

# WORK PROGRAMME

2021





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# 1. Executive Summary

The Work Programme for 2021 will continue to build on BBMRI-ERIC's successful achievements. It is designed to ensure continued sustainability of the services and expansion of the training portfolios in ethical, legal and societal issues (ELSI), quality management (QM) and information technology (IT). Our services will expand in order to substantially accelerate in line with the visions of EOSC and the European Open Data Space, whilst focusing on the requirements for digitalisation and open science that are relevant for sensitive data management in the health research sector. Moreover, it will contribute to the realisation of precision medicine through a focused research agenda in line with the Mission for Cancer and the 1+Million Genomes Initiative. Our research will address foremost disease areas of cancer, rare diseases, and COVID-19 while expanding on novel technologies to leverage the potential of sequencing and NMR spectroscopy advancements. While developing concepts of sustainability for our National Nodes and biobanks is an overarching goal, we will further strengthen our value proposition through intensified activities with our Stakeholder Forum, our Expert Centres and our various governing boards.

Today, BBMRI-ERIC's infrastructure with 20 Member States and the International Agency for Research on Cancer (IARC) forms one of the largest health Research Infrastructures in Europe. BBMRI-ERIC's mission is to establish, operate, and develop a pan-European distributed research infrastructure of biobanks and biomolecular resources to facilitate the access to resources as well as facilities and to support high-quality biomolecular and medical research. BBMRI-ERIC has increasingly facilitated sample and data access through our network of National Nodes and biobanks, successfully

offering a growing portfolio of services and trainings on ELSI, QM and IT. Addressing current needs during the COVID-19 pandemic was and is effective in all our core activities as a united effort by our biobanks, National Nodes and Headquarters. In parallel, H2020 projects (e.g., CINECA, EJP RD, EUCAN-Connect, EOSC-Life, ConcePTION, CY-Biobank, CETOCOEN II, Diamonds, IC2PerMed, EuCanImage, and B1MG; see Appendix) will continue and further corroborate BBMRI-ERIC's developments towards our future sustainability. However, we will conscientiously account for a more

stringent alignment of core and project activities in the coming years in order to foster synergies were possible, to close structural gaps were needed, and to free resources for new yet fundamental objectives.

**Ethical, Legal and Societal Issues** will be a continued backbone of BBMRI-ERIC's service portfolio including its Knowledge Base, Helpdesk, and Task Forces on GDPR and Societal matters. A specific emphasis will be drafting the Code of Conduct for Health Research for consultation, which has the potential to ensure data privacy rules for the health research sector.

The **Quality Management** services will further expand on their three pillar activities – Knowledge Hub, Training/ Support, and Auditing – while conceptualizing a fourth one: Quality Assurance. This will entail defining quality markers and conceptualizing a proficiency testing programme; both will be focused on liquid biopsies. QM activities will be expanded towards data quality, assembling a BBMRI.QM Training Curriculum and conceptualizing a BBMRI.QM Academy. The development of a QM implementation plan for Headquarters' operations will help to streamline our expanding services and will subsequently be provided to the National Nodes.

The **Common Service IT** has been restructured and relaunched in 2020. Its structure and key topics will be further developed in 2021 including the Directory, Negotiator, and Helpdesk. However, BBMRI-ERIC must and will strengthen its digitalization portfolio by (i) a federated search system on both sample-level and

patient-/donor-level data, (ii) data quality and certification, (iii) expedited access procedures for samples & data, (iv) data pooling, and (v) big data analysis. These topics will be addressed by new Task Forces in collaboration with other Research Infrastructures and beyond.

While ELSI, Quality, and IT will further develop and excel individually, they all contribute to and interlink with BBMRI-ERIC's objectives for **Research and Education**: we will formalize our educational activities (e.g., BBMRI.QM Academy), expand our conference portfolio with an IT symposium, and explore new avenues on network exchange opportunities at the graduate and post-graduate levels. BBMRI-ERIC's developments on GDPR guidance, data quality, data provenance, and digitalization will further enable precision medicine with a focus on cancer, rare diseases, and COVID-19; e.g., by a federated search system for these three entities. Utilizing novel technologies will contribute to the EU's 1+Million Genomes Initiative and address sample quality measures, e.g., by NMR spectroscopy. Inquiring common interests with BBMRI-ERIC's Expert Centres can reinforce and advance our research capacities. These tasks will be accompanied by further development of BBMRI-ERIC's grant application and publication policies.

BBMRI-ERIC's **Strategy and Partnerships Development** will continue its leading role in relation to other Research Infrastructures, ERICs, EU institutions and international organisations. We will be further positioning BBMRI within broader EU science policy makers, growing BBMRI

## 1. Executive Summary


membership and developing concepts for affiliates outside the EU. By intensifying activities in our Stakeholder Forum within the patient, industry and scientific societies pillars, we will seek continued advice and guidance from all our stakeholders. BBMRI-ERIC is particularly privileged by the close partnership with our excellent patient advocates and their role in BBMRI-ERIC's decision-making process. Consequently, leveraging the full potential of this close alliance will be an integral part of our internal retreat. This internal retreat should ultimately lead to even stronger bounds between the Headquarters, the National Nodes and biobanks. Another key activity will address operations and sustainability of our National Nodes and biobanks. While learning from each other, we will develop concepts for sustainability that can then be instrumental for new members. This activity is closely bound to revisiting our Key Performance Indicators (KPIs) which we will align with our Member States and EU expectations.

BBMRI-ERIC's **Marketing and Communications** will continuously build the brand of BBMRI, increase the visibility

of European biobanks, and foster common outreach activities. Dedicated resources will be invested to capture and highlight success and impact stories while consolidating BBMRI-ERIC's events, newsletter and website, and supporting activities in awarded projects and grant applications to come. We see further potential for outreach beyond the overall biobanking community and will conceptualize an overarching marketing strategy.

The Work Programme for 2021 is a reflection of the continued collaboration and guidance by the entire BBMRI community. On behalf of the Headquarters team, I would like to thank our stakeholders, National Nodes, Members and Observers, the various governing bodies of BBMRI-ERIC and our partners and collaborators in academia, industry and the public. Furthermore, I would like to wholeheartedly invite you all to join forces in pursuing our 2021 Work Programme together in order to address our worlds current and future challenges in a concerted and most efficient team effort.

Sincerely,

A handwritten signature in blue ink that reads "Jens Habermann". The signature is fluid and cursive, with a long horizontal stroke at the end.

Prof. Jens K. Habermann, M.D., Ph.D.

