BBMRI-ERIC DIRECTORY

MANUAL FOR DATA MANAGERS

Version 3.6.12

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INTRODUCTION

This manual is a technical description of the BBMRI-ERIC Directory data model and the process of updating data in the Directory. The intended audience of this manual is the National Node Data Manager. Throughout this document the BBMRI-ERIC Directory is used for the examples. However, this manual also applies to local BBMRI instances. Although the model remains the same, minor differences between the local and ERIC Directories exist, these will be indicated in the footnotes.

DATA INTEGRATION PROCESS

The BBMRI-ERIC Directory has a federated process of updating the data, where each National Node is responsible for updating the data for the biobanks in the node. This is done in a staging area that gives the national node exclusive access to update the data.¹ Data in the Directory can be managed in four different ways:

- 1. Manual data entry if the National Node does not host a National Directory
- 2. Manual upload of Excel or CSV files exported from the National Directory
- 3. Scheduled file ingest of CSV files from the National Directory
- 4. Programmatic updates initiated by the National Directory (using the Directory's RESTful API's, see the Interoperability on https://molgenis.gitbooks.io/molgenis/content/)



Regardless of the method used to update the staging area the data from the staging area is integrated into the Directory through a nightly scheduled job. This means that it takes one day before changes are visible for the outside world. In the meantime, the data manager of the National Node can access and verify the data in the National Node's staging area.

Next to the data that is provided by the National Node the Directory holds quality marks that are based upon the self-assessment filled in by the biobanks. These parameters are managed by BBMRI-ERIC's quality management team and cannot be updated by the National Node. However, for a smooth process of application for the quality marks it is paramount that the biobank and the collections are registered in the Directory before the self-assessment is filled in.

MANUAL DATA ENTRY

The manual data entry option is to be used only as a last resort option if no National Directory or database is available. Data entry is done in the staging area for the National Node and changes will

¹ This part only applies to the BBMRI-ERIC Directory, the local directory instances do not contain staging areas and can upload the data directly to the directory model.

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be published to the production version on a daily basis based on a scheduled job that runs during the night.



1. Go to https://directory.bbmri-eric.eu/

2. Click on "Sign in" in the right top corner of the screen.

Sign in	×
I have read and agree to the privacy policy described at https://www.molgenis.org/MOLGENIS_Privacy_Policy.pdf	
With BBMRI-ERIC AAI - BBMRI-ERIC Catalogue	
Use a local user	

- 3. Sign in "With BBMRI-ERIC AAI". If you haven't an account yet, create it (see <u>manual</u>). After creating it, send a mail to <u>molgenis-support@umcg.nl</u> to get permission(PI in CC). If you have an account, sign in.
- 4. Click on "Data integration" in the menu. and Click on "Navigator" in the menu.

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	1 collection available Arrhythmia genetics in the Netherlands Type: Case-Control	1 collection available Ability to collect COVID-19 cases Type: Disease specific	1 collection available AMC Renal Transplant Biobank Type: Disease specific	collection available Main Collection Available: 1000 samples	Collection available Main Collection	

 Click in the following screen on the link to go to your national node's staging area. All countries are denoted by their eu_bbmri_eric_<CC>, where <CC> is your country code, e.g.² eu_bbmri_eric_NL.

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² This only applies to the BBMRI-ERIC Directory, local instances can use the model without country code: *eu_bbmri_eric.*

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6. Click on the link for the data table you want to edit.

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Please cite Holub Petr, Swertz Morris, Reihe Robert, van Enckevort David, Müller Heimo, and Litton Jan-Eric. Biopreservation and Biobanking. December 2016, 14(6): 559–662. doi:10.1088/bio.2016.0088 upon use. This database was created using the open source MOLGENIS sourcemen 10.10 built on 2029-01-30 11:41 UTC. Please cite Van der Velde et al (2018). Swertz et al (2010) or Swertz & Jansen(2007) on use.

7. Edit the data using the edit and delete buttons.

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8. When you press the edit button you get a popup to edit the data of one record.

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9. To save the record you might have to scroll down to reveal the save button.

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			Please cite Holub Petr, Swertz Morris, Relins Robert, van Enckevort David, Müller Heimo, and Litton Jan-Eric. Biopreservation and Biobanking. December		
			ZUTD, 14(p): b39-b62. doi:10.1089/pio.2016.0088 Upon Use. This database was created using the pone source MOI GENIS software		
			Please city of an der Velde et al (2018), Swertz et al (2010) or Swertz & Jansen (2007) on use.		

