

## Biobanks and Biomolecular Resources Research Infrastructure BBMRI

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<b>Scientific area:</b>	(Bio)Medical Sciences
<b>Host country:</b>	Austria
<b>Infrastructure type:</b>	Distributed
<b>Dutch node or similar:</b>	BBMRI-NL
<b>Legal entity</b>	ERIC
<b>Established:</b>	2013
<b>The Netherlands member since:</b>	2013
<b>Phase:</b>	Operational

### Duration of agreement

Ongoing

### Terms of withdrawal

By a written notice to the Chair of the Assembly of Members and to the Director-General, at the latest six months before the approval of the following year's budget.

### Access to facilities

Not applicable. Services are available to all organizations and facilitated via the nodes in the member states.

### Access to data

Via individual biobanks and facilitated through the use of open-access BBMRI-ERIC tools.

### User definition

BBMRI-ERIC is a European research infrastructure for biobanking, which bring together all the main players from the biobanking field – researchers, biobankers, industry, and patients – to boost biomedical research. To that end, we offer quality management services, support with ethical, legal and societal issues, and a number of online tools and software solutions.

### Description

The Biobanks and Biomolecular Resources Research Infrastructure is a European research infrastructure for biobanking of 18 member countries and 6 observers. BBMRI-ERIC aids biobanks and researchers in order to facilitate the use of biological samples and data. To that end, BBMRI-ERIC offers quality management (QM) services, support with ethical, legal and societal issues (ELSI), and a number of online tools and software solutions. Austria functions as the host member state of BBMRI-ERIC. BBMRI-NL is the Dutch node.

### Financial details

**Mean Dutch membership over 5 year period (€K):** 313\*

**Mean Dutch share of contribution over 5 year period (%):** 5,9\*

*\*Since 2020 the Dutch contribution was raised to 6,5% on average.*

Year	NL membership (k€)	NL Contribution (% of total*)	Total membership (k€)	Total expenditure (k€)	Turn-over (k€)
2016	97	5.24	1684	2354	2380
2017	100	5.28	1895	2213	2213
2018	104	5.13	1917	2546	2546
2019	106	5.41	1965	2814	2814
2020	110	6.44	1706	2274	2274

\* During the period of 2017-200, The Netherlands contributed in-kind to the construction of IT-systems. This in kind contribution was discounted from the Dutch membership fee. During the period of 2016-2018, The Netherlands contributed in-kind to CS ELSI. This in-kind contribution was discounted from the Dutch membership fee.

#### Employee statistics

	Female	Male	Other	Total
<b>Total*</b>	27	13	0	18,5
<b>Of which Dutch**</b>	0	0	0	14

\*The total number of people employed is 40. The total amount of full time equivalents (FTEs) amount to 18.55, given that several employees have part time contracts or are employed by BBMRI and one of its partners (universities, national research institutes etc). \*\*The total number of FTEs in 2019 working for BBMRI.nl was 14 (13 FTE for development, and 1 for NN office).

#### Use of the infrastructure

##### User Information

Year	Number of users
<b>2016</b>	0
<b>2017</b>	54
<b>2018</b>	175
<b>2019</b>	390
<b>2020</b>	n/a

##### Dutch share of users

n/a

##### Type of users

n/a

##### Comments by the RI:

BBMRI users can be divided in 2 groups: a) academic or private researchers and research institutes accessing the Directory and Negotiator b) biobanks and researchers from Member Countries accessing ELSI, QM services and IT services other than the Directory and Negotiator. For group a (Directory/Negotiator users) we have detailed data on the number of users. For group b), since several users are organisations, it is not possible to calculate an exact number or split them by category. In 2018, over approx. 439 users per month logged in the Directory to submit queries. In 2018, the number grew to approx. 478 users/month. The number reported above refers to the number of Negotiator registered users over time. The Negotiator in 2017 had 54 registered users, which grew to 390 in 2019. As of June 2020, 500 users registered to the Negotiator, an almost ten-fold increase in less than 4 years. Concerning QM services, in 2019 BBMRI supported 54 self-assessment survey completions, and awarded 32 collections in the Directory with 32 quality marks (Q mark). In 2018, QM delivered 88 self-Assessments and 15 Q Marks. Concerning ELSI, in 2019 BBMRI delivered 15 ethics checks for Horizon 2020 projects, and responded to 93% of the questions submitted to the BBMRI ELSI Helpdesk. In 2018, ELSI delivered 11 ethics checks, and answered 94.3% of the questions received. Referring to the number of users of the Directory and Negotiator, the continuous development of the platforms gradually and steadily increased the number of users. In particular, the launch of Negotiator in 2018, dramatically increased the quantity and quality of users interactions with BBMRI. When including visitors of the ELSI Servicedesk and BBMRI.nl Catalogue it has been 1000s over the years. We cannot keep track exactly, since part of the resources/tooling/services are publicly accessible. Data Provides are minimum estimates as we are not able to track the full use of all resources/services/tooling.

