

Michaela Th Mayrhofer, senior project manager at BBMRI-ERIC, outlines how collaboration and sharing resources are helping to unleash the potential of Europe's biobanking community

Adopting a gateway for health

IN 1999, the OECD described biobanks as 'essential' for underpinning the Life Sciences and biotechnology. A decade later, *Time* magazine identified biobanks as one of 'ten ideas changing the world right now'. As interlinked collections of biological samples and biomedical data, biobanks form a foundation to modern biomedical research for better understanding disease mechanisms and the development of novel therapies and diagnostic tools for common and rare diseases. This is particularly important for addressing the grand societal challenges regarding the health of an ageing population but also to better apprehend the role of the environment and nutrition in human health at large. Europe's long tradition of collecting and storing human biospecimens and associated data, largely through national healthcare systems, calls for a leading role in building on existing resources and establishing research infrastructures.

Growing BBMRI

In 2008, the Biobanking and BioMolecular Resources Research Infrastructure (BBMRI) was one of the first projects entering the preparatory phase of the European Strategy Forum on Research Infrastructures (ESFRI). Following the successful completion of the preparatory project and the commitment of the EU member states to support this research infrastructure, the European Commission officially awarded BBMRI the 'Community legal framework for a European Research Infrastructure Consortium' (ERIC) in 2013.

This specific legal form is designed to facilitate the joint establishment and operation of research infrastructures of European interest. The ERIC status allows the pulling together of biobanks and biomolecular resources into a pan-European facility providing access to collections of partner biobanks and biomolecular resources, as well as their expertise and services on a non-economic basis.

BBMRI-ERIC aims at facilitating the fair access to quality-defined, human disease-relevant biological resources, including associated data. This is undertaken in an efficient, ethically and legally compliant manner by reducing the fragmentation of the biomedical research landscape through harmonisation of procedures and by implementing common standards and by fostering high level collaboration. This will be achieved by defining criteria for high quality-assured samples and their clinical data to be provided by members for selected disease entities (cancer) and by defining the quality of samples and data.

BBMRI-ERIC is part of the ISO/TC 276 Biotechnology committee. The standard development process ISO/TC 276 Biotechnology is of major interest to BBMRI-ERIC. This is particularly because this emerging norm will directly influence the working procedures of European biobanks, repositories and expert centres connected to BBMRI-ERIC. Common biobanking and resource services shall guarantee that



Michaela Th Mayrhofer

procedures and standards for different types of population-based, clinical-oriented biobanks and biomolecular resources are regularly updated according to the development of new standards and requirements.

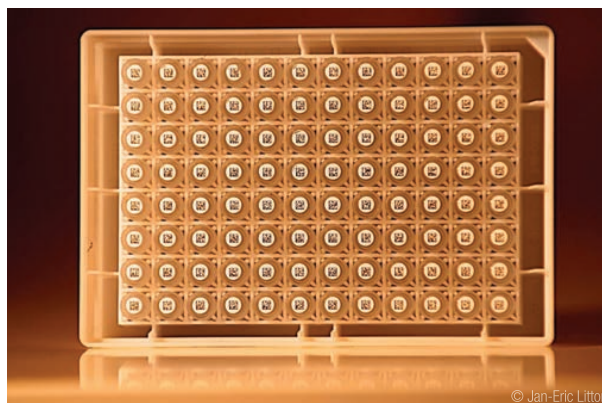
Moreover, BBMRI-ERIC relies on its common services, which consist of facilities that provide expertise and tools. The Common Service ELSI (ethical, legal and social issues), for example, ensures the proper consideration of ethical, legal and societal aspects relevant to biobanking, especially in relation to cross-border exchange of human biological resources and data.

