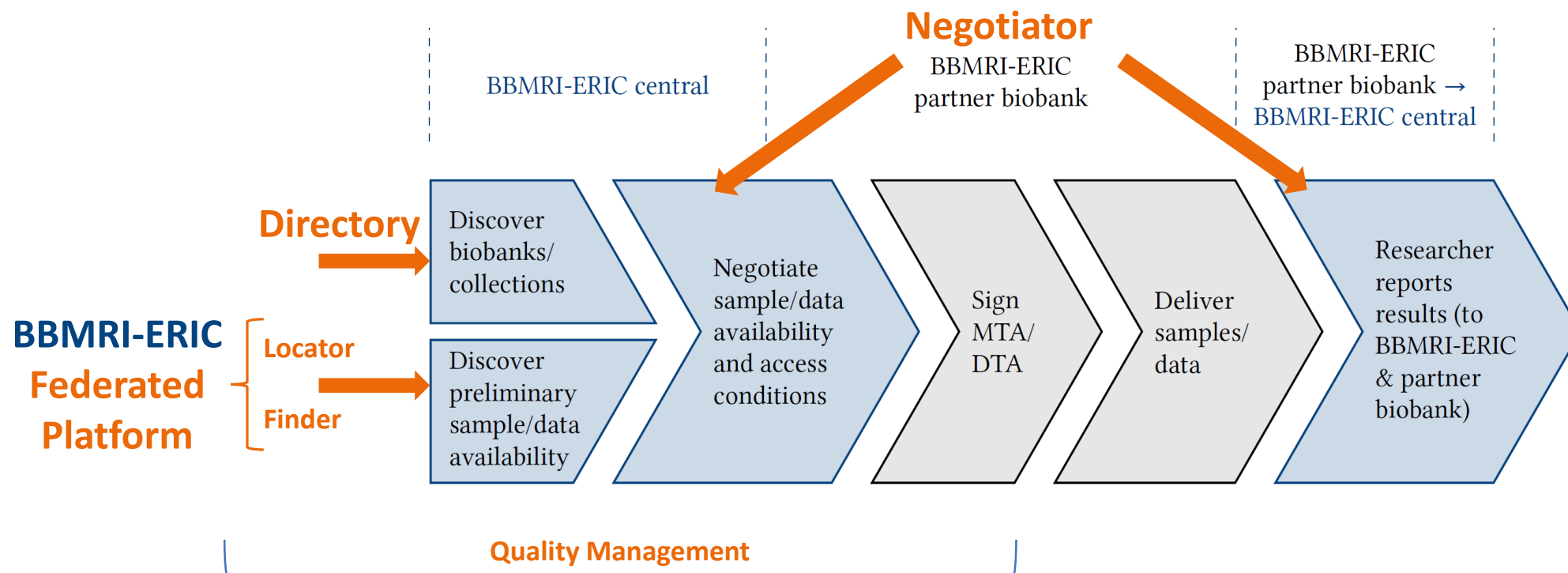
OUTREACH
900
participants
56 countries

BBMRI-ERIC ACCESS PIPELINE

BBMRI-ERIC Directory

- > 700 biobanks
- *Estimated* >100,000,000 samples and associated data

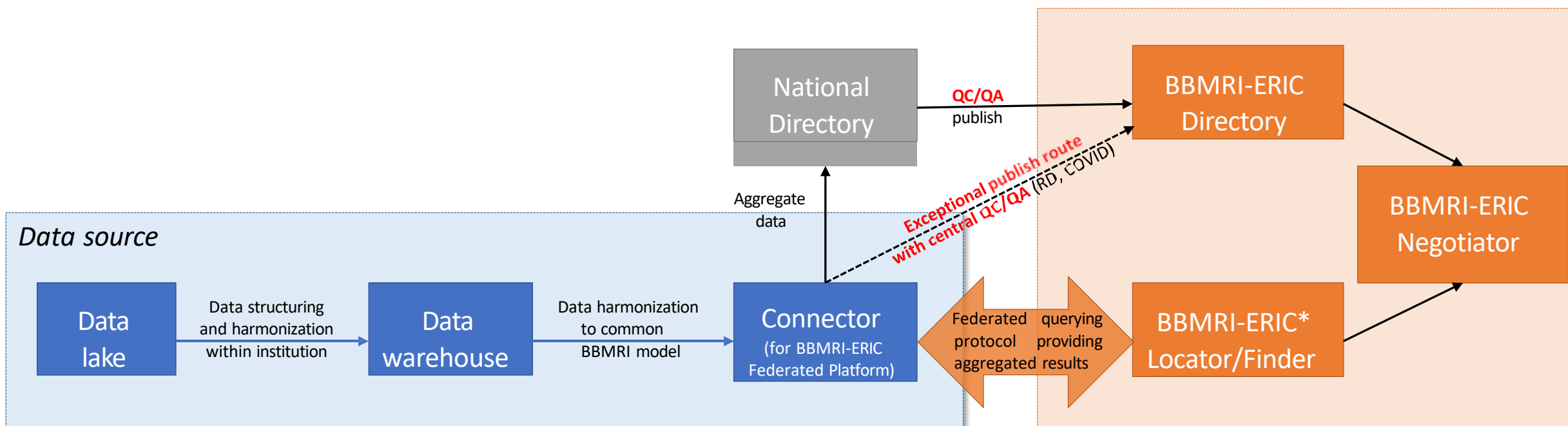
Directory is open for **any** biobank to visualize **COVID** or **Rare Disease** samples & data for use!



BBMRI-ERIC ACCESS PIPELINE

BBMRI-ERIC IT Ecosystem

- Allows privacy-preserving querying (and analysing) of individual [pseudonymized] data to build virtual cohorts of patients/donors in a federated fashion



* Locator/Finder can have also national Instance relaying to central BBMRI-ERIC

ACCESS PROCEDURE

▶ **BBMRI-ERIC Directory:**

<https://directory.bbmri-eric.eu/>

- **COVID-19** cohorts
- **Cancer** cohorts
- **Rare Disease** cohorts
- **Pediatrics** cohorts
- other disease cohorts

