

BBMRI-ERIC

Biobanking and
BioMolecular resources
Research Infrastructure

PERFORMANCE INDICATORS FOR BBMRI-ERIC

V1.2

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Glossary

ELSI Ethical, Legals, Societal Issues

IT Information Technologies

KPI Key Performance Indicator

NN National Node

PI Performance Indicator

PoM Place of Measurement

QM Quality Management

t.b.d. to be defined

1 Introduction

The purpose of this document is to summarize a first set of performance indicators related to the vision, mission, and tasks of BBMRI-ERIC (Figure 1.1) expressed in the BBMRI-ERIC Statutes. It aims at providing ground for further discussions and consensus searching activities within the community and among its various stakeholders. After a consensus is reached, the performance indicators will be adopted and implemented on all levels (see Figure 1.2).

The current proposed set of performance indicators is excessive and serves only as a cookbook for selection of the appropriate ones, the most important of which will be established as *key performance indicators*.

Definitions. *Performance measures* are quantifiable and relevant to a specific goal and relate to an activity in BBMRI-ERIC. Performance measures can be either absolute numbers (e.g., number of users) or relative numbers (e.g., ratio of number of active users to all users). When performance measures are used to define goals for a given time period, they are used as a relative difference between the *baseline value* $m_{baseline}$ at the beginning of the period and *target value* m_{target} at the end of period. The relative difference¹ i is called a *performance indicator* – this can be e.g., .2 (or 20% expressed in percents) increase of number of users. Performance indicators are then used for *performance evaluation* as defined in ISO 9001.²

In this document, we will describe performance measures, as each performance indicator can be constructed from the corresponding measure using the formula above. Performance measures, including their definition, are listed in the summary table in Chapter 4 and numbered at no particular order using symbols like #88. Performance measures attached to the Tasks are sorted based on decreasing order of importance and are provided with a reference to the definition and levels on which the measure is obtained. Each performance measure or indicator may be used for different Tasks possibly with different importance (hence no specific overall measure sorting).

¹ Relative difference for the purposes of performance indicators is defined as

$$i = \frac{m_{target} - m_{baseline}}{m_{baseline}} [*100\%]$$

and assuming $m_{baseline} > 0$ and $m_{target} > 0$, otherwise the performance indicator is not defined. Performance indicators can be given directly as unit-less numbers, or in percents (where *100% applies).

² ISO/IEC 9001:2015 – *Quality management systems – Requirements*. Sept. 2015, Chapter 9.

Once the key performance indicators are selected out of the proposed pool of measures/ indicators in Chapter 4, they will be defined in detail in a new section of future revision of this document. This is necessary to ensure consistent implementation of these key performance indicators.

Definition of a “biobank”. For the purposes of performance evaluation, *only biobanks that have signed Partner Charter of BBMRI-ERIC should be included.*

Overview of the evolution towards BBMRI-ERIC performance measures. Major events where performance measures have been discussed so far:

- BBMRI-ERIC Scientific Retreat #2 – June 1–3, 2015, Schloss Obermayerhofer, Austria
- BBMRI-ERIC Scientific Retreat #3 – May 23–25, 2016, Athens, Greece
- Reviewed by the BBMRI-ERIC Management Committee members – July – September, 2016

Furthermore the key performance indicators is a deliverable of H2020 project ADOPT BBMRI-ERIC and are in line with the following deliverables/milestones:

- D1.3: “Implementation of performance, outcome and impact indicators”
report of ADOPT BBMRI-ERIC– September 2016
- D2.6: “Performance indicators for biobanks”
report of ADOPT BBMRI-ERIC– September 2017
- MS5: “Performance indicators for biobanks monitored in all Member States”
milestone ADOPT BBMRI-ERIC to have performance indicators practically implemented
– September 2018



Figure 1.1: Relation between vision, mission, performance indicators, and actions.