Pooling resources

Using a distributed governance structure, BBMRI-ERIC facilitates a gateway to access the biobanks and biomolecular resources of 17 EU member states and an international organisation, namely: Austria, Belgium, Czech Republic, Estonia, Finland, France, Germany, Greece, Italy, Malta, the Netherlands, Sweden and the United Kingdom. Furthermore, Norway, Poland, Switzerland and Turkey act as observers, along with IARC/WHO. As a consequence, this makes BBMRI-ERIC one of the largest research infrastructures for health research in Europe.

In a first step, enriched data pools will facilitate the transnational, cross-biobank search for suitable biospecimens. Thus, the IT-Gateway to European biobanks will provide a single access point to the European biobank network and lays

BBMRI-ERIC: imagine the countless possible applications for the billions of biological samples that are available from biobanks across Europe



© Jan-Eric Litton



© @BBMRI.at/MUG

the basis for national, as well as transnational, research consortia based on the entire samples and data from various sites. It also allows for highly targeted research where small teams achieve statistical significance of their results by combining their resources throughout Europe. This approach extends previous catalogue-based solutions by enabling the processing of requests on a sample-based level, explicitly challenging the privacy aspect and solving it at least on the first level by delivering highly aggregated data.

Human biological samples with 2D barcode replacing donor's identity

BBMRI-ERIC will provide a one-stop access to the collections of the European biobanking community, expertise and services, ultimately facilitated by the Common Service IT. The access procedure was initially outlined during the preparatory phase in the BBMRI business plan. BBMRI-ERIC aims at evolving into one of the most important instruments for biomedical and clinical discovery and takes up the responsibility to ensure that samples and data, which donors have entrusted for the common good, are used in the best way possible for the advancement of knowledge, eventually contributing to improved healthcare.

Realising potential

Bearing in mind the need for better prevention, diagnostics and therapy for all European citizens, we are aware that every single sample affects our ability to comprehend disease. Acknowledging that the majority of samples stored in the various biobanks across Europe are currently underused, we believe in the moral responsibility to properly safeguard as

well as ensure knowledge about and access to these resources for research, which have been entrusted to the scientific community by patients and donors for altruistic reasons of solidarity.

In relation to the work on the General Data Protection Regulation (GDPR), BBMRI-ERIC acknowledges and embraces its great potential for the European Research Area. In relation to health research, it could become a major tool for allowing simplified transnational research and cross-border exchange of data. Thus, the GDPR has to be set up in a manner to provide a balance of protecting the individual and allowing the benefits to reach society at large.

It is equally important to ensure the close collaboration and dialogue between not only researchers and biobankers but also the public, patient advocacy groups and the biotech/pharmaceutical industry, which BBMRI-ERIC addresses through its Stakeholder Forum, which could pave the way for a new research and engagement culture.

Connecting the community

In reaching its pan-European goals, BBMRI-ERIC largely builds on the participation in Horizon 2020 projects. The ADOPT BBMRI-ERIC project, for instance, aims at boosting and accelerating the implementation of BBMRI-ERIC and its common services.

Furthermore, the CORBEL project will establish a collaborative framework of shared services between all the ESFRI biological and medical sciences (BMS) research infrastructures that transform the European research community, from discovery of basic biological mechanisms to applied medical translation through the provision of a unified interface, aligned services and co-ordinated user access to a range of advanced technology platforms.

BBMRI-ERIC is co-leading the CORBEL project and leads the ELSI work package, which aims at establishing one common service ELSI for all BMS research infrastructure. BBMRI-ERIC furthermore co-ordinates the RITRAIN project and participates in B3Africa, CY Biobank, PhenoMenNal, EGI-ENGAGE, EMTRAIN and BioMedBridges, as well as BBMRI-LPC and RD Connect.

Ultimately, BBMRI-ERIC is a specific European asset having become a fundamental component in addressing the ongoing and future requirements of Europe's health service frameworks, in particular, including the competitiveness and innovativeness of health-related industries.

 HORIZON 2020

MT Mayrhofer
BBMRI-ERIC
Common Service ELSI

[BROWSE www.bbmri-eric.eu](http://www.bbmri-eric.eu)