### Application information

Year	Number of applications/requests		Number of approved applications/requests		Percentage of approved applications/requests to use (%)	
	NL	Other countries	NL	Other Countries	NL	Other Countries
2016	200	200	200	0	100	0
2017	250	196	250	250	100	0
2018	1000	561	1000	991	100	2.05
2019	1000	522	1000	961	100	8.15

#### *Comments by the RI:*

BBMRI does not provide direct access to samples or data. Through our Directory, users can find biobanks holding samples that match they needs. Through the Negotiator, users can contact BBMRI biobanks and immediately kick off the negotiation process to access the samples. However, biobanks have no obligation to use the Negotiator to provide access to the samples. In the period January - June 2020, the number of request via the Negotiator (54) already exceed the sum of requests in 2018 and 2019, showing the growing success/effectiveness of the Negotiator. There is no registration of our number of applications/ requests, based on their sex. Based on pathology and omics-data requests, and users of the BBMRI.nl Catalogue and Request Portal Podium. For other resources, tooling and services, we don't keep track. Almost all are approved. Based on pathology and omics-data requests, and users of the BBMRI.nl Catalogue and Request Portal Podium. For other resources, tooling and services, we do nott keep track.

### Sample information

Year	Number of sample requests		Number of approved sample requests		Rate of approval of sample requests (%)	
	NL	Other countries	NL	Other Countries	NL	Other Countries
2016	150	n/a	150	n/a	100	n/a
2017	200	n/a	200	n/a	100	n/a
2018	300	n/a	300	n/a	100	n/a
2019	280	n/a	280	n/a	100	n/a

#### *Comments by the RI:*

BBMRI does not provide direct access to samples or data. See answer to 'Application information'. Only based on pathology sample requests, we do not keep track of other sample types. Almost all requests are approved.

### Data request information

Year	Number of data requests		Number of approved data requests		Rate of approval of data requests (%)	
	NL	Other countries	NL	Other Countries	NL	Other Countries
2016	150	n/a	150	n/a	100	n/a
2017	200	n/a	200	n/a	100	n/a
2018	900	n/a	900	n/a	100	n/a
2019	880	n/a	880	n/a	100	n/a

#### *Comments by the RI:*

BBMRI does not provide direct access to samples or data. See answer to 'Application information'. Only based on pathology and omics-data requests, we do not keep track of other data sets. Almost all are approved.

### Contributions provided by organisations or companies in the participating countries

Year	Contributions by organisations or companies in the participating countries (k€)		Dutch percentage out of contributions provided by organisations or companies	
	NL	Other countries	NL	Other Countries
2016	38.5	77.7	49.5	n/a
2017	38.5	70.5	54.6	n/a
2018	6.5	40.0	16.0	n/a
2019	n/a	38.4	n/a	n/a

### Total sum spent on other deliveries (equipment, services and consumables) and user fees

n/a

#### *Comments by the RI:*

BBMRI-ERIC has not received any consumables, services or equipment as a contribution from an organisation or company. BBMRI.nl has not contributed any consumables, services or equipment.

### Income from user fees

Year	Income from user fees (k€)	
	NL	Other countries
2016	0	0
2017	0	0
2018	0	1.38
2019	0	0

### Dutch percentage out of RI's income from user fees

n/a

#### *Comments by the RI*

BBMRI services are free of charge for users from Member countries. Directory/Negotiators users can register for free. The 2018 income comes from a one-off consultation provided to Japanese partners concerning quality management. BBMRI-nl services are free of charge. Catalogue and Podium users can register for free.

### Additional questions to the RI (2020)

#### **What is the Dutch contribution to the RI?**

BBMRI.nl has participated in (successful and unsuccessful) EU grant applications, coordinated by or together with BBMRI-ERIC. Development and maintenance of the BBMRI-ERIC Directory is done by Dutch partners. BBMRI.nl has been involved in part of the common services ELSI and IT of BBMRI-ERIC. Dutch biobankers had prominent roles within the Europe Biobank Week, organised yearly by BBMRI, in partnership with ESBB. Dutch partners delivered a guide for handling incidental findings (and translation in English); a webinar about this topic was organized by BBMRI.nl and BBMRI-ERIC together. Outreach activities between BBMRI-ERIC and BBMRI.nl are aligned monthly.