10. All changes are automatically published from staging to production during the night.

Manual data upload of Excel or CSV files

Manual upload is done in the staging area for the National Node³ and changes will be published to the production version on a daily basis based on a scheduled job that runs during the night. The Excel

³ Local BBMRI instances can directly upload to the directory model without using the staging area and two letter country code in the table names. For example: *eu_bbmri_collections*.

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file or CSV files have to adhere to a specific structure. CSV files can be bundled together in a ZIP file, where each file has the name of the table and Excel files can have multiple sheets, where each sheet has the name of the table. The names are as follows:

- Collection: eu_bbmri_eric_<CC>_collections, e.g. eu_bbmri_eric_NL_collections
- Biobanks: eu_bbmri_eric_<CC>_biobanks, e.g. eu_bbmri_eric_NL_biobanks
- Networks: eu_bbmri_eric_<CC>_networks, e.g. eu_bbmri_eric_NL_networks
- Contact information: eu_bbmri_eric_<CC>_persons, e.g. eu_bbmri_eric_NL_persons
- Facts: eu_bbmri_eric_<CC>_facts, e.g. eu_bbmri_eric_NL_facts
- Also known in: eu_bbmri_eric_<CC>_also_known_in, e.g.eu_bbmri_eric_NL_also_known_in

Our data management team will provide you with a template upon request, or see section "Download the latest model and data" to retrieve a template yourself.

The steps to upload the files are as follows:

1. Go to https://directory.bbmri-eric.eu/

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				DNA RNA	Plasma RNA Serum		

2. Click on "Sign in" in the right top corner of the screen.



- 3. Sign in "With BBMRI-ERIC AAI". If you haven't an account yet, create it (see <u>manual</u>). After creating it, send an email to <u>molgenis-support@umcg.nl</u> to get permission(PI in CC). If you have an account, sign in.
- 4. Click on "Data integration", "Upload" to go to the data upload wizard.

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5. Select your Excel file to upload and press next.

6. Select the following options: "Ignore/metadata" and "Add entities / update existing" and press next.

Advanced search Rare Disease Biobanks Background User Manual Privacy Statement References Data Integration - Admin - Account Help Stevent				_	🔒 dir	ectory.bbmri-eric.eu	_	Ċ			I	ð Ø
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7. Accept the default options and select next.

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8. Verify that there are no Errors (denoted with a red background colour) indicated during the validation and press "Next". There might be some warnings (denoted with a yellow colour)

indicated during the validation process when your file contains additional columns or does not provide data for optional columns.



9. The actual updating will now start, and at the end give a report with the number of updated records. At the end you can press "Finish" to complete the process. If the upload fails, please take a screenshot of the error report and contact the helpdesk.

Scheduled file ingest of $\ensuremath{\mathsf{CSV}}$ files

To set up a scheduled file ingest of CSV files you will have to provide separate files for the five different entities (biobanks, collections, networks, contact information and also known in) and they should be made available for download by the system using HTTP or HTTPS. We currently do not support authentication, but if necessary you can limit the access to your files to the IP address of the Directory. To report on failures you need to provide us with an e-mail address that will receive error notifications. You should file a ticket in the Directory queue of the BBMRI-ERIC at https://helpdesk.bbmri-eric.eu/ to get the system setup.

STRUCTURE OF THE CSV FILES

The CSV files should be well structured and adhere to a few specific rules:

- No embedded newlines
- Text should be enclosed with double quotes
- Lists should be enclosed with double quotes and use commas as separator for the list elements
- Dates should be ISO8601 formatted
- When there is no value for a certain field you should leave it completely empty

PROGRAMMATIC UPDATES THROUGH THE RESTFUL API'S

The Directory is built using the MOLGENIS Software. MOLGENIS offers a RESTful + JSON API to perform basic Create, Read, Update, Delete (CRUD) operations on the data in the Directory. Examples of these commands can be found in the accompanying Postman configuration (<u>https://doi.org/10.5281/zenodo.3367102</u>). An extensive manual for the RESTful API can be found in our Swagger developer documentation, which you will find in the 'Data Integration' menu. When using the REST-API, please make sure you use the staging area's endpoint for your national node, by using the country code (CC) according to the valid ISO-3166-1 alpha 2 standards⁴.

- For API V2 use: /api/v2/eu_bbmri_eric_<CC>_<Entity>
- For the Data API use: /api/data/eu_bbmri_eric_<CC>_<Entity>

The entity is either *collections*, *biobanks*, *networks*, *persons*, *also_known_in* or *facts*.