## 2. Services and Tools

### 2.1. ELSI

In order to provide support on ethical, legal and societal issues (ELSI), we operate on the basis of a federated model, in partnership with a network of experts from academia and practice from across our National Nodes and project partners. Focus areas are identified in collaboration with the National Nodes, national ELSI experts and helpdesk users, facilitated by the headquarters and realised via the Task Forces. Project participation ensures the provision of our extended services to a specific consortium. Project results are translated into practical how-to-guides and shall benefit the wider community. Whereas project participation ensures further development of our services and gaining of new insights, our headquarter activities ensure their operation. Our vision remains to deliver reliable, practical and sustainable services based on state-of-the-art research for the immediate benefit of the community by setting standards, providing a platform for knowledge exchange and advancing debate and implementation.

#### 2.1.1. BBMRI-ERIC Ethical, Legal and Societal Issues (ELSI) Services

We support the biobanking and life science RI communities by facilitating compliance with regulatory requirements, best practice standards and guidance on ethical, legal and societal issues. We will continue the activities established in previous years (Knowledge Base, Task Forces, Dialogue platform, Helpdesk, Ethics Check, Code of Conduct) and add – upon user request – the Ethics Review as a new item.

Responsible	Deliverable	Timing
Headquarters	<b>ELSI Knowledge Base</b> <ul style="list-style-type: none"> <li>• Develop practical guidance by translating research outputs into FAQs or how-to guides</li> <li>• Integrate research outputs in the Knowledge Base</li> <li>• Ensure accuracy of content and sustainability of service</li> </ul>	Q1-Q4
	<b>ELSI Helpdesk</b> <ul style="list-style-type: none"> <li>• Promote national helpdesks and services</li> <li>• Provide a platform for knowledge exchange across national helpdesks</li> <li>• Coordinate joint responses to transnational questions</li> <li>• Provide insights, ideas, consultancy based on expertise and state-of-the-art research (e.g. ethical risk management)</li> </ul>	Q1-Q4

## 2. Services and Tools

Responsible	Deliverable	Timing
	<b>Ethics Check</b> <ul style="list-style-type: none"> <li>• Review and when necessary propose improvements of the compulsory Ethics Self-Assessment section for research proposals</li> </ul>	Q1-Q4
	<b>Ethics Review</b> <ul style="list-style-type: none"> <li>• Provide ELSI assessment during a running project (review report)</li> </ul>	Q1-Q4
	<b>Task Force REC</b> <ul style="list-style-type: none"> <li>• Carry out mapping exercise on the practices of research ethics committees and access committees</li> </ul>	Q1-Q4
	<b>Task Force GDPR</b> <ul style="list-style-type: none"> <li>• Assess trans-national GDPR implementation and transnational consequences</li> </ul>	Q1-Q4
	<b>Task Force Societal</b> <ul style="list-style-type: none"> <li>• Provide reliable, feasible and practical knowledge on societal issues</li> </ul>	Q1-Q4
	<b>ELSI Dialogue</b> <ul style="list-style-type: none"> <li>• Identify 'hot topics' for biobankers (e.g., datafication, vulnerability, minors in research)</li> <li>• Establish a platform of knowledge exchange</li> <li>• Implement public training activities, workshops and webinars, etc., in collaboration with projects and National Nodes</li> <li>• Disseminate and advance knowledge on state-of-the-art research findings</li> </ul>	Q1-Q4
	<b>Code of Conduct for Health Research</b> <ul style="list-style-type: none"> <li>• Prepare the draft code for consultation</li> </ul>	Q1-Q4
National Nodes	<b>In-kind contribution to services and knowledge exchange</b> <ul style="list-style-type: none"> <li>• Nominate experts to <b>Task Forces</b> and <b>Helpdesk network</b></li> <li>• Provide updates on national ethical, legal and societal issues</li> <li>• Contribute to task forces and transnational helpdesk requests based on (country) expertise</li> <li>• Propose and/or co-organise joint workshops, webinars and debates</li> <li>• Translate FAQs or how-to guides on National Nodes level if needed</li> </ul>	Q1-Q4



### 2.1.2 Complementary ELSI Development in Projects

The following table provides an overview how the funded projects are aligned with the overarching ELSI tasks and as such are integrated in core service developments. More information on the distinct project goals is provided in the Appendix. Please note that of all ELSI tasks, currently 38% are covered by BBMRI-ERIC core budget while 62% are based on grant funding.

Table: Interdependencies between core and project tasks and budget

	R&D	Services					Trainings	GDPR & ethical compliance, contracts	Code of Conduct	
		Knowledge Base	Ethics Check	Ethics Advice	Ethics Review	Helpdesk Network				
<b>Core</b> 38% (2.25 FTE)		-	Ops	Ops	-	Ops	Ops*	Ops*	Ops	Coor & drafting
<b>Projects</b> 62%	CY-Biobank	Dev*	Dev	-	Dev*	-	-	Ops*	-	-
	EOSC-Life	Dev*	Dev	Ops	-	-	-	Ops	-	Coor
	CINECA	Dev	-	Ops	-	-	-	Ops	-	Coor
	EUCAN-Connect	Dev	-	Ops	-	-	-	Ops	-	Coor
	EUCAN-Image	Dev	-	Ops*	-	-	-	-	-	Coor
	EJP RD	-	-	-	Ops	-	-	Ops	-	-
	DIAMONDS	-	-	-	-	-	-	Ops	-	-
	B1MG	-	-	-	Dev	-	-	-	-	Coor
	Big Picture	Dev*	-	Ops	Dev	-	-	-	-	-
	EDIREX	-	-	-	Ops	-	-	-	-	-
	EOSC-hub	-	-	-	Dev*	-	-	-	-	-
	euCanSHare	-	-	-	Dev	-	-	-	-	-
	EOSC-Future	-	-	-	-	-	-	-	-	Coor
	and others to come									

\* = National Nodes involvement; Ops = operations; Coor = coordination; Dev = development; FTE = Fulltime Employee

### 2.1.3. Milestone and Key Performance Indicator by Headquarters\*\*

Milestone Q3/2021: Code of Conduct Consultation starts with draft sections

Key Performance Indicator: Number of Ethics Checks, ELSI Helpdesk requests and consultations (current in 2020 – prospect in 2021: 76 – 95)

\*\* To define and agree on BBMRI-ERIC's overarching KPIs for Headquarters and National Nodes in alignment with member states and EU expectations (ESFRI guidance) will be a specific task of the Work Programme 2021 (see 4.1.1).

## 2. Services and Tools

### 2.2. Quality

Continuous improvement is key for the sustainable development of biobanks. A cornerstone of this development is the provision of the well-known international standard for biobanking and technical specifications for applicable methods for sample handling (ISO.org). However, biobanks must also consider themselves within the entire field of biomedical research and development and network intensively through close cooperation with the respective interfaces within universities, clinics, and research institutions. In 2021, BBMRI-ERIC will focus on providing QM services and training on biobank-relevant standards while taking a holistic approach from quality management systems for biomedical research. Performance evaluation will be offered to enable the quality assessment of biobanks and collections.