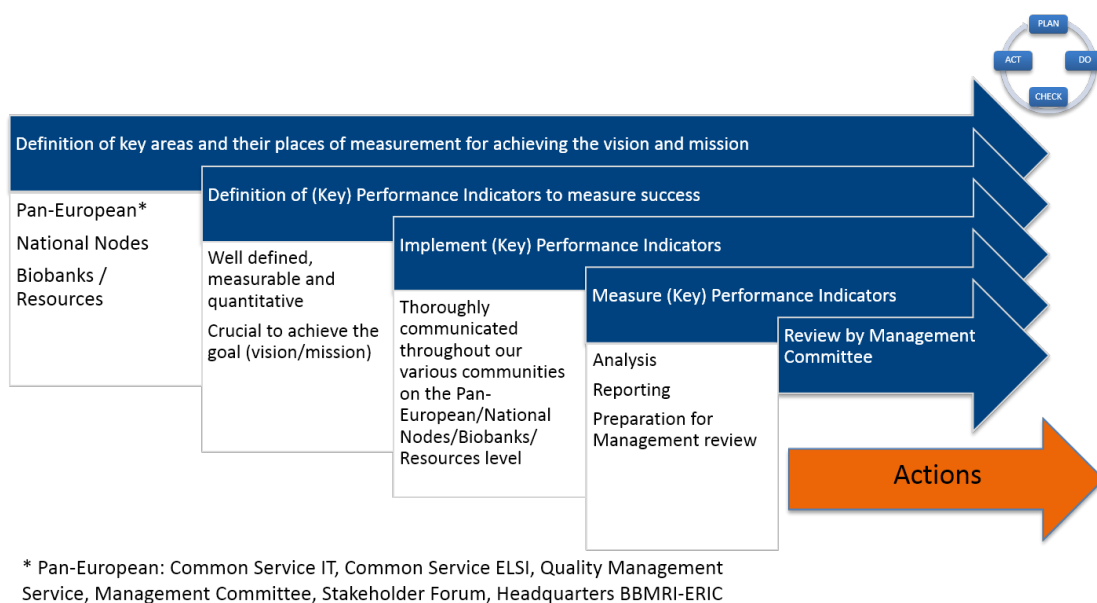


Figure 1.2: Process of designing and implementing performance indicators.

2 Vision and Mission Statement

BBMRI-ERIC Vision

^aBBMRI-ERIC will increase efficacy and excellence of European bio-medical research.

^a Business Plan v21.1 03.12.2012, p. 6

BBMRI-ERIC Mission

^a BBMRI-ERIC shall establish, operate and develop a pan-European distributed research infrastructure of Biobanks and Biomolecular Resources in order to facilitate the access to resources as well as facilities and to support high quality biomolecular and medical research. BBMRI-ERIC shall implement its Work Programme as adopted by the Assembly of Members.

^a Statutes of BBMRI-ERIC, 3 December 2013, L320/62-80, Article 3 (Rev 1, 19 June 2015)

3 Tasks and Proposed Performance Measures

BBMRI-ERIC Task

- (a) **grant effective access to its resources and services** in accordance with the rules defined in these Statutes to the European research community, composed of researchers from Members;

Relevant proposed performance measures for this task:

- **Number of recognized individual users using services (a per service and aggregated) (#4, Pan-European, Nodes, biobanks)**

^a“Pan-European” stands for BBMRI-ERIC Common Services (ELSI, IT), Stakeholder Forum, and headquarters; “Nodes” stands for National and Organizational Nodes of BBMRI-ERIC; “biobanks” stands for biobanks and bioresources. Candidates for key performance indicators are marked in **bold**.

- **Number of biobanks connected to core BBMRI-ERIC CS IT services (#36, Nodes)**
- Ratio between number of samples delivered to requesters and the total number of samples stored by the biobank (#37, biobanks)
- **Ratio between number of accepted applications and number of received applications for samples and/or data. (#38, biobanks)**
- **Median time to access samples/data (#39, biobanks)**
- **Number of biobanks that signed Partner Charter (#32, Nodes)**
- Number of published success stories related to the main mission and tasks of BBMRI-ERIC (#15, Pan-European, Nodes, biobanks)
- **Number of papers where biobank was acknowledged as provider of samples, data, or expertise (#40, biobanks)**
- Number of ELSI requests dealt with in relation to projects (#18, Pan-European)
- Number of ELSI requests dealt with in relation to biobanks (#19, Pan-European)
- Number of webinars related to ELSI education and training and experience sharing (#20, Pan-European)

BBMRI-ERIC Task

(b) **improve the interoperability** between Biobanks and Biological Resource Centres of Members;

Relevant proposed performance measures for this task:

- **Number of recognized individual users using services (a per service and aggregated) (#4, Pan-European, Nodes, biobanks)**
- **Number of biobanks connected to core BBMRI-ERIC CS IT services (#36, Nodes)**
- **Number of new community standards, guidelines, policies as outcomes of the BBMRI-ERIC Working Groups and Common Services (#9, Pan-European)**
- Number of domain experts involved (per service/working group and aggregated) (#7, Pan-European, Nodes)
- Number of countries involved in BBMRI-ERIC Working Groups (#8, Pan-European)
- **Number of samples with quality label report attached (#10, biobanks)**
- **Number of data sets with complete provenance information available (#11, biobanks)**
- **Number of biobanks implementing certain quality standards (#35, Nodes)**
- **Number of biobanks connected to core BBMRI-ERIC CS IT services (#36, Nodes)**

“Pan-European” stands for BBMRI-ERIC Common Services (ELSI, IT), Stakeholder Forum, and headquarters; “Nodes” stands for National and Organizational Nodes of BBMRI-ERIC; “biobanks” stands for biobanks and bioresources. Candidates for key performance indicators are marked in **bold**.