DATA MODEL

The data model of the directory consists of 6 entities that have to be managed by the national nodes and several look-up lists for the acceptable values for the fields.

- 1. Contact information: Describes contact information for biobanks, collections or networks
- 2. Also known in: Describes the source in which the biobank, collection or networks also exists
- 3. Network: Describes networks of collaborating biobanks
- 4. Biobank: Describes the biobank organisation
- 5. Collection: Describes the biobank collections and sub collections
- 6. Facts: Describes aggregates of samples of the collections

For simplicity, the supporting entities that describe the look-up lists are not described in this manual. The model can be visually represented as follows.

⁴ Note: for BBMRI-UK, this code is "UK" instead of the ISO standards prescribed "GB".

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DOWNLOAD THE LATEST MODEL AND DATA

The latest model and data from your national node staging area can be obtained using the Navigator.

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		E NL: Collection Facts		Collection Fa	cts table					
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		I≡ NL: networks		Description of common agr	f the biobank neements (acces	etworks, like nan s policies, charte	ne, contact informati ers, sops)	on and all k	inds of	
		I≡ NL: persons		Information of address and	n the contact p e-mail address	ersons of a biob	ank, collection of ne	twork, like n	ame,	
	Please	e cite Holub Petr, Swertz Morr This database Pleas	is, Reihs Robert, van E 2016, 14(6) was created using the e cite Van der Velde e l	Enckevort David, M : 559-562. doi:10.1 e open source MOI t al (2018), Swertz	üller Heimo, and 089/bio.2016.0 GENIS software et al (2010) or S	Litton Jan-Eric. 288 upon use. 10.1.0 built on 2 <mark>wertz & Jansen</mark>	. Biopreservation and 2023-01-30 11:41 UT (2007) on use.	d Biobanking °C.	g. Decembe	N.

- 1. Click on "Navigator" in the menu.
- 2. Go to your national node staging area
- 3. Select all the entities you want to download by clicking the checkboxes left to the entity names
- 4. Click the download button

This provides you with the latest model including the currently available data from your national node.

STRUCTURE OF THE IDENTIFIERS

The Directory is a federated infrastructure, and to prevent collisions in identifiers we have defined a specific structure for the identifiers in the Directory.

Biobank ID: bbmri-eric:ID:<CC>_<local id>

Collection ID: <Biobank ID>:collection:<local id>

Network ID: bbmri-eric:networkID:<CC>_<local id>

Contact ID: bbmri-eric:contactID:<CC>_<local id>

Also Known In ID: bbmri-eric:akiID:<CC>_<local id>

Facts ID: bbmri-eric:factID:<CC>_<local id>

Where <CC> has to be replaced by the valid ISO-3166-1 alpha 2 country code for the country of residence and <local id> with a local ID generated by the national node to be unique within its context. We advise to use the ID of the entity in the national directory if one is present. All local parts should be limited to roman letters and numbers (a-z, A-Z, 0-9).

BIOBANK

The biobank entity (eu_bbmri_eric_biobanks) describes the biobank organisation.

Attribute * = Mandatory	Description	Cardinality	Acceptable values
id *	Unique identifier of this record	1	[a-z][A-Z][0-9][:] starting with the prefix bbmri-eric:ID: + ISO-3166-1 alpha 2 <u>country</u> code
name *	Name of the biobank	1	Text, maximum 255 characters, recommended to be less than 60 characters
acronym	Short name or acronym of the biobank if applicable	01	Text, maximum 255 characters, recommended to be less than 20 characters
description *	Description of the biobank in English	1	Text
url	URL of the website of the biobank	01	URL
location	The city where the biobank is located	01	Text, maximum 255 characters, recommended to be less than 60 characters
country *	The country in which the biobank resides	1	ISO-3166-1 alpha 2 <u>country</u> code
latitude	Latitude of the location of the primary site of the biobank	01	WGS84 coordinate
longitude	Longitude of the location of the primary site of the biobank	01	WGS84 coordinate
head	Person in charge of the biobank.	01	Unique identifier of the referenced contact information record
contact *	Contact information of the primary external contact of the biobank	1	Unique identifier of the referenced contact information record
juridical_person	Name of the organisation (legal entity) of the biobank	01	Text, maximum 255 characters, recommended to be less than