▶ **BBMRI-ERIC/GBA Locator:**

<https://samplelocator.bbmri.de/>

▶ **BBMRI-ERIC Negotiator:**

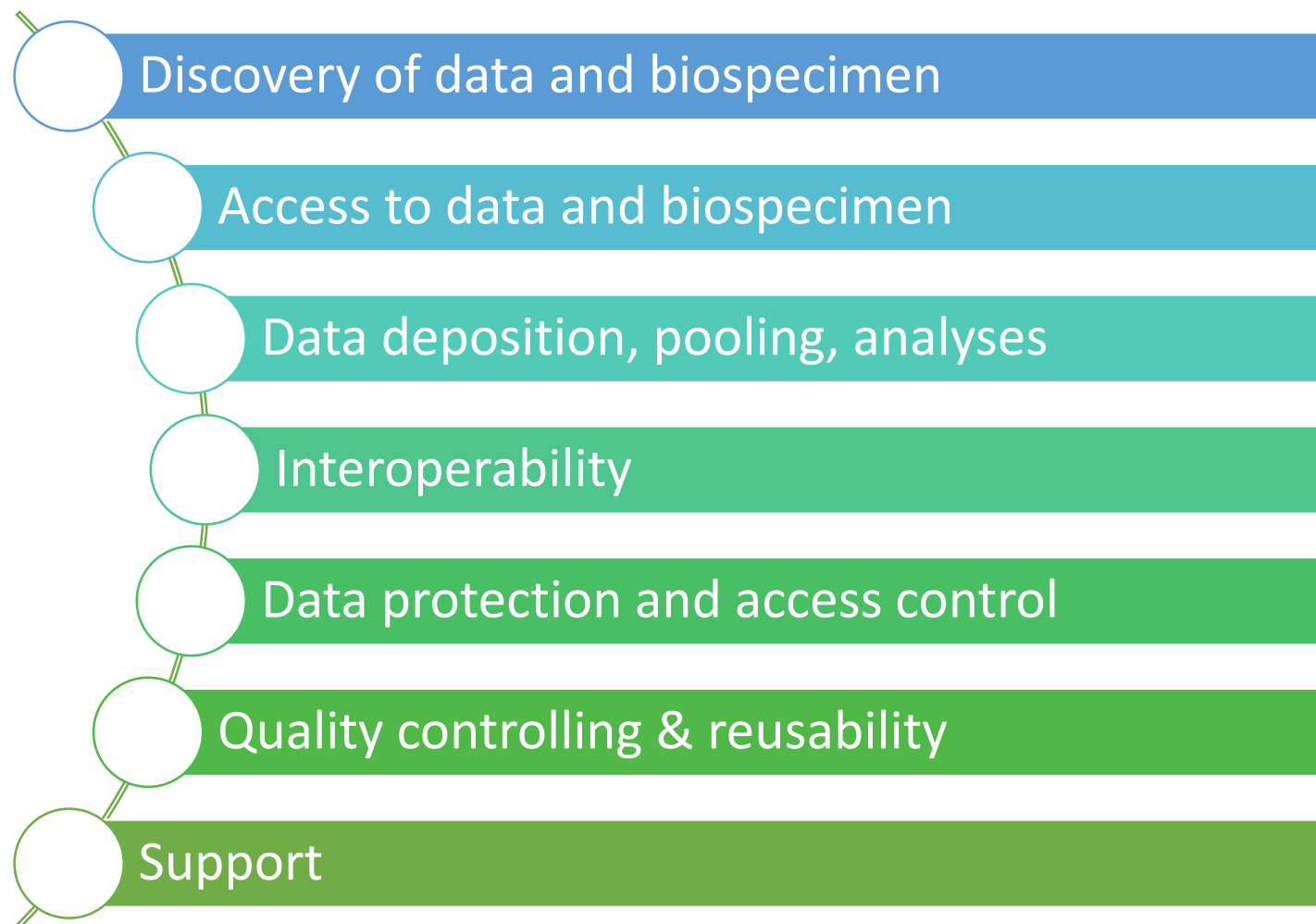
<https://negotiator.bbmri-eric.eu/>

- or directly via Directory and Locator services

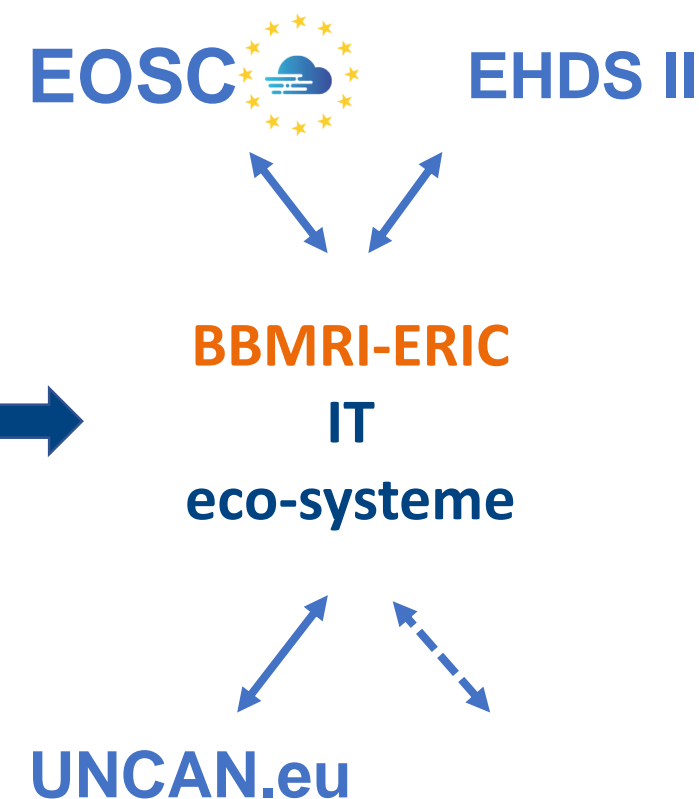
▶ **BBMRI-ERIC Helpdesk:**

negotiator@helpdesk.bbmri-eric.eu

IT SERVICES & RESEARCH



IT Infrastructure



EU RESEARCH INFRASTRUCTURE LANDSCAPE



- providing access to world-class facilities, samples, instruments, services and data
- Currently comprising 13 European LS RIs including BBMRI-ERIC