#### 2.2.1 BBMRI-ERIC Quality Services

BBMRI-ERIC Quality Services will continue to focus on empowering biobankers and researchers through three pillars: information (Knowledge Hub), education (Training & Support) and review (Auditing) while conceptualizing a fourth pillar: quality assurance.

##### Knowledge Hub

BBMRI-ERIC will consolidate the liaison to several ISO Technical Committees (276, 212, 215 and CEN 140) to maintain the information flow from standard development to the biobankers and researchers. In addition, all QM expertise provided to, and extracted from, projects is shared within the community via the Knowledge Hub. BBMRI.QM will offer virtual consultation hours once a quarter on the subject of QM.

Ad-hoc webinars are offered when the need arises, following the example of urgent demand for guidance on how biobanks should act in times of Covid-19.

##### Training & Support

We are expanding the range of training courses for biomedical research and the first steps in the area of training for data quality and data quality assessment are going to be taken. The individual, existing QM training courses will be combined and supplemented with additional modular training courses. These training offers can be summarized in a comprehensive QM training curriculum. Further development into a "BBMRI.QM Academy" and the setup according to the principles of "ISO 21001:2018 Educational organizations - Management systems for educational organizations - Requirements with guidance for use (preview)" will be investigated and conceptualized within 2021 for evaluation, to be implemented in 2022.

##### Auditing

BBMRI.QM will continue to provide the performance evaluation with Self-Assessment, remote and onsite audit.

- a) Auditing the "Quality Management Systems and General Requirements for Biobanking" according to ISO 20387:2018 and ISO 9001:2015, is an onsite audit service.
- b) Auditing "Collection/Sample Handling Processes" according to CEN/TS and ISO is a remote audit service.

These services are based on submitted reports of BBMRI-ERIC Self-Assessment Surveys and can potentially lead to a Q-Label in the BBMRI-ERIC Directory. Onsite audit service will be provided on request and can be performed either from BBMRI-ERIC headquarters or on its behalf and conditions, by national auditors/experts. Quarterly, the National Nodes will receive an update on BBMRI-ERIC SAS utilization performance indicators and will be encouraged to motivate the biobanks to undergo quality assessment.

An additional activity of BBMRI.QM is the audit of BBMRI-ERIC Expert Centres according to defined QA/QC requirements. Any further development can be investigated upon request by the community.

In 2021, an implementation strategy will be developed for the operation of the BBMRI-ERIC headquarters according to the quality management system ISO 9001: 2015.

### **Quality Assurance**

Quality assurance for biobanks is particularly important since it gives the opportunity to monitor the quality and integrity of individual samples. We will address this on two levels:

- a) Define and provide biomarkers (intrinsic/extrinsic) that allow standardized assessment of sample quality through engagement in biospecimen research; application of such biomarkers will allow the pooling of samples of comparably high-quality EU-wide and thus foster large-scale cohort studies, e.g. on cancer and pandemic outbreaks. Here, liquid biopsy samples will be in focus due to their increasing clinical significance.
- b) Conceptualize proficiency testing as a service complementing the quality management system implemented in the biobank. Currently, such programmes target nucleic acid purification, single cell isolation and tissue histology. In contrast, EU-wide initiatives addressing liquid biopsies (serum, plasma, urine and analytes thereof) are lacking.

In addition to liquid biopsies being one common denominator, metabolomics might provide both quality assurance markers as well as standardized technology for proficiency testing – particularly to address factors affecting the preanalytical phase of the biobanking process. For this purpose, we will seek in-kind contribution from National Nodes, biobanks, involve experts from the Member States, join forces with academic and industry partners but also seek external grant funding where possible.

## 2. Services and Tools

Responsible	Deliverable	Timing
Headquarters	<b>Knowledge Hub</b> <ul style="list-style-type: none"> <li>• Maintain liaison to ISO/TC 276, 212, 215 and CEN 140</li> <li>• Conduct QM tasks in funded EU projects</li> <li>• Provide quarterly QM consultation hours to the community</li> <li>• Provide BBMRI.QM webinars (public) and ad hoc web conferences</li> </ul>	Q1-Q4
	<b>Training &amp; Support</b> <ul style="list-style-type: none"> <li>• Provide BBMRI.QM training on relevant standards</li> <li>• Assemble BBMRI.QM training curriculum</li> <li>• Conceptualize BBMRI.QM Academy for evaluation</li> </ul>	Q1-Q4
Headquarters	<b>Auditing</b> <ul style="list-style-type: none"> <li>• Maintain tools (SAS)</li> <li>• Provide BBMRI-ERIC Self-Assessment Surveys</li> <li>• Conduct BBMRI-ERIC remote and onsite audits</li> <li>• Offer quarterly reports to the National Nodes</li> <li>• Develop implementation plan to set up a QM System ISO 9001:2015 for BBMRI-ERIC Headquarters</li> </ul>	Q1-Q4
	<b>Quality Assurance</b> <ul style="list-style-type: none"> <li>• Define quality markers in liquid biopsies</li> <li>• Conceptualize proficiency testing of liquid biopsies</li> </ul>	Q1-Q4
National Nodes	<b>In-Kind contributions to services and developments</b> <ul style="list-style-type: none"> <li>• BBMRI.QM Services</li> <li>• BBMRI-ERIC SAS</li> <li>• Quality assessment according to ISO20387 &amp; technical standards</li> <li>• Experts for BBMRI.QM Services (technical experts, auditors etc.)</li> <li>• Quality assurance development</li> </ul>	Q1-Q4

### 2.2.2. Complementary Quality Development in Projects

The following table provides an overview of how the funded projects are aligned with the overarching QM tasks and as such are integrated in core service developments. More information on the distinct project goals is provided in the Appendix. Please note that of all QM tasks, currently 50% are covered by BBMRI-ERIC core budget while 50% are based on grant funding. This ratio will change by addition of a 0,5 full time position covered by core budget.