BBMRI-ERIC Task

- (c) **implement quality management** including standardised procedures, best practices and appropriate tools to increase the quality of the resources collected and their associated data;

Relevant proposed performance measures for this task:

- **Number of new community standards, guidelines, policies as outcomes of the BBMRI-ERIC Working Groups and Common Services** (#9, Pan-European)
- **Number of samples with quality label report attached** (#10, biobanks)
- **Number of data sets with complete provenance information available** (#11, biobanks)
- **Number of biobanks implementing certain quality standards** (#35, Nodes)
- **Number of biobanks that filled out the quality self-assessment surveys** (#12, Pan-European)
- Number of biobanks supported for certification & accreditation (#14, Pan-European)

BBMRI-ERIC Task

- (d) **promote continuous enrichment of resources in Biobanks and associated data** in order to maintain an adequate supply of specimens to **keep up with the demands of the scientific community** as well as to ensure continuous enrichment of the information associated with and generated by the analysis of biobanked samples. It shall contribute to increased use and dissemination of knowledge as well as optimisation of the results of biobank-based research activities throughout Europe;

Relevant proposed performance measures for this task:

- **Number of projects that return data to biobanks** (#41, biobanks)
- **Number of Expert Centres** (#5, Pan-European)
- **Number of biobanks offering prospective collection service and capable of following custom SOPs** (#33, Nodes)
- Number of members participating in the CS IT User Forum (#29, Pan-European)
- Response ratio for request sent to the CS IT User Forum (#30, Pan-European)

Additional relevant (K)PIs to be developed as a part of initialization of “biomolecular resources” (second “B” of BBMRI-ERIC).

“Pan-European” stands for BBMRI-ERIC Common Services (ELSI, IT), Stakeholder Forum, and headquarters; “Nodes” stands for National and Organizational Nodes of BBMRI-ERIC; “biobanks” stands for biobanks and bioresources. Candidates for key performance indicators are marked in **bold**.

BBMRI-ERIC Task

(e) establish and operate Common Services for the European biobanking community;

Relevant proposed performance measures for this task:

- **Number of recognized individual users using services (a per service and aggregated)** (#4, Pan-European, Nodes, biobanks)
- Number of commented recommendations, guidance documents, directives (#16, Pan-European)
- Number of ELSI requests dealt with in relation to projects (#18, Pan-European)
- Number of ELSI requests dealt with in relation to biobanks (#19, Pan-European)
- Number of webinars related to ELSI education and training and experience sharing (#20, Pan-European)
- **Number of biobanks connected to core BBMRI-ERIC CS IT services** (#36, Nodes)
- Number of domain experts involved (per service/working group and aggregated) (#7, Pan-European, Nodes)
- Number of countries involved in BBMRI-ERIC Working Groups (#8, Pan-European)

BBMRI-ERIC Task

(f) perform research services for public and private institutions;

Relevant proposed performance measures for this task:

- **Number of Expert Centres** (#5, Pan-European)

Additional relevant (K)PIs to be developed as a part of initialization of “biomolecular resources” (second “B” of BBMRI-ERIC).

BBMRI-ERIC Task

(g) establish and implement **technological developments related to the resources and services**;

Relevant proposed performance measures for this task:

- **Number of services** (#3, Pan-European)
- Technology development related to operation of biobanks (#42, biobanks)

Additional relevant (K)PIs to be developed as a part of initialization of “biomolecular resources” (second “B” of BBMRI-ERIC).

“Pan-European” stands for BBMRI-ERIC Common Services (ELSI, IT), Stakeholder Forum, and headquarters; “Nodes” stands for National and Organizational Nodes of BBMRI-ERIC; “biobanks” stands for biobanks and bioresources. Candidates for key performance indicators are marked in **bold**.