- The Forum currently comprises all 24 ERICs
- BBMRI-ERIC is project coordinator & runs the ERIC Forum secretariat
- Creation of a strong RI ecosystem



47 EU-FUNDED PROJECTS with our PARTNERS

Project management & engagement



20 completed projects



23 active projects

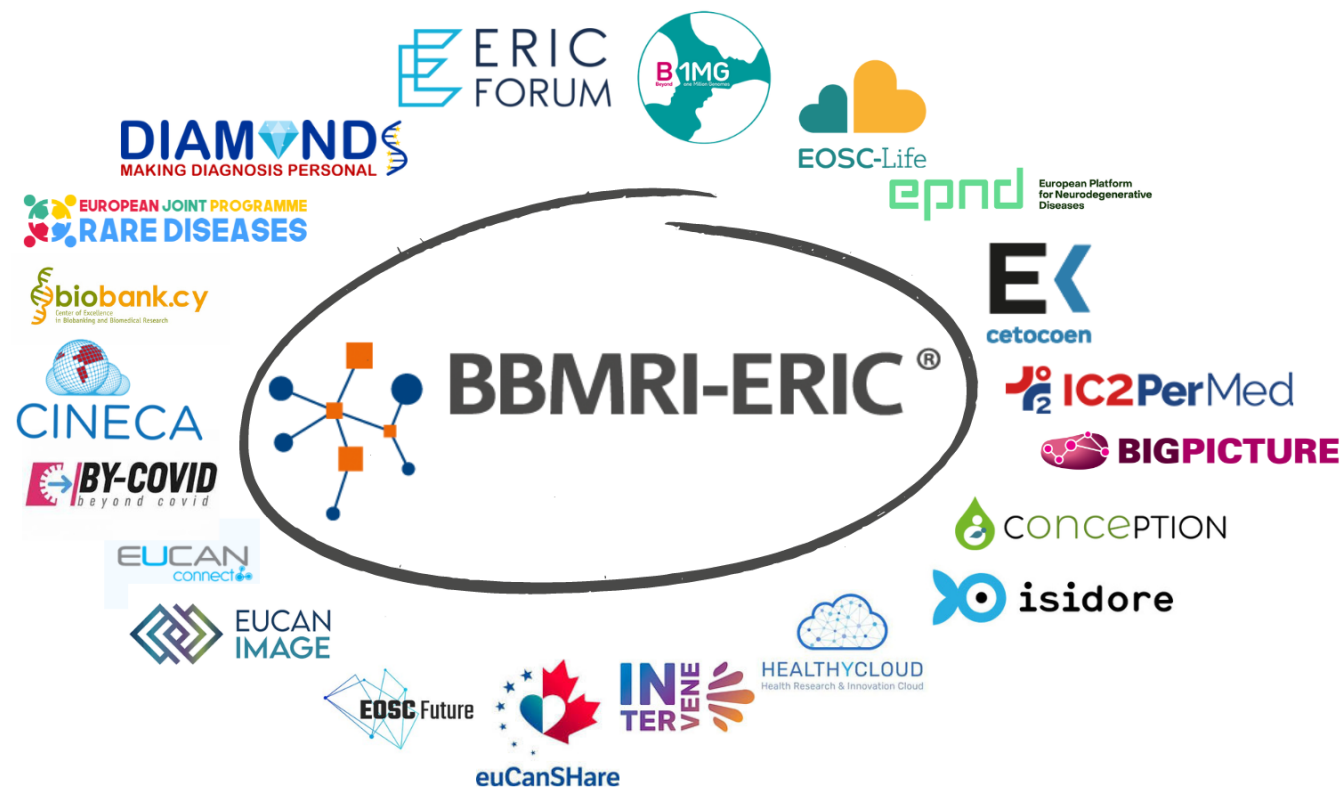


2 project coordination

- ERIC Forum
- CanSERV



4 projects in preparation



EU PROPOSAL

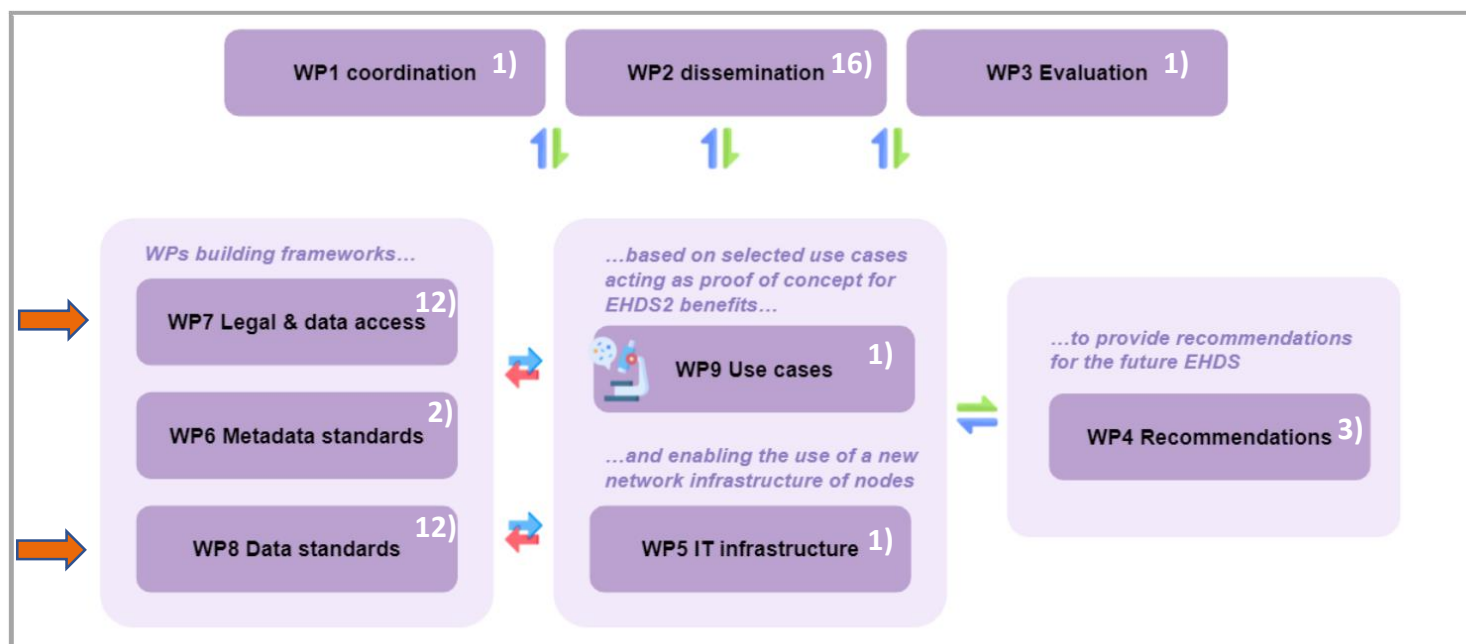
Grant Agreement stage

EHDS2: Pilot for a European Health Data Space on secondary use of health data (Lead: French Health Data Hub)

Consortium

- 1) Health Data Hub France (HDH)*
- 2) Sciensano Belgium*
- 3) Danish Health Data Authority (DHDA)*
- 4) Findata / THL / VTT
- 5) Health Data Lab, BfArM, Germany
- 6) Norwegian Directorate of eHealth
- 7) Nationale Directorate General for Hospitals Hungary (OKFÖ)
- 8) Croatian Institute of Public Health (CIPH)
- 9) Aragon Health Sciences Institute (IACS)
- 10) European Centre for Disease Prevention and Control (ECDC)
- 11) European Medicines Agency (EMA)
- 12) BBMRI-ERIC***
- 13) eBRAINS
- 14) ELIXIR
- 15) Orphanet-INSERM US-14
- 16) European Public Health Association (EUPHA)*