Table: Interdependencies between core and project tasks and budget

		Liaison to ISO and CEN	Knowledge hub	Training & Education	Audit	Quality Assurance
<b>Core</b> 50% (1,35 + 0,5 FTE)	<b>Tasks</b>	Ops	Ops	Ops*	Ops*	Dev*
<b>Projects</b> 50%	SPIDIA4P	Ops	Dev	Dev	Dev	-
	ConcePTION	Ops	Ops*	-	-	-
	CY-Biobank	Ops	Ops*	Ops	Ops	-
	EDIReX	-	Ops	-	Ops	-
	IC2PerMed	Ops	Ops	Ops	-	-
	CliniMARK	-	Ops	-	-	-
	and others to come					

\* National Nodes involvement; Ops = Operations; Dev = Development; Coor = Coordination; FTE = Fulltime Employment; FTE = Fulltime Employee

### 2.2.3. Milestone and Key Performance Indicator by Headquarters\*\*

Milestone Q2/2021: Assembly of BBMRI.QM training curriculum

Key Performance Indicator: Number of QM-information transfer consultation hours (public)  
(current in 2020 – prospect in 2021: 0 – 4)

\*\* To define and agree on BBMRI-ERIC's overarching KPIs for Headquarters and National Nodes in alignment with member states and EU expectations (ESFRI guidance) will be a specific task of the Work Programme 2021 (see 4.1.1).

## 2. Services and Tools

### 2.3 IT

#### 2.3.1. Common Service IT (CS IT)

Based on the outcomes of the consultations with the National Nodes of BBMRI-ERIC in 2018-2019, the new CS IT was set up in 2020. The main change was prioritization of focus on fewer core services: Directory, Negotiator, Authentication and Authorization Infrastructure (AAI), interoperability work including MIABIS, Helpdesk, and user experience analysis. The aim of this change was to concentrate development and operational resources and thus speed up the development and improve the quality of these core services. Each of these core services should be implemented by more than one group to provide more robustness as different teams can back up each other. Other services such as Locator or BIBBOX were left up to the National Nodes to pursue individually or in alliances and to support their further development using projects.

The focus of development and operations of the Common Service IT in 2021 targets several key topics:

#### - Improving quality of user experience

This builds on the feedback on services collected by the user experience group of the CS IT. Examples include more intuitive search mechanisms in the Directory (e.g., improved free text search and finding diagnosis using different synonyms), reworking the user interface technology in the Negotiator, or simplification of the registration and login procedures in the AAI. This also includes adding prioritized functionality of BBMRI-ERIC's access pipeline, such as the dynamic composition of requests in the Negotiator, which has been demanded by biobank operators to allow them to collect specific information per biobank they need to decide on availability and accessibility of data/ biological material, or enabling negotiation to other services beyond existing data/ material collections, such as setting up a prospective collection, organizing clinical trials, laboratory and analytical services, or data analysis and integration services.

#### - Improving quality and extent of data in centrally collected data resources and making them more compliant with FAIR and FAIR-Health principles

Feedback collected on the Directory shows that most user concerns are not related to the functionality of the Directory as such, but on the quality of the underlying data, which is collected from the federated biobanks via National Nodes. Similarly, reusability of the CRC-Cohort data depends on the quality and reliability of the data; a major effort in collecting the cohort has been in developing data quality analytical tools and improving the quality of the data in collaboration with the contributing biobanks. Improving and systematically implementing these processes will continue in 2021. Reusability of high-quality data can then be boosted by improving compliance to the FAIR principles – annotating the data with richer metadata (e.g., BioSchemas in the Directory), using persistent identifiers for them, improving existing and implementing new application programming interfaces to efficiently access the data (e.g., FAIR Data Points or GA4GH Beacon interfaces), as well as registering the data resources in external findability services such as FAIRSharing.

#### - Supporting BBMRI-ERIC Key Performance Indicator (KPI) measurements

Convergence of BBMRI-ERIC on defining the KPIs is one of the main goals for 2021, and IT services of BBMRI-ERIC are contributing to many of the anticipated or possible KPIs – from access-related KPIs to visibility of BBMRI-ERIC. Implementation of initial KPIs on the BBMRI-ERIC level started in 2019 and initial implementation of their automated retrieval has been implemented in 2020. As it is expected that KPIs will evolve in 2021, their implementation in IT tools will need to follow these developments. The Directory can be also used as an information service to publish performance indicators related to the biobanks.

#### - Increasing focus on improving interoperability

The core of CS IT has been fostering the MIABIS community over the past 5 years. In 2021 we aim to intensify collaboration with producers of various IT solutions and accelerate a vendor-neutral Interoperability Forum. Another goal is to increase involvement of the BBMRI-ERIC IT community in other global interoperability initiatives such as GA4GH, ISO and OHDSI, mostly supported from complementary project funding (EJP RD, EOSC-Life). Last but not least we will explore recent development in interoperability of AAI solutions – namely to use the eID mechanism (part of European EIDAS regulation) to get access to government-backed identities for purposes of authentication and authorization.

A substantial portion of the CS IT is about operations of the core services: from ensuring availability, security and trustworthiness of the services to reacting to user requests and feedback via the IT Helpdesk.

Responsible	Deliverable	Timing
Common Services - IT	<b>Directory</b> <ul style="list-style-type: none"> <li>• Manage operations &amp; data (incl. data quality analysis, documentation maintenance and API (Application Programming Interface) documentation development, and support of National Nodes by e.g. new integration and data updating problems)</li> <li>• Improve search and request experience               <ul style="list-style-type: none"> <li>– Pilot more detailed information using updated MIABIS CORE 3.0 component (including refined representation of biobank collections)</li> </ul> </li> <li>• Support evaluation/negotiation of the user needs for biobank services</li> <li>• Enable FAIR services (Persistent Identifiers, FAIR Data Point, BioSchemas)</li> </ul>	Q1-Q4
	<b>Negotiator</b> <ul style="list-style-type: none"> <li>• Support evaluation/negotiation of the user needs for biobank services</li> <li>• Enable flexible generation of request forms based on specifications of individual biobank required data structures</li> <li>• Support KPI generation once defined (see chapter 4.1.1)</li> <li>• Redesign user interface technology and backend</li> </ul>	Q1-Q4

## 2. Services and Tools

Responsible	Deliverable	Timing
Common Services - IT	<b>AAI provide single sign-on to BBMRI-ERIC services</b> <ul style="list-style-type: none"> <li>• Implement new authorization model (collections/ biobanks/networks)</li> <li>• Provide support for GA4GH Passports and Visas</li> <li>• Provide support for multi-factor authentication</li> <li>• Investigate eID integration</li> <li>• Migrate to LifeScience AAI (dependent on outcomes of EOSC-Life)</li> </ul>	Q1-Q4
	<b>Interoperability/MIABIS</b> <ul style="list-style-type: none"> <li>• Specify domain-specific data models extending the updated CORE component in cooperation with the respective OMICs and imaging communities:               <ul style="list-style-type: none"> <li>- Disease-specific models</li> <li>- Omics/Analysis</li> <li>- Continue with imaging module</li> <li>- Sample/Data quality</li> <li>- Consent/Use conditions</li> </ul> </li> <li>• Develop Interoperability Forum</li> </ul>	Q1-Q4
	<b>Helpdesk</b> <ul style="list-style-type: none"> <li>• Maintenance and operations</li> <li>• Support for KPI generation</li> </ul>	Q1-Q4
	<b>User experience (UX)</b> <ul style="list-style-type: none"> <li>• Create user characterisation: analyse and report on User Survey</li> <li>• Perform systematic reviewing for planning purposes: Review of Directory, Negotiator and AAI in collaboration with other WPs; regular and systematic user interface evaluation</li> <li>• Test new releases: Directory, Negotiator and AAI will be reviewed on demand before deployment</li> </ul>	Q1-Q4
Headquarters	<b>ADOPT BBMRI-ERIC data</b> <ul style="list-style-type: none"> <li>• Curate and host Colorectal Cancer Cohort (CRC-Cohort) for further use (see chapters 3.1.1 and 3.1.2)</li> </ul>	Q1-Q4