BBMRI-ERIC Task

- (h) provide training and facilitate mobility of researchers to support the establishment of new Biobanks and Biomolecular Resource Centres to strengthen and structure the European Research Area;

Relevant proposed performance measures for this task:

- **Number of recognized individual users using services (a per service and aggregated)** (#4, Pan-European, Nodes, biobanks)
- Number of dissemination events related to QM and interoperability standards (#13, Pan-European)
- Number of dissemination events (#21, Pan-European)
- Number of projects focused on mobility (#23, Pan-European)
- **Number of Members and Observers of BBMRI-ERIC** (#1, Pan-European)

BBMRI-ERIC Task

- (i) establish international relationships and launch joint activities with other European and non-European organisations concerned with its activities and in related fields, and when appropriate become a member of such organisations;

Relevant proposed performance measures for this task:

- **Number of new community standards, guidelines, policies as outcomes of the BBMRI-ERIC Working Groups and Common Services** (#9, Pan-European)
- Number of BBMRI-ERIC presentations in Europe (#24, Pan-European)
- Number of BBMRI-ERIC presentations outside of Europe (#25, Pan-European)
- Number of agreements between BBMRI-ERIC and learned societies (#26, Pan-European)
- Number of MoUs BBMRI-ERIC has signed with other research infrastructures and organisations (#27, Pan-European)
- Number of launched joint activities (#28, Pan-European)
- **Number of Members and Observers of BBMRI-ERIC** (#1, Pan-European)
- Number of ELSI requests dealt with in relation to projects (#18, Pan-European)

BBMRI-ERIC Task

- (j) undertake any other activity necessary to fulfil its tasks.

Relevant proposed performance measures for this task:

- **Number of subscribers in the e-newsflash** (#31, Pan-European)

“Pan-European” stands for BBMRI-ERIC Common Services (ELSI, IT), Stakeholder Forum, and headquarters; “Nodes” stands for National and Organizational Nodes of BBMRI-ERIC; “biobanks” stands for biobanks and bioresources. Candidates for key performance indicators are marked in **bold**.

- **Number of users receiving outputs of dissemination activities from National or Organizational Node** (#34, Nodes)
- Number of posts in social networks by BBMRI-ERIC or mentioning BBMRI-ERIC (#22, Pan-European, Nodes, biobanks)

“Pan-European” stands for BBMRI-ERIC Common Services (ELSI, IT), Stakeholder Forum, and headquarters; “Nodes” stands for National and Organizational Nodes of BBMRI-ERIC; “biobanks” stands for biobanks and bioresources. Candidates for key performance indicators are marked in **bold**.

4 Overview of Candidates for Performance Measures

The following list of uses **bold** text to denote candidate performance measures that are candidates for turning into Key Performance Indicators (see Chapter 1 for relation between performance measures and indicators).

Point of Measurement can be: Pan-European (on the level of whole BBMRI-ERIC including its headquarters and common services) or BBMRI-ERIC national (organizational) node or biobank.

For the purposes of performance evaluation, *only biobanks that have signed Partner Charter of BBMRI-ERIC should be included.*

Once adopted, these measures will receive baseline value and the target value (see construction of performance indicators in Chapter 1).

#	Name	Definition	Point of Measurement	Frequency
#1	Number of Members and Observers of BBMRI-ERIC	Number of countries and international organizations that were Members or of Observers of BBMRI-ERIC (as defined in BBMRI-ERIC Statutes).	Pan-European	yearly
#2	Proportion of external sources to overall budget of BBMRI-ERIC.	Proportion of external sources to overall budget of BBMRI-ERIC. This includes all external sources, such as H2020 projects, IMI projects, etc., not including BBMRI-ERIC Core Budget.	Pan-European	yearly
#3	Number of services	Number of services deployed (made available for the users) by BBMRI-ERIC on Pan-European level. Each service must be declared as a service and must be clearly defined, also in terms of its target user group(s). http://www.bbmri-eric.eu/bbmri-eric-services/	Pan-European	yearly

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“Pan-European” stands for BBMRI-ERIC Common Services (ELSI, IT), Stakeholder Forum, and headquarters; “Nodes” stands for National and Organizational Nodes of BBMRI-ERIC; “biobanks” stands for biobanks and bioresources. Candidates for key performance indicators are marked in **bold**.

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#	Name	Definition	Point of Measurement	Frequency
#4	Number of recognized individual users using services (a per service and aggregated)	Number of recognized individual (e.g., authenticated) users using services collected per service, and then aggregated across all the services. The aggregation of per-service data into overall result will be done in two ways: (1) by counting individual users, i.e., one user should not be counted multiple times, (2) by summing up all the service-users. Examples of services include BBMRI-ERIC Negotiator and Locator, ELSI Helpdesk, or QM Consultancy.	Pan-European, Nodes, biobanks	quarterly
#5	Number of Expert Centres	Number of Expert Centres established by BBMRI-ERIC.	Pan-European	yearly
#6	Number of invited talks	Number of invited talks of BBMRI-ERIC personnel (presentations).	Pan-European	yearly
#7	Number of domain experts involved (per service/working group and aggregated)	Number of domain experts involved (per service/working group and aggregated). The aggregation is done by counting physical persons (not multiple-counting).	Pan-European, Nodes	yearly
#8	Number of countries involved in BBMRI-ERIC Working Groups	Number of countries involved in BBMRI-ERIC Working Groups and ELSI Task Forces.	Pan-European	yearly
#9	Number of new community standards, guidelines, policies as outcomes of the BBMRI-ERIC Working Groups and Common Services	Number of new community standards, guidelines, policies as outcomes of the BBMRI-ERIC Working Groups and Common Services. Examples include MIABIS 2.0 Core and CoBRA guidelines.	Pan-European	yearly