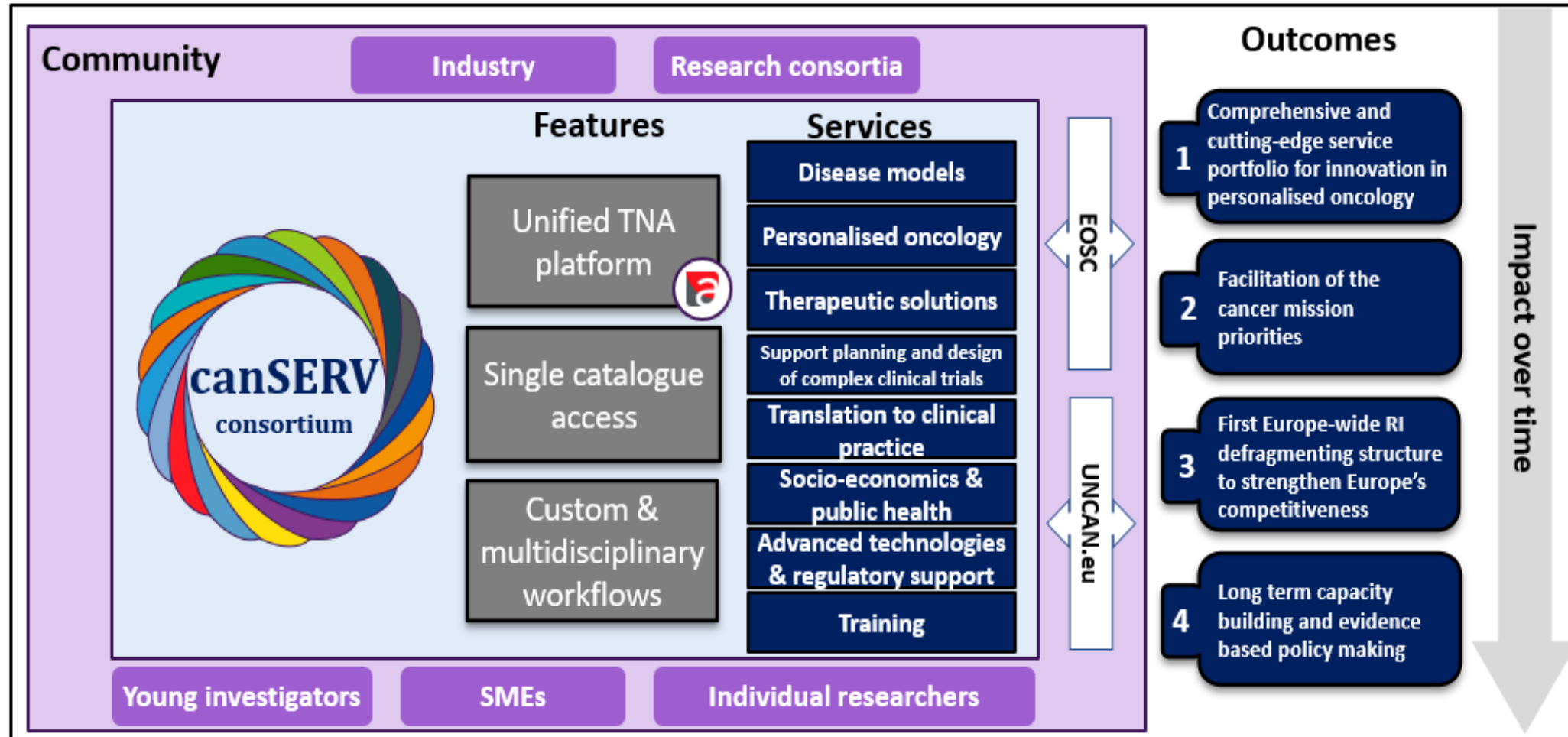
* Work Package Leads



canSERV

Providing cutting edge cancer research services across Europe

- BBMRI coordinated consortium with 13x RIs, 2x SMEs plus IARC, ECPC, EORTC & CCE
- BBMRI community & BBMRI Expert Centres involved in all 12 Work Packages
- **BBMRI Community:**
 - TNA (*Trans National Access*) service providing sites as new funding opportunity
 - > challenges & opportunities
 - > Community Engagement!
 - new TNA services likely to be onboarded
 - Consortium to continue beyond project duration!