### 2.3.2. Complementary IT Development in Projects

The following table provides an overview of how the funded projects are aligned with the overarching IT developments and as such are integrated in core service developments. More information on the distinct project goals is provided in the Appendix. Please note that of all IT tasks, currently 30% are covered by BBMRI-ERIC core budget while 70% are based on grant funding.

Table: Interdependencies between core and project tasks and budget

		Findability	Accessibility	Interoperability	Reproducibility & Reuability	Infrastructure	Accessibility & Infrastructure	Reference tools for biobanks	Findability
		Directory	Negotiator	MIABIS	Provenance	Helpdesk	AAI	BIBBOX	Locator
CS IT 30% (4,3 FTE)	Tasks	Ops	Ops	Ops	-	Ops	Ops	-	-
		Dev	Dev	Dev	-	Dev	Dev	-	-
Projects 70%	EOSC-Life	(Dev)	Dev/Use	-	Dev	-	Dev	-	-
	EJP RD	(Dev)/Use	(Dev)/Use	Dev	-	-	-	-	Dev/Ops
	ConcePTION	Dev	Use	-	Use	Dev/Ops	-	-	-
	CY-Biobank	-	-	Use	Use	-	-	Dev/Ops	Ops
	CETOCOEN	-	-	Dev	Use	-	-	Dev/Ops	Ops
	and others to come								

Abbreviations: Ops = Operations; Dev = Development; FTE = Fulltime Employee

### 2.3.3. Establishing Task Forces with National Nodes by In-kind Contribution & Core Budget

The following task forces are of highest strategic importance for BBMRI-ERIC in order to facilitate access to samples and data of high quality in an accelerated form to serve our stakeholders sufficiently. Moreover, the task forces will complement each other and will secure BBMRI-ERIC's value proposition in accordance with, e.g., the European Open Science Cloud (EOSC) in particular and the EU Data Strategy overall.

#### TF on Federated Search

The Task Force will prepare and perform a procurement process for federated search system that allows an intuitive user-search on both sample-level and patient-/donor-level data distributed in the biobanks. The aim is to support search through deep phenotype, clinical and omics data and speed up the deployment process by allowing both commercial and non-commercial solutions to compete for implementation that would be

## 2. Services and Tools

operated by and branded by BBMRI-ERIC. The TF will explore possible models for supporting biobanks in populating the data into their local components of the federated system (called "Connectors" for simplicity); however, the process of populating the Connectors cannot be supported from the 2021 core budget.

There will be three primary use cases for this system in 2021 – enabling search through the data on (a) COVID-19 (partially supported from EOSC-Life thanks to the amendment providing additional resources for COVID-19 data activities), (b) various cancer types (supporting the European Mission on Cancer, building on the biobanks that demonstrated their readiness as a part of the CRC-Cohort building process), and (c) rare diseases (partially supported through the involvement of BBMRI-ERIC in the project EJP RD). Across these three use cases, the TF will advise on sample and data integration into the federated search system to those biobanks that are locally well situated to connect in terms of technical and regulatory aspects. These activities will flow into defining the organizational and technical readiness levels for members of the federated BBMRI ecosystem; these efforts will be aligned with other ESFRI RIs (namely ELIXIR).

### **TF on Biobank Data Quality and Certification**

This TF will look into developing certification mechanisms for the biobanks on data collection and data preservation/curation in the biobanks and on data quality controlling done in the biobanks. The certified biobanks would have procedures and sustainable models for long-term data preservation and curation compatible with the FAIR and FAIR-Health principles. The data quality would be analysed to the best commonly accessible standards. Liaise with QM chapter 2.2.1. Again, this will also be integrated into the development of organizational and technical readiness levels (see above).

### **TF on Expedited Access Procedure for Samples & Data**

In parallel, one TF will explore concepts for accelerated sample & data delivery for requests from academia and industry to allow full use of the federated search system of biobanks. This will explore opportunities for applying more broadly the mechanisms developed in the ADOPT BBMRI-ERIC project as a part of the CRC-Cohort, where a simplified data access procedure has been designed: the access is realized via BBMRI-ERIC, allowing complexities of access to be handled internally within the RI, hence removing the burden from the requester.

### **2.3.4. Establishing Task Forces with National Nodes by In-kind Contributions TF on Data Pooling in BBMRI-ERIC**

Collecting data centrally within BBMRI-ERIC, following the foundations built as a part of the ADOPT BBMRI-ERIC project's CRC-Cohort, can be a major asset for BBMRI-ERIC to serve our stakeholders and the Life Science community overall. The integrated data sets can be quality checked with documented provenance, made compliant with FAIR and FAIR-Health principles and thus readily accessible for effective access to the researchers. The TF will define the requirements on data collection process (data format and exchange protocols), the construction of the central storage to be usable for the storage of data from different BBMRI-ERIC Member countries, and definition of processes for data modelling and validation, and streamlined data access conditions and regulations. If commercial systems are used for hosting the data, the TF will also look into licensing issues to allow BBMRI-ERIC to have the whole data system as a central asset. Based on the challenges identified when building the CRC-Cohort in terms of the costs of collecting and curating high-quality data with documented provenance for research purposes, the TF will also look into incentive schemes for building this ecosystem and into funding schemes to support its initial development.

#### **TF on Big Data Analysis**

Analysis of big data, from omics data to digital pathology and radiology, has become an essential task of the more advanced European biobanks, National Nodes and Expert Centres. The goal of this TF is to bring together the groups involved in this domain, share experiences, provide recommendations to the biobanks starting out with such analysis, and also to find synergies with project-related activities within the BBMRI-ERIC ecosystem (such as EOSC-Life).

