

MAKING NEW TREAT MENTS MENTS POSSIBLE

WHAT DATA SHOULD BE ACCESSIBLE TO WHOM AND WHEN BBMRI-ERIC EXPERIENCE

ERIK STEINFELDER

WHO WE ARE



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 data for the benefit of human health.

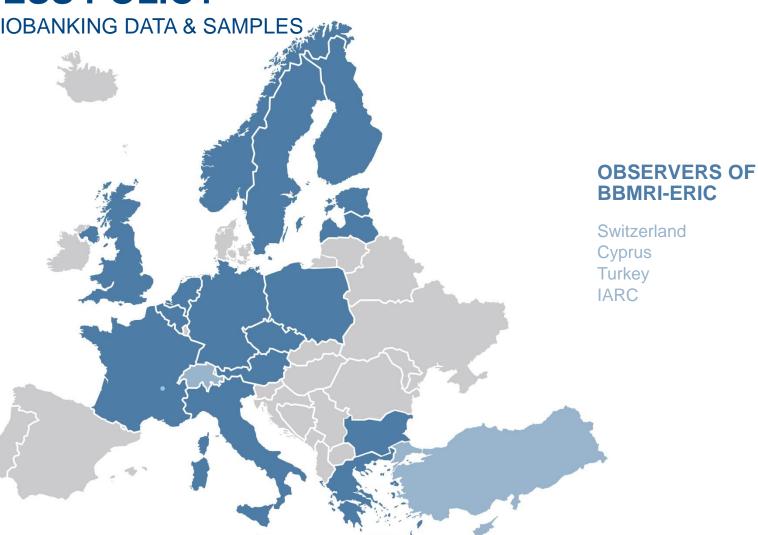


BBMRI-ERIC ACCESS POLICY

HARMONISING ACCESS TO BIOBANKING DATA & SAMPLES

MEMBERS OF BBMRI-ERIC

Austria Belgium Bulgaria Czech Republic Estonia Finland France Germany Greece Italy Latvia Malta Netherlands Norway Poland Sweden United Kingdom





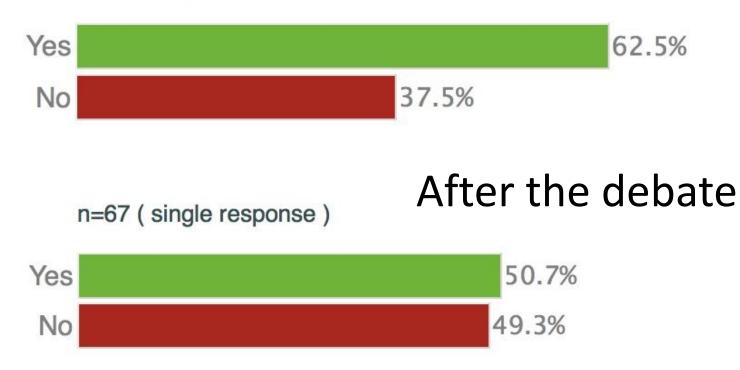
• BBMRI-ERIC[®] **BUILDING TRUST OUR STAKEHOLDER FORUM** ADVISORY BOARD Scientific and Ethical Assembly of Members Advisory Board (SEAB) BBMRI-**Finance Committee** Stakeholder Forum MRI-ERIC Stakeholder Forum Meetin **Steering Committee DECISION MAKING EXECUTIVE** Management Committee DIRECTOR GENERAL • Director General National Node Directors **Central Executive** • Directors of Common Services Management Office ********** **EXECUTIVE OPERATIVE** BBMRI.xx BBMRI.xx **Common Services** Stake- Common Service ELSI holder • Common Service IT Forum National National Secretariat • Other Common Services **Node Partners Node Partners**

SHOULD INDIVIDUAL RESEARCH RESULTS BE RETURNED TO PATIENTS/CITIZENS?



Before the debate

n=64 (single response)



GOAL OF THE NEW BBMRI-ERIC STRATEGY

MOVE FROM RESEARCH-ORIENTED ORGANISATION TO SERVICE ORIENTED ORGANISATION



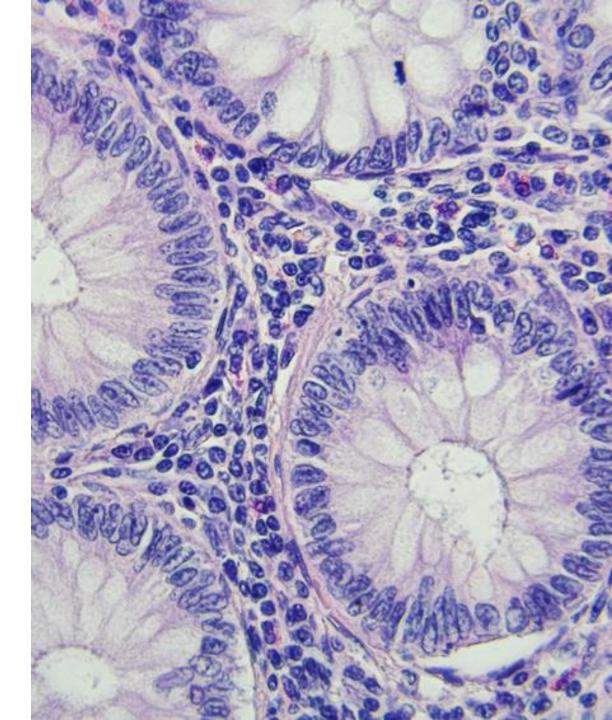
WHAT WE OFFER

EUROPEAN COLLECTION OF 10,000 COLORECTAL CANCER COHORT DATASETS SOON AVAILABLE VIA

ADOPT BBMRI-ERIC PROJECT



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IN SUM

• Our Access Policy gives a common ground for the organized/harmonized sharing of biobanking data

- Our Stakeholder Forum ensures that the BBMRI-ERIC community keeps building trust with all the biobanking stakeholders
 - This is crucial to make sure BBMRI-ERIC is not only a provider of data, but helps bridging science and society expectations
- We do not work for academia only: we need to move from pure research to SERVICES, including access to samples and data
- ADOPT CRC as an example



MAKING NEW TREAT MENTS DESSIBLE

THANK YOU!

contact@bbmri-eric.eu
www.bbmri-eric.eu
@BBMRIERIC
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