

“BBMRI Cohorts DNA” in BBMRI-ERIC Directory

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by

BBMRI-ERIC Headquarters & BBMRI-ERIC National Nodes

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Agenda

- **Introduction: Building BBMRI Cohorts**
- **Potential new business collaborations**
- **Overview and clarifications on topics that appeared in the first round**
 - Maintenance of data (collections and facts tables) in BBMRI-ERIC Directory
 - Networks and how to use them
 - Why having 2 networks for the BBMRI Cohorts DNA
 - How to prepare and upload file
 - How to work with facts tables
- **Demo**
 - Get access to the Directory / logging in (for National Nodes, biobanks)
 - Ways to flag collections as BBMRI Cohorts DNA in the Directory (for National Nodes, biobanks)
 - Prepare data sets for contributing detailed statistics (for biobanks)
 - Prepare templates for upload of data to Directory (for National Nodes)
 - Add or update data sets in Directory (for National Nodes)
 - Clean up the Facts table in Directory (for National Nodes)
- **Questions and answers from first round**
- **Q & A**

Building BBMRI Cohorts

Background:

Over the last 10 years, we have built together an increasingly strong network to facilitate access to samples, data and biomolecular resources. Our Directory reflects millions of samples and data available for health and life science research within our BBMRI community.

While we continuously take care of requests received locally, nationally or internationally, **exchanges with many biobanks and National Nodes have shown a growing eagerness within our BBMRI family to proactively make use of our carefully curated, precious, samples and data**

Objectives:

- Build cohort visibility - either for pilot specific community projects or as part of alliances with scientific societies and/or industry which would increase the use and turn-over-rate of samples and data and proactively support research.
- Prepare our community ahead of time for upcoming EU calls or provide the momentum to start lobbying for EU calls we find of utmost clinical and scientific need.
- Further enhance BBMRI biobanks' visibility and add to an overarching sustainability concept.

Our proposal

The National Node Directors and Headquarters propose to **retrospectively build “BBMRI Cohorts” in the BBMRI Directory**. We aim to capture the following selection criteria for the 1st Call:

Mandatory:

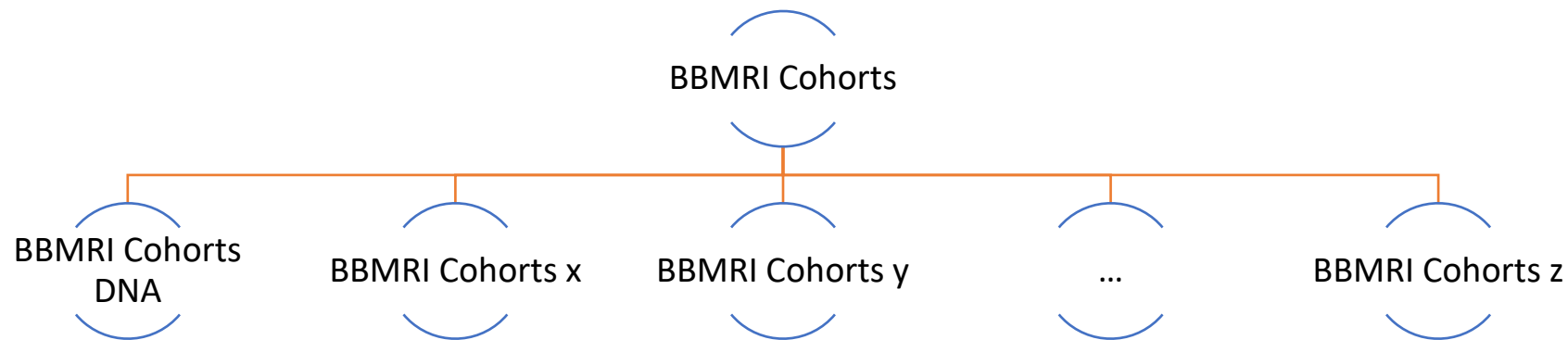
- **The consent should allow sharing** samples & data with collaboration partners from **academia and industry** at least within Europe
- The selected sample type for this 1st call is **isolated or non-isolated DNA from blood**
- Sample data needs to be **accompanied with clinical phenotype data**
- **Main Diagnosis** (can be any disease entity)
- Possibility to collect additional clinical data

Of additional advantage:

- Clinical data including **co-morbidities**
- Clinical data including **medication**
- Clinical data including **longitudinal follow-up** clinical phenotype data
- Any **OMICs** data
- Any type of **images** and/or related data

Why is this activity important to Biobanks

- Benefit patients and society
- Build consortia ready to apply for future EU calls & lobby for them
- Initiate new projects & partnerships including industry