### **2.3.5. Milestone and Key Performance Indicator by Headquarters\*\***

Milestone Q1/2021: FAIR & FAIR-Health services enabled in the Directory

Key Performance Indicator: Number of requests in the Negotiator  
(current in 2020 – prospect in 2021: 84 - 100)

\*\* To define and agree on BBMRI-ERIC's overarching KPIs for Headquarters and National Nodes in alignment with member states and EU expectations (ESFRI guidance) will be a specific task of the Work Programme 2021 (see 4.1.1).

# 3. Research & Education

BBMRI-ERIC’s considerable involvement in research projects not only proves the value of our infrastructure and expertise, it also allows us to substantially develop our services further. Thus, expanding our research activities while focusing on key aspects will allow BBMRI-ERIC to further excel. Research projects will utilize our infrastructure resources and allow success/impact stories to materialize.

Europe Biobank Week (EBW) in partnership with ESBB has become a renowned event providing education, promoting networks and building community identification. We will build on the experiences of the 2020 digital event format and seek the most appropriate way forward for 2021, whether digital, hybrid or – if possible – face-to-face. We will continue our successful events and explore additional exchange and community-building formats.

In addition, streamlining and consolidating our educational tasks into a BBMRI-ERIC overarching training and education programme will be conceptualized while we seek and promote exchange programmes within our BBMRI-ERIC community.

## 3.1.1 Research Engagement and Service Development

Responsible	Deliverable	Timing
Headquarters	<p><b>Foster research opportunities for National Nodes and biobanks</b></p> <ul style="list-style-type: none"> <li>• Determine Standard Operation Procedures (SOPs) for transparent and timely communications of calls</li> <li>• Obtain a matrix of expertise and available/affiliated experts per National Node to efficiently support building topic-specific consortia – for knowledge exchange and common grant applications</li> <li>• Develop grant application policies to guarantee BBMRI-ERIC’s Headquarter neutrality and to avoid conflicts of interest</li> <li>• Define publication policies for the different stakeholder groups (scientific, communication, etc.)</li> </ul>	Q1-Q4

Responsible	Deliverable	Timing
Headquarters	<b>Engage BBMRI-ERIC Expert Centres</b> <ul style="list-style-type: none"> <li>• Grow partnerships with existing ones and evaluate possibilities for new ones by               <ul style="list-style-type: none"> <li>– Defining strategies for common research engagements</li> </ul> </li> <li>• Identifying at least one common project per expert centre potentially serving as success/impact story for which funding should be commonly applied for or by in-kind contribution on both sides (Expert Centres, biobanks, National Nodes, Headquarters)</li> <li>• Promote Expert Centres' engagement in Stakeholder Forum (Patients, Industry, Scientific Societies)</li> </ul>	Q1-Q4
National Nodes, Assembly of Members	<b>In-Kind contribution for approval and activities</b> <ul style="list-style-type: none"> <li>• Review &amp; approve SOPs and policies where necessary</li> <li>• Engage with expert centres and/or topic-specific consortia for knowledge exchange or grant applications</li> </ul>	Q1-Q4

### 3.1.2 Research Focus on Disease Entities and Novel Technologies

Responsible	Deliverable	Timing
Headquarters	<b>Strategically focus activities on the following three disease areas:</b> <ul style="list-style-type: none"> <li>• <b>COVID-19</b> by identifying and promoting existing and prospective cohorts &amp; associated data globally and by facilitating their accessibility to develop novel tests and treatments</li> <li>• <b>Cancer</b> by promoting our health-care integrated biobanks as basis for any sample &amp; data related calls within the upcoming Mission for Cancer framework programme</li> <li>• <b>Rare Diseases</b> by proceeding with the tasks as agreed with EUROBIOBANK and further expand and promote our cohorts in and beyond currently funded projects</li> </ul>	Q1-Q4
	<b>Promote network activities utilizing novel technologies</b> <ul style="list-style-type: none"> <li>• <b>Genomics Medicine</b> to enable precision medicine particularly in cancer and rare diseases while contributing to the EU's 1+Million Genomes Initiative</li> <li>• <b>Proteomics/Metabolomics</b> to enable deep phenotyping for precision medicine (e.g., through liquid biopsies) and new avenues for sample quality assurance (e.g., through NMR spectroscopy)</li> </ul>	Q1-Q4
National Nodes	<b>In-kind contribution for engagement in research networks for</b> <ul style="list-style-type: none"> <li>• Knowledge exchange</li> <li>• Proof-of-principle projects</li> <li>• Grant applications</li> </ul>	Q1-Q4

### 3. Research & Education

#### 3.1.3 Exploring Further Educational Services

Responsible	Deliverable	Timing
Headquarters	<p><b>Continue and expand on educational and community building conferences and events with</b></p> <ul style="list-style-type: none"> <li>• <b>Europe Biobank Week (EBW)</b> in partnership with ESBB</li> <li>• The <b>International Biobank Conference Doha</b>, Qatar, as supporting partner</li> <li>• An <b>IT symposium</b> in line with the task forces on federated sample and data search/quality, and</li> <li>• Potentially other events alone or in collaboration (e.g. Global Biobank Week)</li> </ul>	Q1-Q4
	<p><b>Consolidate and expand current training activities by</b></p> <ul style="list-style-type: none"> <li>• Building on the existing training and education services</li> <li>• Conceptualizing and streamlining an BBMRI-ERIC overarching education &amp; training programme including activities of National Nodes voluntarily; e.g., by providing a BBMRI-ERIC annual training programme calendar on our website</li> </ul>	Q1-Q4
	<p><b>Promote network exchange activities between National Nodes, Expert Centres and biobanks</b></p> <ul style="list-style-type: none"> <li>• As COVID-19 travel restrictions allow</li> <li>• On graduate and post-graduate level</li> <li>• Short- or long-term</li> <li>• Fostered through EU exchange funding opportunities within the scope of training &amp; education or research projects</li> </ul>	Q1-Q4
National Nodes	<p><b>In-kind contribution for</b></p> <ul style="list-style-type: none"> <li>• Conference/event preparation</li> <li>• Facilitating exchanges/visit opportunities</li> </ul>	Q1-Q4

### **3.1.4. Complementary Research and Education Development in Projects**

Research and Education tasks outlined in this chapter are addressed across the Headquarters. Hence, no staff allocation in terms of full-time employee equivalents is given here, as this would overlap with those summarized in the other chapters. Together with the National Nodes, biobanks and Expert Centres we will promote and seek project funding particularly in the focus areas as outlined above.

### **3.1.5. Milestone and Key Performance Indicator by Headquarters\*\***

Milestone Q3/2021: Grant application and publication policies approved

Key Performance Indicator: Number of projects with Expert Centres initiated/facilitated  
(current in 2020 – prospect in 2021: 0 - 3)

\*\* To define and agree on BBMRI-ERIC's overarching KPIs for Headquarters and National Nodes in alignment with member states and EU expectations (ESFRI guidance) will be a specific task of the Work Programme 2021 (see 4.1.1).