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“Pan-European” stands for BBMRI-ERIC Common Services (ELSI, IT), Stakeholder Forum, and headquarters; “Nodes” stands for National and Organizational Nodes of BBMRI-ERIC; “biobanks” stands for biobanks and bioresources. Candidates for key performance indicators are marked in **bold**.

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#	Name	Definition	Point of Measurement	Frequency
#10	Number of samples with quality label report attached	Number of samples with quality label report attached. (Quality label is now under development by BBMRI-ERIC.)	biobanks	yearly
#11	Number of data sets with complete provenance information available	Number of data sets with complete provenance information available. Complete provenance information includes link from the data via samples (if the data is generated from samples) to the research participant. The provenance information also includes "quality labels" of samples, if samples are involved.	biobanks	yearly
#12	Number of biobanks that filled out the quality self-assessment surveys	Number of biobanks that filled out the quality self-assessment surveys.	Pan-European	yearly
#13	Number of dissemination events related to QM and interoperability standards	Number of dissemination events (both physical or online – trainings, webinars, etc.) related to QM and interoperability standards.	Pan-European	yearly
#14	Number of biobanks supported for certification & accreditation	How many biobanks were supported by Quality Service of BBMRI-ERIC in the process of obtaining certification & accreditation.	Pan-European	yearly
#15	Number of published success stories related to the main mission and tasks of BBMRI-ERIC	Number of success stories related to the main mission and tasks of BBMRI-ERIC, published by the users of biobanks or about them, with a link to the biobanks.	Pan-European, Nodes, biobanks	yearly
#16	Number of commented recommendations, guidance documents, directives	Number of commented recommendations, guidance documents, directives, such as WHO, Council of Europe, OECD, GDPR, etc.	Pan-European	yearly

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"Pan-European" stands for BBMRI-ERIC Common Services (ELSI, IT), Stakeholder Forum, and headquarters; "Nodes" stands for National and Organizational Nodes of BBMRI-ERIC; "biobanks" stands for biobanks and bioresources. Candidates for key performance indicators are marked in **bold**.

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#	Name	Definition	Point of Measurement	Frequency
#17	Ratio between number of ELSI requests accomplished and total number of ELSI requests	Ratio between number of ELSI requests accomplished and total number of ELSI requests	Pan-European	yearly
#18	Number of ELSI requests dealt with in relation to projects	Number of ELSI requests dealt with in relation to projects. Assistance and advise with ethical reviews, ethical assessments	Pan-European	yearly
#19	Number of ELSI requests dealt with in relation to biobanks	Number of ELSI requests dealt with in relation to biobanks, e.g., assistance with setting up material and data transfer agreement templates, governance structure, or particular ELSI issue such as across boarder issue or reuse of samples.	Pan-European	yearly
#20	Number of webinars related to ELSI education and training and experience sharing	Number of webinars related to ELSI education and training and experience sharing	Pan-European	yearly
#21	Number of dissemination events	Number of dissemination events, including courses, webinars, etc.	Pan-European	yearly
#22	Number of posts in social networks by BBMRI-ERIC or mentioning BBMRI-ERIC	Number of posts in social networks by BBMRI-ERIC or mentioning BBMRI-ERIC (currently Twitter and LinkedIn).	Pan-European, Nodes, biobanks	yearly
#23	Number of projects focused on mobility	Number of projects focused on mobility (such as COST), involving BBMRI-ERIC or at least participants related to the National or Organizational Nodes from two BBMRI-ERIC members or observers.	Pan-European	yearly
#24	Number of BBMRI-ERIC presentations in Europe	Number of BBMRI-ERIC presentations in Europe.	Pan-European	yearly

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“Pan-European” stands for BBMRI-ERIC Common Services (ELSI, IT), Stakeholder Forum, and headquarters; “Nodes” stands for National and Organizational Nodes of BBMRI-ERIC; “biobanks” stands for biobanks and bioresources. Candidates for key performance indicators are marked in **bold**.