			60 characters
network	List of networks in which the biobank participants	0n	Comma separated list of unique identifiers of the referenced network information records
also_known	List of also known in which are linked to collection participates	0n	Comma separated list of unique identifiers of the referenced also known information records
capabilities	List of the capabilities that the biobank can offer to a researcher as a service	0n	Comma separated list of unique identifiers of the <u>capabilities</u> .
collaboration_commercial	Indication if the biobank is able to participate in commercial collaborations	01	true, false
collaboration_non_for_profit	Indication if the biobank is able to participate in collaborations with not-for-profit organisations	01	true, false
withdrawn	This biobank is withdrawn from the Directory	01	true, false

The biobank entity in the published production version contains some extra attributes, which are filled automatically or by external parties:

Attribute	Description	Cardinality	Acceptable values
pid *	persistent identifier (read only)	1	Text, maximum 255 characters, recommended to be less than 60 characters
quality	Biobank quality assessment (read only)	01	Comma separated list of quality assessment marks
national_node *	The biobanks originates from this national node	1	ISO-3166-1 alpha 2 <u>country</u> code

COLLECTION

The collection entity (eu_bbmri_eric_collections) describes the data and samples collected in the biobank at the (sub)collection level. The collection can be described with sub collections to provide detailed information on the available materials, diseases or other attributes. A collection can be subdivided on any distinct criterion, but should always maintain strict partitioning (i.e. there should not be overlap between sub collections. Each sample should be represented in only one sub collection).

N.B.: In order for COVID-19 collections to be found, the collection must be a member of the COVID-19 network (see network attribute)

Attribute * = Mandatory	Description	Cardinality	Acceptable values
	Descriptives		
id *	The unique identifier of the record	1	[a-z][A-Z][0-9][:] starting with the ID of the biobank in which the collection resides + :collection:
name *	Name of the collection	1	Text, maximum 255 characters, recommended to be less than

			60 characters
acronym	Short name or acronym of the collection if applicable	01	Text, maximum 255 characters, recommended to be less than 20 characters
description *	Description of the collection in English	1	Text
url	URL of the website of the collection	01	URL
location	The city where the collection is located	01	Text, maximum 255 characters, recommended to be less than 60 characters
country *	The country in which the collection resides	1	ISO-3166-1 alpha 2 <u>country</u> code
latitude	Latitude of the location of the primary site of the collection	01	WGS84 coordinate
longitude	Longitude of the location of the primary site of the collection	01	WGS84 coordinate
head	Person in charge of the collection.	01	Unique identifier of the referenced contact information record
contact *	Contact information of the primary external contact of the collection	1	Unique identifier of the referenced contact information record
withdrawn	This collection is withdrawn from the Directory	01	true, false
	Belongs to		
parent_collection	Parent collection of which the collection is a part	01	Unique identifier of the referenced collection
sub_collection	sub collection of which the collection is a part	01	(automatically filled field)
biobank *	The biobank that hosts the collection	1	Unique identifier of the referenced biobank
network	List of networks in which the collection participates	0n	Comma separated list of unique identifiers of the referenced network information records
also_known	List of also known in which are linked to collection participates	0n	Comma separated list of unique identifiers of the referenced also known information records
	Characteristics		
type *	The type of the sample collection	1	Comma separated list of collection types
data_categories *	The categories of data that are available as part of the collection	1n	Comma separated list of <u>data</u> types
order_of_magnitude *	Number of samples in the collection expressed as orders of magnitude	1	Integer n, where 10 ⁿ is the best approximation of the number of samples in the collection (range 0 - 8)
size	Exact size of collection in number of unique sample ID's at the point in time given in the specified timestamp	01	Integer ≥ 0
timestamp	Exact timestamp at which the size of the collection as specified in size was determined	01	Timestamp in ISO 8601 format (yyyy-mm-ddThh:mm:ss+nnnn), e.g. 2016-11-15T09:53:13+0100, it is acceptable to set the time component to 00:00:00 when not known.
	Donor data		
number of donors	Exact number of donors for	01	Integer ≥ 0