Potential new business collaborations

BBMRI virtual cohorts – disease & population cohorts

- BBMRI to establish collaborations with industry/biotech to generate OMICS profiles for these cohorts (Genomics, Transcriptomics, Proteomics, Metabolomics)
- **Benefits for the biobanks participating:** Increase the visibility and value of their collections with OMICS data

Prospective collections for industry partners

Benefits for the biobanks participating:

- Revenue generation
- New collections
- Increased visibility of the biobanks and their services
- Return of Data to biobanks

Maintenance of data (collections and facts tables) in BBMRI-ERIC Directory

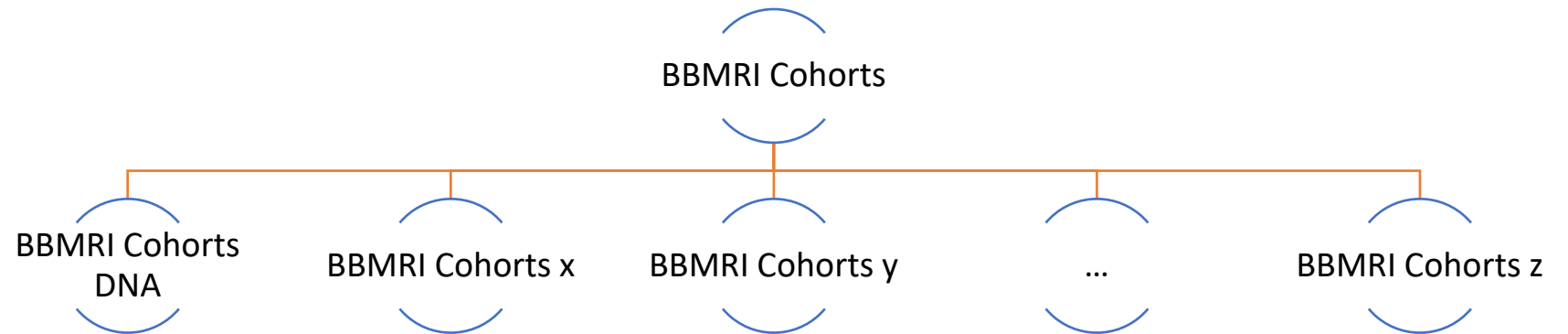
- **updates and uploads of data are done by the particular biobanks or by National Nodes as to the usances in the country**
 - UMCG data management team may help for special issues and deal with problems of the software and the database (file a ticket in the BBMRI-ERIC helpdesk by sending an email to directory@helpdesk.bbmri-eric.eu)
 - routine daily maintenance of data for biobanks is not scalable with UMCG team and therefore not foreseen for them
- **please do not send any data to BBMRI-ERIC HQ** as we don't have appropriate access and such process would also not scale

Networks and how to use them

- **network (in MIABIS Core v3)**
 - group of interconnected biobanks, collections and/or research resources
 - defined common governance
 - via a network entity this new level of organisational aspects can be described
 - networks do not contain any samples and data directly
- **practically, networks may be added to collection entries in BBMRI-ERIC Directory**
 - technically they may be also added to biobank entries but this is not needed as only the collections are of interest (requests are done on their samples and data)

Why having 2 networks for the BBMRI Cohorts DNA

- we are piloting with **BBMRI Cohorts DNA**
- further particular cohorts may be asked for in the future
 - **BBMRI Cohorts** is an umbrella for all these cohorts



- So please add both networks to your collections!

How to prepare and upload files

- **add, update or enhance the data in the EXCEL file you already have for describing your collection(s)**
 - either download existing data (EXCEL) from BBMRI-ERIC Directory
 - or if you do not yet have data in BBMRI-ERIC Directory get a template (EXCEL) from BBMRI-ERIC Directory team or your National Node IT representative
- **upload data (again) or have them uploaded by your National Node's IT representative**

How to work with facts tables

- **start with YOUR data** corresponding to the cohort in mind on record level
- **for each category** in the facts table **collect per record the category values** for YOUR data according to the codebooks in BBMRI-Cohorts_Categories

A	B	C	D
Material type	Sex	Age range	Disease codes

- **extract all combinations of existing category** values in YOUR collected data
- **for each combination count** the **appearances** within YOUR data
 - Note: aggregated data DO NOT include any particular records / ID

Valuable resources to support your endeavours for the BBMRI Cohorts

- **FAQ (will be available soon and evolve with new incoming questions)**
- **Following Files can be downloaded from this [folder](#)**
 - Guidelines (*BBMRI-Cohorts_Guide-for-biobanks.pdf*)
 - Template file (*BBMRI-Cohorts_Template.xlsx*)
 - Categories tables (*BBMRI-Cohorts_Categories.xlsx*)
- **Helpdesk email addresses**
 - Directory issues (general): directory@helpdesk.bbmri-eric.eu
 - BBMRI Cohorts: bbmri-cohorts@helpdesk.bbmri-eric.eu

Thank you!

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