



# Patient Participation in Biobanking Research Infrastructure

Derick Mitchell PhD, Michael Griffith

BBMRI Stakeholders Forum, Irish Platform for Patient Organisations, Science and Industry (IPPOSI)



## INTRODUCTION

National and regional biobanks play a vital role in modern health research. In order to make better use of these invaluable resources, a massive pan-European collaboration across international borders is being prepared - the Biobanking and Biomolecular Resources Research Infrastructure (BBMRI). As an important part of a comprehensive public consultation and engagement process during the preparatory phase of BBMRI, the BBMRI Stakeholders Forum has been assembling the input and requirements of the broad and heterogeneous stakeholder community of BBMRI and is managed by the Irish Platform for Patient Organisations, Science and Industry (IPPOSI).

## WHAT ARE BIOBANKS?



A biobank stores, processes and distributes biological materials and data associated with the material. These biological materials include all types of human biospecimens such as tissue, cells, blood or DNA.

As research data from such samples can be combined with data from medical records, environmental exposure and lifestyle information, biobanks are considered invaluable resources for medical research.

The samples stored in biobanks are used by researchers for studying the underlying factors of many common and rare diseases.

In many cases, scientists need to pool and exchange relevant information held in other similar biobanks to reach the statistical power needed to compare research data generated from different populations. Therefore, the ability of biobanks to interoperate thus facilitating international collaboration is essential.

## WHAT IS BBMRI?

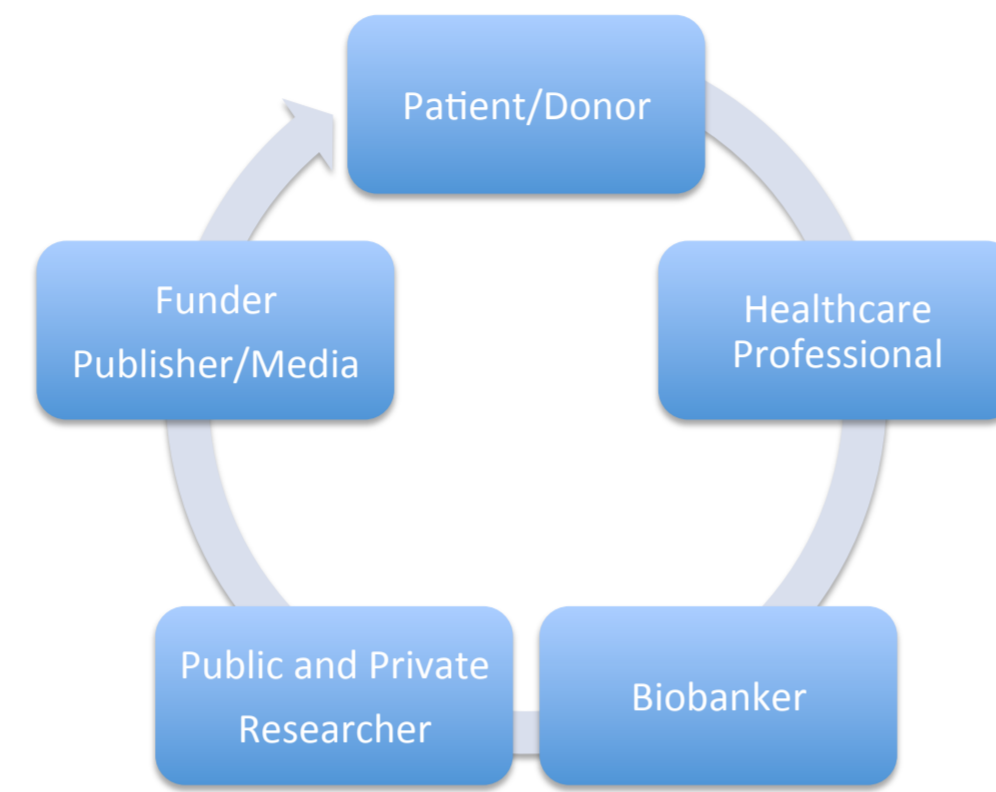


BBMRI (Biobanking and Biomolecular Resources Research Infrastructure) is a pan-European network of more than 270 institutions from more than 33 countries who are planning the construction and future operation of a unique pan-European biobanking research facility.

BBMRI is building on existing biobanks, resources, technologies and expertise, and is integrating them into a European-wide infrastructure which is properly embedded into European scientific, ethical, legal and societal frameworks.

Once implemented, BBMRI will act as an interface between sample donors and scientific researchers and has many responsibilities towards patients/donors such as preventing sensitive information flowing inappropriately, protecting donors privacy and confidentiality, preventing research negatively impacting on clinical care and ensuring that samples and data provided by patients contribute to the advancement of healthcare in the most efficient manner.