	whom there are samples and/or data in the collection		
order_of_magnitude_donors	Number of donors for whom there are samples and/or data in the collection expressed as orders of magnitude	0n	Integer n, where 10 ⁿ is the best approximation of the size of the collection (range 0 - 8)
sex	The sex of the individuals whose samples are part of the collection	0n	Comma separated list of sex
diagnosis_available	Diagnosis available in the collection	0n	ICD-10 with the prefix urn:miriam:icd: Available diagnosis can denoted by entire chapters (e.g. urn:miriam:icd:1), blocks (e.g. urn:miriam:icd:A00-A09), or individual codes. (e.g. urn:miriam:icd:A09. OR Orphanet codes with the prefix ORPHA: (e.g. ORPHA:10).
age_low	Age of the youngest individual in the collection at the time the sample was taken	01	Integer ≥ 0 and ≤ age_high
age_high	Age of the oldest individual in the collection at the time the sample was taken	01	Integer ≥ 0 and \geq age_low,
age_unit	Unit defining age low and age high	01	Comma separated list of MIABIS age units.
	Sample data		
materials	The types of biological material present in the collection	0n	Comma separated list of MIABIS <u>material types</u> . When specified the collection type must include Sample Collection.
storage_temperatures	The temperature at which the samples are stored	0n	Comma separated list of storage temperatures according to the MIABIS classification
	Imaging Data		
body_part_examined	The body part that was the target of examination for the image taken	0n	Comma separated list of DICOM <u>body part</u> codes (based on SNOMED-CT codes). When specified the collection type must include Image collection.
imaging_modality	The imaging modality used for generating the image	0n	Comma separated list of DICOM <u>image modality</u> codes. When specified the collection type must include Image collection.
image_dataset_type	The datatype of the images in the collection	0n	Comma separated list of DICOM image <u>dataset types</u> . When specified the collection type must include Image collection.
	Policies		
collaboration_commercial	Indication if the material in the collection is available for use in a commercial context	01	true, false
collaboration_non_for_profit	Indication if the material in the collection is available for use in a not-for-profit context	01	true, false
data_use	Data access policy/policies in data use ontology format.	0n	Comma separated list of unique identifiers of the

			referenced <u>data use</u> ontology
commercial_use	Indication if commercial users can request access to samples and/or data	01	true, false
access_fee	Indication if an access fee is required for access to samples,data or imaging	01	Comma separated list of f unique identifiers of <u>access</u> types
access_joint_project	Indication if a joint project is required for access to samples,data or imaging	01	Comma separated list of f unique identifiers of <u>access</u> types
access_description	Short description of the conditions for access to samples,data or imaging in English	01	Text
access_uri	URL to a detailed description of the access conditions for access to samples,data or imaging	01	URL
PD/SOP	Indication if the samples and/or data does has sop in a way off processing, shipment or storage	01	Comma separated list of f unique identifiers of <u>SOPs</u>

The collection entity in the published production version contains some extra attributes, which are filled automatically or by external parties:

Attribute	Description	Cardinality	Acceptable values
biobank_label *	The label of the biobank that hosts the collection	1	Text, maximum 255 characters, recommended to be less than 60 characters
combined_network	List of networks in which the collection and biobanks participates (read only)	0n	Comma separated list of unique identifiers of the referenced network information records
categories	Collection categories based on diseases (read only)	01	Comma separated list of unique identifiers of the referenced categories information records
quality	Collection quality assessment (read only)	01	Comma separated list of quality assessment marks
combined_quality	Collection and Biobank quality assessment (read only)	01	Comma separated list of quality assessment marks
national_node *	The collection originates from this national node	1	ISO-3166-1 alpha 2 <u>country</u> code

Network

The network entity (eu_bbmri_eric_networks) describes a biobank network.

Attribute * = Mandatory	attribute	Cardinality	Acceptable values
id *	The unique identifier of the record	1	[a-z][A-Z][0-9][:] starting with the prefix bbmri-eric:networkID: + ISO-3166-1 alpha 2 <u>country</u> code
name *	The name of the network	1	Text, maximum 255 characters, recommended to be less than 60 characters
acronym	Short name or acronym of the network, if applicable	01	Text, maximum 255 characters, recommended to be less than 20 characters
description *	Description of the network, in English	1	Text
location	The city where the network is located	01	Text, maximum 255 characters, recommended to be less than 60 characters
latitude	Latitude of the location of the primary site of the network	01	WGS84 coordinate
longitude	Longitude of the location of the primary site of the network	01	WGS84 coordinate
also_known	List of also known in which are linked to collection participates	0n	Comma separated list of unique identifiers of the referenced also known information records
url	URL of the website of the network	01	URL,
juridical_person	Name of the organisation (legal entity) of the network	01	Text
contact *	Contact information of the primary external contact of the network	1	Unique identifier of the referenced contact information record
parent_network	Parent or larger network that this network is a part of	01	Unique identifier of the parent network
common_network_elements	elements who are the same for all biobanks/collections within the network	01	Comma separated list of f unique identifiers of <u>common</u> <u>network</u>
withdrawn	This network is withdrawn from the Directory	01	true, false

The network entity in the published production version contains some extra attributes, which are filled automatically or by external parties:

Attribute	Description	Cardinality	Acceptable values
national_node *	The network originates from this national node	1	ISO-3166-1 alpha 2 <u>country</u> code

C ONTACT INFORMATION

The contact information entity (eu_bbmri_eric_persons) describes the contact information for a biobank, collection or network.