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#	Name	Definition	Point of Measurement	Frequency
#25	Number of BBMRI-ERIC presentations outside of Europe	Number of BBMRI-ERIC presentations outside of Europe.	Pan-European	yearly
#26	Number of agreements between BBMRI-ERIC and learned societies	Number of agreements between BBMRI-ERIC and learned societies.	Pan-European	yearly
#27	Number of MoUs BBMRI-ERIC has signed with other research infrastructures and organisations	Number of MoUs BBMRI-ERIC has signed with other research infrastructures and organisations.	Pan-European	yearly
#28	Number of launched joint activities	Number of launched joint activities (projects, possibly other clearly documented activities), involving BBMRI-ERIC or at least participants related to the National or Organizational Nodes from two BBMRI-ERIC members or observers.	Pan-European	yearly
#29	Number of members participating in the CS IT User Forum	Number of User Forum members, representing various types of users and stakeholders (bio/medical and data-driven researchers requesting samples and data and/or requesting other services, biobankers, funders, citizens, software vendors, etc.).	Pan-European	yearly
#30	Response ratio for request sent to the CS IT User Forum	Average number of responses per request, based on the requests sent to the CS IT User Forum.	Pan-European	yearly
#31	Number of subscribers in the e-newsflash	Number of subscribers in the e-newsflash.	Pan-European	yearly
#32	Number of biobanks that signed Partner Charter	Number of biobanks that signed Partner Charter, either directly or indirectly via contract with a National or Organizational Node.	Nodes	yearly

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“Pan-European” stands for BBMRI-ERIC Common Services (ELSI, IT), Stakeholder Forum, and headquarters; “Nodes” stands for National and Organizational Nodes of BBMRI-ERIC; “biobanks” stands for biobanks and bioresources. Candidates for key performance indicators are marked in **bold**.

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#	Name	Definition	Point of Measurement	Frequency
#33	Number of biobanks offering prospective collection service and capable of following custom SOPs	Number of biobanks offering prospective collection service and capable of following custom SOPs, hereby prepared for enriching their existing collections of samples and data by new resources.	Nodes	yearly
#34	Number of users receiving outputs of dissemination activities from National or Organizational Node	Number of users subscribed to receive outputs of dissemination activities from the National or Organizational Node via communication channels such as email distribution lists, social media, e-newsflash, webinars...	Nodes	yearly
#35	Number of biobanks implementing certain quality standards	Number certifications of biobanks implementing certain quality standards (ISO 9001, 15189, 17025). I.e., a biobank with certifications to 2 out of 3 standards counts as 2.	Nodes	yearly
#36	Number of biobanks connected to core BBMRI-ERIC CS IT services	Number of biobanks connected to core BBMRI-ERIC CS IT services (Directory, Locator, Negotiator, data harmonization services). Biobanks can be connected either directly or via its National or Organizational Node. One biobank is counted once per each service (i.e., 1 biobank connected to 4 services is counted as 4).	Nodes	yearly
#37	Ratio between number of samples delivered to requesters and the total number of samples stored by the biobank	Ratio between number of samples delivered to requesters and the total number of samples stored by the biobank, based on the definition of the sample by ISO TC 276 outcomes.	biobanks	yearly

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“Pan-European” stands for BBMRI-ERIC Common Services (ELSI, IT), Stakeholder Forum, and headquarters; “Nodes” stands for National and Organizational Nodes of BBMRI-ERIC; “biobanks” stands for biobanks and bioresources. Candidates for key performance indicators are marked in **bold**.

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#	Name	Definition	Point of Measurement	Frequency
#38	Ratio between number of accepted applications and number of received applications for samples and/or data.	Ratio between number of accepted applications and number of received applications for samples and/or data. The number of received applications is the total number of applications received by the biobank during the given measurement period. The accepted application means that the access to the samples/data has been granted.	biobanks	yearly
#39	Median time to access samples/data	Median time to access samples/data, from filing the official request for access to delivery. Rejected requests are not counted into this indicator.	biobanks	yearly
#40	Number of papers where biobank was acknowledged as provider of samples, data, or expertise	Number of papers where biobank was acknowledged as provider of samples, data, or expertise.	biobanks	yearly
#41	Number of projects that return data to biobanks	Number of formally approved and ongoing projects that return data to biobanks.	biobanks	yearly
#42	Technology development related to operation of biobanks	Technology development related to operation of biobanks, such as storage and processing of material and data. Countables are: number of publications, prototypes, patents, products delivered to market.	biobanks	yearly

“Pan-European” stands for BBMRI-ERIC Common Services (ELSI, IT), Stakeholder Forum, and headquarters; “Nodes” stands for National and Organizational Nodes of BBMRI-ERIC; “biobanks” stands for biobanks and bioresources. Candidates for key performance indicators are marked in **bold**.