# 4. Strategy and Partnerships Development

While ELSI, QM, and IT are BBMRI-ERIC's cornerstone services, BBMRI-ERIC's success depends on strong strategic alliances and trustworthy partnerships. Therefore, transparent and efficient communication lines and a common understanding of BBMRI's mission and vision are key to deliver the full potential of BBMRI.

BBMRI-ERIC's strategy shall adapt itself to a changing panorama, influenced by local, national and global factors, such as the sustainability of local biobanks, national research priorities, the new Framework Programme, the growing challenges to the sustainability and development of European research infrastructures, and global health threats like COVID-19.

Hence, we need to address BBMRI's strategy, involving both internal and external stakeholders, to refine what BBMRI can and should achieve in the future. This was also strongly emphasized by BBMRI-ERIC's Scientific & Ethical Advisory Board (SEAB), which shall continue to offer valuable strategic advice.

## 4.1.1 BBMRI-ERIC Internal Infrastructure and Strategy

Responsible	Deliverable	Timing
Headquarters	<b>Headquarter (HQ) internal infrastructure</b> <ul style="list-style-type: none"> <li>• Produce a strategic document for BBMRI for the next 5 years               <ul style="list-style-type: none"> <li>- Perform an internal retreat, including SWOT analyses</li> <li>- Perform a strategy retreat with the SEAB and SC informed by the internal retreat results</li> <li>- Present the results of the retreats to the MC and AoM for discussion</li> </ul> </li> </ul>	Q1-Q4 Q1-Q2
	<ul style="list-style-type: none"> <li>• Redefine Headquarter's internal organigram including responsibilities, communication and reporting lines inside the Headquarters and to the outside</li> </ul>	Q1
	<ul style="list-style-type: none"> <li>• Develop transparent standard operation procedures (SOPs) and policies on all major routine activities (e.g. travel) in line with the preparation of the envisioned quality management (ISO 9001:2015) setup (see also QM section)</li> </ul>	Q1-Q4
	<ul style="list-style-type: none"> <li>• Define BBMRI-ERIC overarching key performance indicators (KPIs) for Headquarters and National Nodes, in alignment with member states &amp; EU expectations (ESFRI guidance)</li> </ul>	Q2
	<b>Scientific &amp; Ethical Advisory Board (SEAB)</b> <ul style="list-style-type: none"> <li>• Keep the SEAB informed of BBMRI's activities (e.g. organigrams of Headquarters and BBMRI overall, SWOT results, key performance indicators, appraisal of BBMRI by stakeholders and beyond)</li> <li>• Prepare and conduct SEAB meeting at least twice in 2021 including the retreat and Work Programme 2022 guidance (if possible one face-to-face meeting)</li> </ul>	Q1-Q4



Responsible	Deliverable	Timing
Headquarters	<b>Steering Committee (SC)</b> <ul style="list-style-type: none"> <li>• Prepare and conduct monthly SC calls on a routine basis</li> <li>• Additional ad hoc SC calls if needed</li> </ul>	Q1-Q4
	<b>Management Committee (MC)</b> <ul style="list-style-type: none"> <li>• Prepare and conduct monthly MC calls on a routine basis</li> <li>• If possible, prepare and conduct two face-to-face meetings</li> <li>• Initiate presentation round of National Nodes; one per MC meeting to foster knowledge exchange and team building (or site visit if face-to-face meeting takes place)</li> <li>• Design strategy and develop QM-based documentation for the establishment of new National Nodes by using the momentum of the CY-Biobank project; this should help to ease and standardize support for new National Nodes in the future</li> <li>• Initiate <b>Task Force</b> on National Nodes operations &amp; sustainability               <ul style="list-style-type: none"> <li>– Collect challenges &amp; solutions for management of established National Nodes</li> <li>– Collect strategies/concepts for sustainability including the exploration of new and different funding opportunities (regional funds, foundations, etc)</li> <li>– Support new members (LT, BG) in establishing their National Node</li> </ul> </li> </ul>	
	<b>Assembly of Members (AoM)</b> <ul style="list-style-type: none"> <li>• Prepare &amp; conduct at least two AoM meetings of which one should preferentially be face-to-face               <ul style="list-style-type: none"> <li>– Organise meetings, minutes, etc</li> </ul> </li> <li>• Develop new membership models for non-EU countries and potentially adjust BBMRI-ERIC organigram</li> <li>• Update BBMRI's value proposition and new members' guidelines according to the new strategic document and tailor them to prospective members</li> </ul>	Q1-Q4
SEAB, SC, MC, AoM, National Nodes	<b>All</b> <ul style="list-style-type: none"> <li>• Review &amp; approve concepts and strategic documentation where necessary</li> </ul> <b>SEAB &amp; SC</b> <ul style="list-style-type: none"> <li>• Attend retreats and provide guidance on the strategy document</li> </ul> <b>National Nodes</b> <ul style="list-style-type: none"> <li>• In-kind contribution for participation in <b>Task Force</b> on National Node operations &amp; sustainability</li> </ul>	Q1-Q4

## 4. Strategy and Partnerships Development

### 4.1.2 BBMRI-ERIC Strategic Alliances and Partnerships Development

Responsible	Deliverable	Timing
Headquarters	<p><b>Stakeholder Forum</b></p> <ul style="list-style-type: none"> <li>• Continue to develop <b>Patients' pillar</b> by:               <ul style="list-style-type: none"> <li>- Organising two meetings (preferably one face-to-face meeting)</li> <li>- Identifying priorities of action for 2021</li> <li>- Defining at least one priority area of action and implement at least one initiative, in partnership with National Nodes</li> </ul> </li> <li>• Continue to develop the <b>Industry pillar</b> by:               <ul style="list-style-type: none"> <li>- Organising two meetings (preferentially one face-to-face meeting)</li> <li>- Identifying priorities of action</li> <li>- Defining at least one priority area of action and implement at least one initiative</li> </ul> </li> <li>• Initiate the <b>Scientific Societies pillar</b> by:               <ul style="list-style-type: none"> <li>- Identifying &amp; selecting societies of strategic importance to BBMRI</li> <li>- Initiating bilateral contacts, exchange on scope of collaboration and confirmation of interest (LoI)</li> <li>- Organising one kick-off meeting</li> </ul> </li> <li>• By involving the ELSI, QM and IT teams and National Nodes in all three pillar activities</li> </ul>	Q1-Q4
	<p><b>BBMRI membership &amp; observership growth</b></p> <ul style="list-style-type: none"> <li>• Attract new members within the EU by:               <ul style="list-style-type: none"> <li>- Identifying, contacting and leading negotiations with new BBMRI members</li> </ul> </li> <li>• Develop concepts for collaboration with countries outside the EU by:               <ul style="list-style-type: none"> <li>- Identifying, contacting and leading negotiations with new BBMRI members</li> <li>- Developing specific guidelines and concepts for candidates beyond the EU</li> </ul> </li> </ul>	Q1-Q4