Attribute * = Mandatory	Description	Cardinality	Acceptable values
id *	Unique identifier of this record	1	[a-z][A-Z][0-9][:], starting with bbmri-eric:contactID: + ISO-3166-1 alpha 2 <u>country</u> code.
title_before_name	Titles that are prefixed to the name	01	Test, maximum 255 characters, recommended to be less than 60 characters
first_name	First name of the person to contact	01	Text, maximum 255 characters, recommended to be less that 60 characters
last_name	Last name of the person to contact	01	Text, maximum 255 characters, recommended to be less that 60 characters
title_after_name	Titles that are appended to the name (e.g. MD, PhD)	01	Test, maximum 255 characters, recommended to be less than 60 characters
email *	E-mail address to contact	1	text
phone	Telephone number including international prefix	01	Compliant to the E.123 norm, international notation including the international access number and using spaces to visually separate groups of numbers, e.g. +31 20 1234567
address	Address including routing information where necessary	01	text
zip	ZIP or postal code	01	text
city	City	01	text
country*	Country	1	ISO-3166-1 alpha 2 <u>country</u> code
role	Official role of the person	01	text
biobanks	Person is linked to this biobank	01	(automatically filled field)
collections	Person is linked to this collection	01	(automatically filled field)
network	Person is linked to this network	01	(automatically filled field)

The "contact-information" entity in the published production version contains some extra attributes, which are filled automatically or by external parties:

Attribute	Description	Cardinality	Acceptable values
national_node *	The contact originates from this national node	1	ISO-3166-1 alpha 2 <u>country</u> code

Also known in

The "also known in" entity (eu_bbmri_eric_also_known_in) describes in where the network, biobank or collection also exists.

Attribute * = Mandatory	Description	Cardinality	Acceptable values
id *	Unique identifier of this record	1	[a-z][A-Z][0-9][:], starting with bbmri-eric:akiID: + ISO-3166-1 alpha 2 <u>country</u> code. (automatically generated field)
name_system *	Name of the source in which the biobank, collection or network also exists	1	Text, maximum 255 characters, recommended to be less than 60 characters
pid	Persistent Identifier of the biobank, collection or network in the other source	01	Text, maximum 255 characters, recommended to be less that 60 characters
url *	Link to the biobank, collection or network in the other source	1	URL

The "also known in " entity in the published production version contains some extra attributes, which are filled automatically or by external parties:

Attribute	Description	Cardinality	Acceptable values
national_node *	The "also known in" originates from this national node	1	ISO-3166-1 alpha 2 <u>country</u> code

STAR MODEL

In order to generate aggregated data from individual level data the "fact table/ star model" can be used. Which is a special form of a *Dimensional Data Model* developed.

The star schema is the simplest form or building block of a dimensional data model organizing data into facts and dimensions. A fact table contains the numeric measures produced by an operational measurement event. Within the Star Model data schema, a fact is an itemized entity that is countable or measureable and is characterized by a number of attributes which are grouped into so-called dimensions(attributes in the table below). The MIABIS Star Model selects only the most important data elements from the MIABIS core components (see table below).

The fact table provides a tool for researchers to run feasibility queries and find suitable donors, samples, and/or data for their research question.

Queries like:

- the number of donors with certain characteristics
- the number of samples with certain characteristics
- the number of data sets with certain characteristics
- the number of collections with certain characteristics

or arbitrary combinations of these can be answered with the implemented data model at MIABIS core level.

REMARK"Because of the adopted method of data creation and collection the number of donors presented in the table below should not be added as it may give the wrong sums"

Attribute * = Mandatory	Description	Cardinality	Acceptable values
id *	Unique identifier of this record	1	[a-z][A-Z][0-9][:], starting with bbmri-eric:factID: + ISO-3166-1 alpha 2 <u>country</u> code.
collection *	The collection that hosts the facts	1	Unique identifier of the referenced collection
sex	The sex of the individuals whose samples are part of the collection	01	List of <u>sex</u>
age	Unit defining age of sample donor at time of sample donation	01	List of age range.
sample_type	The types of biological material	01	list of MIABIS <u>material types</u> . When specified the facts type must include Sample Collection.
disease	Diagnosis available in the collection	01	ICD-10 with the prefix urn:miriam:icd: Available diagnosis Use only the individual codes. (e.g. urn:miriam:icd:A09. OR Orphanet codes with the prefix ORPHA: (e.g. ORPHA:10). Do not use entire chapters (e.g. urn:miriam:icd:1), blocks