## WHO ARE THE STAKEHOLDERS?

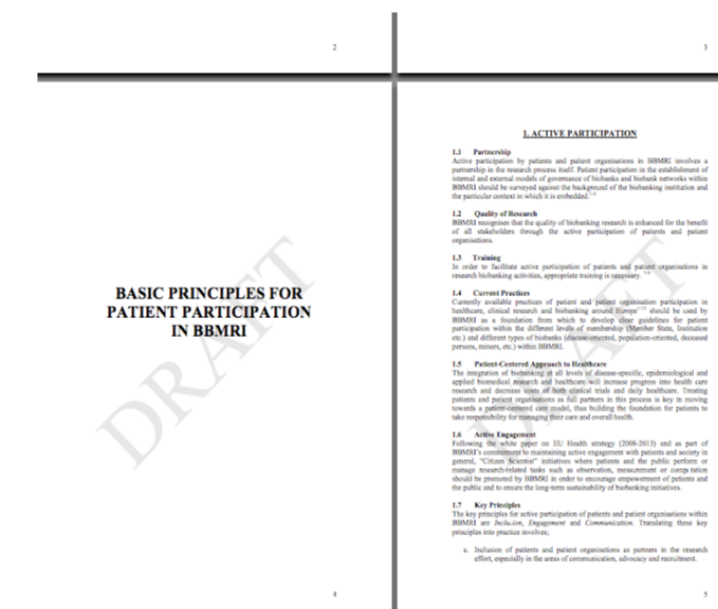


### PRINCIPAL BBMRI STAKEHOLDERS

- Patients
- Healthcare Professionals
- Biobankers
- Public and Private Researchers
- Funders
- Users of Research Infrastructure
- Media and Publishers
- Regulators and Ethics Bodies

## PATIENT CONSULTATION

A consultation document entitled “Patient Participation in BBMRI” was created by a BBMRI Stakeholders Forum working group of patient and stakeholder representatives from 17 organisations from over 10 countries. This document is not only ensuring that patients’ needs and expectations in the field of biobanking are taken into account, but is also highlighting the good biobanking practices that exist among patient organisations who are making sizeable contributions to this field.



## MAIN THEMES

### I - Active Patient Participation

The key principles for active participation of patients and patient organisations within BBMRI are defined as *Inclusion*, *Engagement* and *Communication*. Examples of translating these into practice include training of patient organisations and regular and reasonable feedback to patients regarding use, sharing and transfer of samples.

### II - Ethics

The paper also includes ethical guidelines addressing delicate issues for patients such as transparency, consent, privacy, confidentiality, use and withdrawal.

### III - Access

Access policies and procedures, including industry collaboration, identifiability of donors from samples and return of information to the public are also documented.

### IV - Patients Rights and Expectations

The document outlines patients’ rights and expectations regarding their donations, as well as a list of examples of good practices in regard to active participation of patients and patient organisations in biobanking and related activities.

### V - Good Practices

This consultation is open to other examples of good practices and patient organisations interested in adding their specific experience are welcome to add their contributions online at [www.bbMRI.eu/index.php/stakeholders-forum/events-and-consultations](http://www.bbMRI.eu/index.php/stakeholders-forum/events-and-consultations)

## ENDORSEMENT

The draft document has been distributed for consultation to European Patient Organisations as a mechanism by which they may wish to indicate their general support for the BBMRI initiative and for appropriate patient representation in the proposed infrastructure. The basic principles have been reviewed and endorsed by the following pan-European and Member State Patient Organisations:

- European Organisation for Rare Diseases (EURORDIS)
- International Alliance of Patient Organisations (IAPO)
- European Genetic Alliance Network (EGAN)
- European Federation of Neurological (EFNA)
- Europa Donna – The European Breast Cancer Coalition
- European Network for Research on Alternating Hemiplegia (ENRAH)
- Dutch Genetic Alliance (VSOP)
- Genetic Alliance UK

To review the document or to register your organisations support, see the contact details below.

## PRESENTATION

A draft version of the “Patient Participation in BBMRI” consultation document was presented at a recent Stakeholders Forum event in Brussels, to the coordinator of BBMRI, Kurt Zatloukal. The document is expected to be used in the drafting of policies and procedures for the implementation of the upcoming BBMRI infrastructure.



“The next step is to ensure that patients are present in the governance structure of BBMRI and that they are represented in each biobank - beyond tokenism” - Fabrizia Bignami, EURORDIS.

## SUMMARY

- BBMRI is being constructed as a pan-European research infrastructure for biobanking.
- BBMRI Stakeholders Forum acts as a platform for patients views to be brought to the table.
- There is wide support for the “Patient Participation in BBMRI” document from both the biobanking world and the patient community.
- The draft document is seeking the support of relevant patient organisations.

## CONTACT

Derick Mitchell, Executive Manager, BBMRI Stakeholders Forum, [dmitchell@ipposi.ie](mailto:dmitchell@ipposi.ie)



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