5 Detailed Information on Performance Measures Suggested for Key Performance Indicators

5.1 Pan-European Level

- **Indicator: Number of Members and Observers of BBMRI-ERIC (#1)**
Definition: Number of countries and international organizations that were Members or of Observers of BBMRI-ERIC (as defined in BBMRI-ERIC Statutes).
Levels: Pan-European
Frequency: yearly
Discussion: Each country or international organization is counted once, even if they upgraded from an Observer to a Member in the given measurement period.
- **Indicator: Proportion of external sources to overall budget of BBMRI-ERIC. (#2)**
Definition: Proportion of external sources to overall budget of BBMRI-ERIC. This includes all external sources, such as H2020 projects, IMI projects, etc., not including BBMRI-ERIC Core Budget.
Levels: Pan-European
Frequency: yearly
- **Indicator: Number of services (#3)**
Definition: Number of services deployed (made available for the users) by BBMRI-ERIC on Pan-European level. Each service must be declared as a service and must be clearly defined, also in terms of its target user group(s). <http://www.bbmri-eric.eu/bbmri-eric-services/>
Levels: Pan-European
Frequency: yearly
Discussion: BBMRI-ERIC website will contain a common catalogue of services, which will be used to declare the service and its target user group(s).
- **Indicator: Number of recognized individual users using services (a per service and aggregated) (#4)**
Definition: Number of recognized individual (e.g., authenticated) users using services collected per service, and then aggregated across all the services. The aggregation of per-service data into overall result will be done in two ways: (1) by counting individual users, i.e., one user should not be counted multiple times, (2) by summing up all the service-users. Examples of services include BBMRI-ERIC Negotiator and Locator, ELSI Helpdesk, or QM Consultancy.
Levels: Pan-European, Nodes, biobanks
Frequency: quarterly
Discussion: For services delivered directly by humans (such as ELSI legal advice), this may create substantial administrative overhead, particularly if service delivery is in small chunks).

It is also to be discussed whether we want to distinguish between (a) primary users (using samples/data/expertise), (b) secondary users (using outcomes achieved by primary users – i.e., derived), (c) citizens in general.

For simplicity reasons, the aggregation will be done by summing up, i.e., if a user uses three services, s/he will be counted 3 times.

- **Indicator: Number of Expert Centres (#5)**
Definition: Number of Expert Centres established by BBMRI-ERIC.
Levels: Pan-European
Frequency: yearly
- **Indicator: Number of new community standards, guidelines, policies as outcomes of the BBMRI-ERIC Working Groups and Common Services (#9)**
Definition: Number of new community standards, guidelines, policies as outcomes of the BBMRI-ERIC Working Groups and Common Services. Examples include MIABIS 2.0 Core and CoBRA guidelines.
Levels: Pan-European
Frequency: yearly
- **Indicator: Number of biobanks that filled out the quality self-assessment surveys (#12)**
Definition: Number of biobanks that filled out the quality self-assessment surveys.
Levels: Pan-European
Frequency: yearly
- **Indicator: Number of subscribers in the e-newsflash (#31)**
Definition: Number of subscribers in the e-newsflash.
Levels: Pan-European
Frequency: yearly

5.2 National or Organization Node Level

- **Indicator: Number of recognized individual users using services (a per service and aggregated) (#4)**
Definition: Number of recognized individual (e.g., authenticated) users using services collected per service, and then aggregated across all the services. The aggregation of per-service data into overall result will be done in two ways: (1) by counting individual users, i.e., one user should not be counted multiple times, (2) by summing up all the service-users. Examples of services include BBMRI-ERIC Negotiator and Locator, ELSI Helpdesk, or QM Consultancy.
Levels: Pan-European, Nodes, biobanks
Frequency: quarterly
Discussion: For services delivered directly by humans (such as ELSI legal advice), this may create substantial administrative overhead, particularly if service delivery is in small chunks. It is also to be discussed whether we want to distinguish between (a) primary users (using samples/data/expertise), (b) secondary users (using outcomes achieved by primary users – i.e., derived), (c) citizens in general.

“Pan-European” stands for BBMRI-ERIC Common Services (ELSI, IT), Stakeholder Forum, and headquarters; “Nodes” stands for National and Organizational Nodes of BBMRI-ERIC; “biobanks” stands for biobanks and bioresources. Candidates for key performance indicators are marked in **bold**.

For simplicity reasons, the aggregation will be done by summing up, i.e., if a user uses three services, s/he will be counted 3 times.