The Star Model entity "eu_bbmri_eric_facts" describes the individual level data of the collection

			(e.g. urn:miriam:icd:A00-A09)
number_of_samples	Exact number of samples and/or data in the collection	01	Integer ≥ 0
number_of_donors	Exact number of donors for whom there are samples and/or data in the collection	01	Integer≥0
last_update*	Date the fact information was last updated in the source system	1	YYYY-MM-DD

CODE LISTS

The Directory uses code lists to specify the acceptable options where there is a limited choice. Options can be referenced by their identifier and if an attribute can contain only one value the attribute value will be directly set to this identifier. <u>Code lists</u> themselves are maintained by BBMRI-ERIC and cannot be updated by a National Node's data manager.

The tables in this document are for reference only. For the actual values, please refer to the specification at <u>https://directory.bbmri-eric.eu/</u> and click the right table below the menu item CODE LISTS

DISEASE TYPES

The <u>disease type</u> is designed to be an extensible, ontology based code list. Currently it comprises the ICD-10 and Orphanet ontologies, but in the future other disease ontologies such as SNOMED CT might be included. To support this extensibility the ICD-10 codes have been prefixed with the URI scheme urn:miriam:icd: (e.g. urn:miriam:icd:C19, urn:miriam:icd:C00-C97) as specified by the Miriam registry team EMBL-EBI. The disease types table contains entries for all levels of the ICD-10 ontology, chapters, blocks and codes and sub codes. Data integrators should refrain from creating other blocks of contiguous codes that are not specified in ICD-10. For sources that contain disease codes in another ontology data integrators should convert these to the corresponding ICD-10 codes. Both SNOMED-CT and Orphanet maintain mappings for their ontologies. It is strongly advised to provide individual codes instead of blocks of codes. For the Orphanet codes the prefix ORPHA: can be used (e.g. ORPHA:10).

QUALITY

To secure the data quality, checks are performed <u>within the system</u>. During the upload error messages will help correct your data input if for example ID's are not correct. Frequently BBMRI will also give <u>warnings about the completeness</u> of the data entry. This will be done by a python script and sended afterwards to the National nodes. Next to the quality of the data input BBMRI provides also information about the quality of biobanks, collections. BBMRI head office can assign certificates to give an indication about <u>qualities and standards</u>.

QUALITY CHECKS DATA INPUT The table below shows the checks

Tables	Attributes	Description of the check	Check time/phase	Error message
persons	id	check if the ID is correct like the <u>structure of</u> <u>Identity</u>	When entering data in the database (either manually, through a file or via API) and in the process of combining the data from National Nodes into the BBMRI-ERIC Directory	change ID
networks	id	check if the ID is correct like the <u>structure of</u> <u>Identity</u>	When entering data in the database (either manually, through a file or via API) and in the process of combining the data from National Nodes into the BBMRI-ERIC Director	change ID
biobank	id	check if the ID is correct like the <u>structure of</u> <u>Identity</u>	When entering data in the database (either manually, through a file or via API) and in the process of combining the data from National Nodes into the BBMRI-ERIC Director	change ID
collections	id	check if the ID is correct like the <u>structure of</u> <u>Identity</u>	When entering data in the database (either manually, through a file or via API) and in the process of combining the data from National Nodes into the BBMRI-ERIC Director	change ID
collections	age_unit	If there is only 1 age unit selected	between migration National nodes and directory	mail to NN, contact biobank about more than one age_unit, data can not published
collections	age high / age low	if the age high is higher that the age	In the process of combining the data from National Nodes into the BBMRI-ERIC Director	mail to NN, contact biobank about more than one age_unit, data can not published

WARNINGS DATA INPUT

The quality checks /warnings available through python scripts pay attention to attributes at different levels (biobank, collection, etc) taking care of different aspects (access policies, geolocation, etc) and raising the warnings (in *italics*) when the data provided are not compliant with the data model. Please find here the <u>complete list of warning messages</u>.