- ~ 15 Mio. € grant; 60% for TransNational Access (TNA) service provision
- Kick-off in Brussels September 15th/16th

BBMRI-ERIC

Community Engagement

BBMRI Task Forces, Expert & Working Groups

Nominations by NN / Experts only

❖ **ELSI** Expert Groups on

- Helpdesk Network
- Research Ethics Committees
- Code of Conduct
- Ethics of AI

❖ **WG** Quality Management

Open for community registration

IT TF: Federated Search & Analysis Platform

IT TF: Biobank Data Quality & Certification

IT TF: Expedited Access Procedure for Samples & Data

IT TF: Data Pooling

IT TF: Big Data Analysis

TF: NNs/Biobanks **Operations & Sustainability**

TF: **Success Stories**

TF: **Communications & Outreach**

TF: **Quality Assurance**

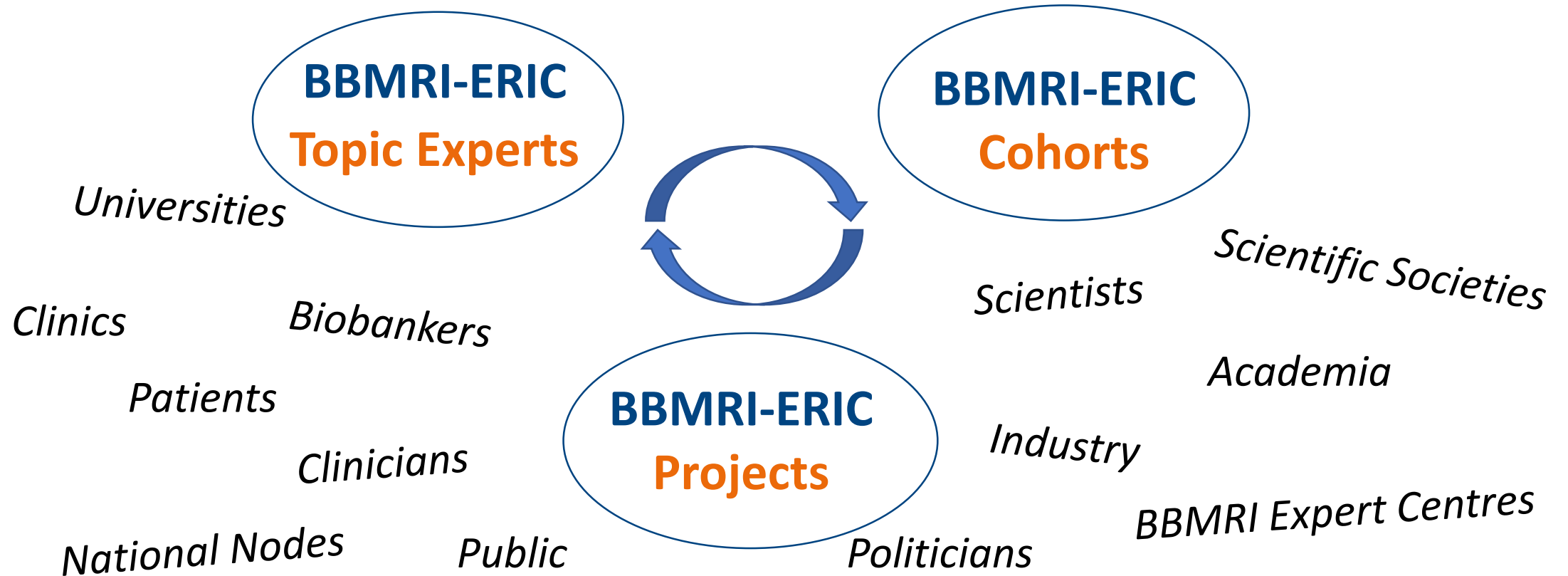
<https://forms.office.com/r/n3UDFQAGaB>

BBMRI-ERIC

Community Engagement



Prospects



EBW22 ROADSHOW

REGISTER AT WWW.ESBB.ORG/PAGE/EVENT_LISTING



Regensburg, 19-20 September 2022

Quality Stage of #EBW22



Rome, 13-14 October 2022

Paediatric Stage of #EBW22

EUROPE BIOBANK WEEK 2023

SAVE THE DATE

#EBW23 - 25-28 APRIL 2023

Bologna, Italy

in partnership with ESBB





THANK YOU!

Jens.Habermann@bbmri-eric.eu

✉ contact@bbmri-eric.eu

🌐 www.bbmri-eric.eu

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in BBMRI-ERIC