#### **Currently, are there any RI's that provide similar kinds of research infrastructure and services as yours in the world?**

BBMRI is the only infrastructure in the world that facilitates not-for-profit, transnational access to biobanking and biomolecular resources, underpinned by quality, ELSI and IT services delivered directly to the biobanks part of the BBMRI network. At the same time, BBMRI does not operate in a vacuum: by their own nature, biobanking and the BBMRI's services are key to make new treatment possible, and needs to be embedded/integrated in broader R&I processes to fully reach their socio-economic impact. As a result, BBMRI's services are propedeutic and complementary to those provided by other RIs. For this reason, BBMRI established a number of

collaborations with several partners to maximise the impact of its services and avoid overlaps and duplication. The best example is the Alliance of Medical Research Infrastructures (AMRI), established by BBMRI with EATRIS and ECRIN. AMRI aims at creating a federation among these three highly complementary RIs, and to share expertise, staff and resources among them to create a one stop shop for academic and industry researchers looking for a total workflow of services in drug development, personalised medicine, medical devices/IVDs development and more. The AMRI reflects also what is happening at the national level in several countries (ie., in The Netherlands, with Health-RI), whereby different research infrastructures national nodes joined forces to maximise resources and ensure cooperation. NGOs and individual membership-based organisations (like ISBER and ESBB) run initiatives that reach out to part of the BBMRI's community. Some of those initiatives (repositories of biobanks, guidelines documents) overlap only slightly with BBMRI's, and are often produced in partnership with BBMRI. BBMRI has memorandum of understandings with both ISBER and ESBB, detailing the scope of collaborations.

**What are the overlaps and what are the main differences? To which extent do you cooperate or compete?**

**1)** EATRIS & ECRIN: BBMRI, EATRIS and ECRIN cover different, but complementary factors in the new treatment development processes. There are few minor overlaps in the delivery of core services (ie., EATRIS includes a modest number of biobanks within its network). However, the aforementioned creation of the AMRI aims at solving the minor overlaps existing, and reinforcing complementarity among the RIs. Within the AMRI, each RIs key competences have been evaluated, and senior staff members are working together to define the exact extend of the collaboration. BBMRI, EATRIS and ECRIN communication and public affairs staff members have created a joint public affairs team, that shares information and produces joint position papers, press releases and coordinates the outreach of each RIs to European and global stakeholders. Similar efforts are in development regarding patients involvement and engagement (exploiting BBMRI's very solid Stakeholder Forum), ELSI and data protection (based on BBMRI's vast experience on the topic), IT and data issues, quality, RIs operation and HR. Recently, AMRI has been used to harmonise the 3 RIs participation to large EU-funded consortia, ensuring minimum competition for EU funds under Horizon 2020, IMI and other programmes; **2)** BBMRI signed or is considering signing Memorandum of Understanding with other RIs providing complementary services to BBMRI's. BBMRI and EVAg signed an MoU in 2014. BBMRI and EuroBioImaging are considering to sign an MoU; **3)** BBMRI and other life science research infrastructures collaborate under the CORBEL and EOSC-life projects, large cluster initiatives funded by the EU. The Life Science Research Infrastructures strategy group (LS RI) is an informal leadership group created within CORBEL that periodically brings together the leadership of the life science RIs to discuss long term strategies and common issues. The LS RI serves as a coordination tool for BBMRI and other RIs, where issues of competition and coordination can be discussed; **4)** The International Society for Biological and Environmental Repositories (ISBER) is a US-based biobanking membership association, with a global outreach and over 1000 individual members. ISBER produces guidelines for biobankers, and organises large biobanking congresses. BBMRI and ISBER collaborate formally on a number of issues, including COVID-19 and hold regular leadership meetings to align each organisation's strategy and ensure no overlap. The European, African and Middle East Society for Biobanking and Biopreservation (ESBB) is an individual membership-based association, similar to ISBER, with a narrower geographical focus and smaller membership, mostly European. ESBB is a long-standing partner of BBMRI: since the early 2010', BBMRI and ESBB organise the Europe Biobank Week (EBW), Europe's largest biobanking congress, with over 700 average attendees; **5)** BBMRI has been involved in the creation and development of several research infrastructures projects, including ERINHA, EPTRI and EurOPDX. Regarding ERINHA, the COVID-19 pandemic fast-tracked our conversation with ERINHA's leadership about possible future collaborations. Overall, ERINHA and BBMRI do not have large overlaps, but there are synergies to be better explored, including the increased access to BSL2 and BSL3 laboratories. Regarding EPTRI, BBMRI, together with EATRIS and ECRIN (all partners in the EPTRI project), shared their concern multiple times that the development of a full EPTRI RI would considerably overlap with existing services from the 3 RIs. Specific paediatric services can be easily developed by the 3 RIs, and some of such services have already been identified and partially developed within the EPTRI project. Regarding EurOPDX, BBMRI was a beneficiary in the EurOPDX project. BBMRI and the temporary EurOPDX office held informal conversations on possible future collaborations, that would also include other LS RIs such as INFRAFRONTIER. A partial assessment of the EurOPDX possible operations as a standalone RI indicates a considerable overlap between BBMRI and INFRAFRONTIER, with some added value produced by the specific EurOPDX project deliverables.

**What are the RI's major educational and outreach activities?**

Europe Biobank week, BBMRI-ERIC together with ESBB organise this conference. It has a great impact to the scientific world and it occurs every year in a different country.

We also organise various workshops & Webinar:

- GRAZ BIOMEDICAL RESEARCH
- Biomedical Research Training Workshop Week
- ETHICAL HANDLING OF INCIDENTAL FINDINGS IN RESEARCH
- BBMRI.QM WEBINAR #5