QUALITY MARKS

The collection entity (eu_bbmri_eric_collections) describes the data and samples collected in the biobank at the (sub)collection level. The collection can be described with sub collections to provide detailed information on the available materials, diseases or other attributes. A collection can be subdivided on any distinct criterion, but should always ma

The results of the BBMRI-ERIC Self Assessment Survey, third-party certifications and Audits, shown as Q-marks in the Directory are managed by the BBMRI.QM team. You will not be able to update these values yourself. request a quality mark via

https://www.bbmri-eric.eu/services/self-assessment-survey/ The document below shows the workflow.

Follow the workflow below to add quality marks.



Process Flow: Q-Assessment Scheme for Biobanks and Sample Collections

1



Legend:

R – Requester DG – Director General NND – National Node Director NNQ - National Node Quality Officer HQM – Head of Quality Management QSO – Quality Management Service Officer C - Conduct D – Decide P – Participate Q-mark - Quality mark SAS – Self-Assessment Survey REDCapTM – online software for creation of Self-Assessment Survey TBC - To be clarified

* ISO 20387:2018 Biotechnology - Biobanking- General requirements for biobanking; ISO 9001: 2015 Quality managements systems - Requirements;

** Specifications for pre-examinations processes for:

- frozen tissue (FT) Part 1: Isolated RNA (ISO 20184-1:2018)
 - frozen tissue (FT) Part 2: Isolated proteins (ISO 20184-2:2018)
- FFPE tissue Part 1: Isolated RNA (ISO 20166-1:2018)
 FFPE tissue Part 2: Isolated proteins (ISO 20166-2:2018)
- FFPE tissue Part 3: Isolated DNA (ISO 20166-3:2018)
- venous whole blood Part 1: isolated cellular RNA (ISO 20186-1:2019) -
- venous whole blood Part 2: Isolated genomic DNA (ISO 20186-2:2019)
- venous whole blood Part 3: Isolated circulating cell free DNA from plasma (ISO 20186-3:2019)
 metabolomics in urine, venous blood serum and plasma (CEN 16945:2016)
- will be continuously updated

Description process flow symbols:

Process Flow Symbols	Meaning
	Start / End
	Activity
\diamond	Decision
	Connection to another process
	Document
	Verbal Information / information via telephone, e-mail
\rightarrow	Connector

Latest document revisions Version 3.5.6 Date: 20/04/2020 Author: Marije van der Geest Edits: Added COVID-19 items (covid19biobank and COVID-19) for biobank and collections table. Added code lists for Services provided by the biobank and Relevant data and products.

Date: 29/04/2020 Author: Marije van der Geest Edits: Updated lists Sex, Material types, Lab standards & Operational standards.

Version 3.6 Date: 02/07/2020 Author: Marije van der Geest Edits: Added section: Download latest model and data.

Version 3.6.1 Date: 07/07/2020 Author: Marije van der Geest Edits: Added information for national nodes and local directory instances.

Version 3.6.2 Date: 28/07/2020 Author: Marije van der Geest Edits: Added Orphanet codes description for *diagnosis_available*, COVID-19 collection information and information about NN endpoints for using the REST-API

Version 3.6.3

Date: 02/12/2020
Author: Brenda Hijmans
Edits: Added DUO code description, changed order of some attributes in collections to match order in Molgenis

Version 3.6.4 Date: 26/4/2021 Author: Aneas Hodselmans Edits: Delete "contact priority" in biobanks, collections and networks, Deleted standard in collections and biobanks. Added quality workflow and changed the list of lab/operational standards.

Version 3.6.5

Date: 11/5/2021 Author: Esther van Enckevort Edits: Updated documentation for the order_of_magnitude and order_of_magnitude_donor fields to specify the acceptable range.

Version 3.6.6 Date: 7/7/2022 Author: Aneas Hodselmans Edits: New application pictures and reference to the codelist tabel via de menu

Version 3.6.7 Date: 14/2/2023 Author: Aneas Hodselmans Edits: qualities and warning messages, codelists via menu, proposal 1 and proposal 2

Version 3.6.8

Author: Aneas Hodselmans Edits: Add starmodel & network improvements Version 3.6.9 Date: 18/10/2023 Author: Aneas Hodselmans Edits: Cardinality

Version 3.6.10 Date: 1/11/2023 Author: Aneas Hodselmans Edits: Cardinality

Version 3.6.11 Date: 22/01/2024 Author: Aneas Hodselmans and Dieuwke Roelofs-Prins Edits: Withdrawn adjustments and update of some pictures

Version 3.6.12 Date: 29/03/2024 Author: Aneas Hodselmans and Dieuwke Roelofs-Prins Edits: Pagenumbers