- **Indicator: Number of biobanks that signed Partner Charter (#32)**
Definition: Number of biobanks that signed Partner Charter, either directly or indirectly via contract with a National or Organizational Node.
Levels: Nodes
Frequency: yearly
Discussion: national expertise and capacity building, we need to look into unification of interpretation of Partner Charter (FAQ?)
- **Indicator: Number of biobanks offering prospective collection service and capable of following custom SOPs (#33)**
Definition: Number of biobanks offering prospective collection service and capable of following custom SOPs, hereby prepared for enriching their existing collections of samples and data by new resources.
Levels: Nodes
Frequency: yearly
Discussion: national expertise and capacity building, reflects also *adaptivity of the biobanks to changing demands by the users*
- **Indicator: Number of users receiving outputs of dissemination activities from National or Organizational Node (#34)**
Definition: Number of users subscribed to receive outputs of dissemination activities from the National or Organizational Node via communication channels such as email distribution lists, social media, e-newsflash, webinars...
Levels: Nodes
Frequency: yearly
- **Indicator: Number of biobanks implementing certain quality standards (#35)**
Definition: Number certifications of biobanks implementing certain quality standards (ISO 9001, 15189, 17025). I.e., a biobank with certifications to 2 out of 3 standards counts as 2.
Levels: Nodes
Frequency: yearly
- **Indicator: Number of biobanks connected to core BBMRI-ERIC CS IT services (#36)**
Definition: Number of biobanks connected to core BBMRI-ERIC CS IT services (Directory, Locator, Negotiator, data harmonization services). Biobanks can be connected either directly or via its National or Organizational Node. One biobank is counted once per each service (i.e., 1 biobank connected to 4 services is counted as 4).
Levels: Nodes
Frequency: yearly

5.3 Biobank Level

- **Indicator: Number of recognized individual users using services (a per service and aggregated) (#4)**

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Definition: Number of recognized individual (e.g., authenticated) users using services collected per service, and then aggregated across all the services. The aggregation of per-service data into overall result will be done in two ways: (1) by counting individual users, i.e., one user should not be counted multiple times, (2) by summing up all the service-users. Examples of services include BBMRI-ERIC Negotiator and Locator, ELSI Helpdesk, or QM Consultancy.

Levels: Pan-European, Nodes, biobanks

Frequency: quarterly

Discussion: For services delivered directly by humans (such as ELSI legal advice), this may create substantial administrative overhead, particularly if service delivery is in small chunks). It is also to be discussed whether we want to distinguish between (a) primary users (using samples/data/expertise), (b) secondary users (using outcomes achieved by primary users – i.e., derived), (c) citizens in general.

For simplicity reasons, the aggregation will be done by summing up, i.e., if a user uses three services, s/he will be counted 3 times.

- **Indicator: Number of samples with quality label report attached (#10)**

Definition: Number of samples with quality label report attached. (Quality label is now under development by BBMRI-ERIC.)

Levels: biobanks

Frequency: yearly

Discussion: Minimum requirements for quality label report needs to be clearly defined, referencing either CEN or ISO standards. It also assumes consensus is reached on the definition of a sample (ideally from ISO TC 276) so that there is unambiguous definition of how biological material is counted.

- **Indicator: Number of data sets with complete provenance information available (#11)**

Definition: Number of data sets with complete provenance information available. Complete provenance information includes link from the data via samples (if the data is generated from samples) to the research participant. The provenance information also includes "quality labels" of samples, if samples are involved.

Levels: biobanks

Frequency: yearly

Discussion: Requires acceptance of common provenance information standards and declaration of data sets (in the Directory or similar metadata repository service). Complete provenance information must link data all the way to the source, i.e. research participant. For privacy reason, the provenance information is likely to be naturally distributed across multiple institutions, but must be linkable together.

If samples are source of the data in the data set, the all used samples must have attached quality label report, in order to ensure the data set can be counted for as having complete provenance information – see #10.

- **Indicator: Ratio between number of accepted applications and number of received applications for samples and/or data. (#38)**

Definition: Ratio between number of accepted applications and number of received applications for samples and/or data. The number of received applications is the total number of applications received by the biobank during the given measurement period. The accepted application means that the access to the samples/data has been granted.

Levels: biobanks

Frequency: yearly

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- **Indicator: Median time to access samples/data (#39)**
Definition: Median time to access samples/data, from filing the official request for access to delivery. Rejected requests are not counted into this indicator.
Levels: biobanks
Frequency: yearly
Discussion: separate categories for single-country and transnational requests.
- **Indicator: Number of papers where biobank was acknowledged as provider of samples, data, or expertise (#40)**
Definition: Number of papers where biobank was acknowledged as provider of samples, data, or expertise.
Levels: biobanks
Frequency: yearly
- **Indicator: Number of projects that return data to biobanks (#41)**
Definition: Number of formally approved and ongoing projects that return data to biobanks.
Levels: biobanks
Frequency: yearly

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