Responsible	Deliverable	Timing
Headquarters	<p><b>Relationships with other RIs, EU &amp; international organisations</b></p> <ul style="list-style-type: none"> <li>• <b>EU institutions, ESFRI, ICRI, EMA, OECD, and other international organisations</b> <ul style="list-style-type: none"> <li>- Continue to increase BBMRI's visibility and influence at EU and global level</li> <li>- Keep raising awareness about BBMRI's value proposition</li> <li>- Continue to develop links and collaborations with international organisations</li> </ul> </li> <li>• <b>Alliance of Medical Research Infrastructures (AMRI)</b> <ul style="list-style-type: none"> <li>- Coordinate BBMRI's contribution to the Alliance</li> <li>- Drive and implement the Alliance strategic plan with EATRIS and ECRIN</li> </ul> </li> <li>• <b>Other RIs</b> <ul style="list-style-type: none"> <li>- Consolidate BBMRI's role within the Life Science Research Infrastructures (LS RIs) and within the broader research infrastructures' panorama (ERIC Forum, EOSC)</li> <li>- Identify and develop possible new partnerships with existing RIs and advanced communities</li> </ul> </li> <li>• <b>Analyse and plan the collaboration with key biobanking organizations (ESBB, ISBER, EuroBiobank, etc.)</b> <ul style="list-style-type: none"> <li>- Conduct a strategic workshop with ESBB to discuss plans for future collaboration besides EBW conference</li> </ul> </li> </ul>	Q1-Q4
	<p><b>Public Affairs</b></p> <ul style="list-style-type: none"> <li>• Position BBMRI within broader EU science policy decision makers <ul style="list-style-type: none"> <li>- Promote the role of BBMRI and National Nodes in delivering Horizon Europe, its Mission on Cancer and other large EU initiatives</li> <li>- Continue to develop the AMRI Public Affairs Team in partnership with EATRIS and ECRIN</li> </ul> </li> <li>• Monitor relevant stakeholders and policy files</li> <li>• Produce position papers, public consultation replies and other policy documents in collaboration with National Nodes, AMRI, and other stakeholders</li> </ul>	Q1-Q4
SC, AoM, National Nodes	<b>In-kind information/input on the different activities</b>	Q1-Q4

## 4. Strategy and Partnerships Development

### 4.1.3. Complementary Strategy & Partnerships Development in Projects

The following table provides an overview of how the funded projects are aligned with the overarching strategies and partnerships. More information on the distinct project goals is provided in the Appendix. Please note that of all tasks, currently 50% are covered by BBMRI-ERIC core budget while 50% are based on grant funding. This ratio will change by addition of 1 full time position covered by core budget. This additional position will also support tasks described in chapter 3.

Table: Interdependencies between core and project tasks and budget

		HQ internal infrastructure	Scientific & Ethical Advisory Board	BBMRI Governing Bodies	TF Operations & Sustainability	Stakeholders Forum	Membership	Relationship with RIs, Eu & intl. Organisations	Public Affairs
<b>Core</b> 50% (0,5 + 1 FTE)	<b>Tasks</b>	X	X	X	X	X	X	X	X
<b>Projects</b> 50%	ERIC Forum	-	-	-	-	-	X	X	X
	RI-VIS	-	-	-	-	-	X	X	X
	IC2PerMed	-	-	-	-	-	X	X	X
	SPIDIA	-	-	-	-	X	-	X	X
	CORBEL/EOSC-Life	X	-	-	-	-	-	X	X
	BIGPICTURE	-	X	-	-	-	-	X	X
	and others to come								

Abbreviations: FTE = Fulltime Employee

### 4.1.4. Milestone and Key Performance Indicator by Headquarters\*\*

Milestone Q2/2021: Headquarters, SC and SEAB retreats conducted and concluded

Key Performance Indicator: Number of Industry representatives in Stakeholder Forum  
Industry pillar (current in 2020 – prospect in 2021: 17 – 25)

\*\* To define and agree on BBMRI-ERIC's overarching KPIs for Headquarters and National Nodes in alignment with member states and EU expectations (ESFRI guidance) will be a specific task of the Work Programme 2021 (see 4.1.1).



# 5. Marketing & Communications

One of the goals of BBMRI-ERIC is to increase the visibility of European Biobanks in the Member States, which requires alignment between many actors in the biobank ecosystem. The current pandemic has demonstrated the importance of biobanking to research on treatments and vaccines. Thus, we have brought certain activities to light that are applicable to COVID-19 research – both from the Headquarters and our National Nodes and member biobanks. However, coronavirus is only one of 3 pillars we will focus on in 2021, along with cancer and rare diseases, as these are areas in which BBMRI-ERIC’s services for the biobanking community can make significant contributions.

## 5.1.1 Corporate Identity and Branding

To increase the recognizability of BBMRI-ERIC and the BBMRI National Nodes, we will work to create a consistent corporate identity. We will also ensure that our corporate identity is reflected in the homepages of the National Nodes (to be agreed upon on a case-by-case basis). A toolbox of logos, colour codes, presentation templates and document templates will be made available to all National Nodes for ease of use.

2020 saw the redesign of the ELSI Services & Research section of the BBMRI-ERIC website, and especially the functionality of the ELSI Knowledge Base. Visually, the ELSI section is now aligned with the previously redesigned Quality Management section; thus, a priority in 2021 will be to redesign the IT section of the website to be consistent visually while also improving the user experience based on feedback and changes made in 2020.

In addition, we will set up our website to support initiatives within the headquarters to create a robust training & education programme within the BBMRI community. A dedicated training page with easy-to-find entries will serve our users from our member and observer states and beyond.

Responsible	Deliverable	Timing
Headquarters	<b>Corporate Identity</b>	Q1-Q4
	<ul style="list-style-type: none"> <li>• Further develop corporate identity to ensure all communication channels and material, such as the website, logos, newsletter, letterhead, business cards, presentations, posters, booths, rollups, conference material, etc., feature a consistent design</li> <li>• Create toolbox for National Nodes of BBMRI-related communication resources (e.g., ppt templates)</li> </ul>	Q1-Q2
	<b>Web design</b>	Q3-Q4
	<ul style="list-style-type: none"> <li>• Design landing page for IT section of website to align with QM and ELSI</li> <li>• Conceptualize training section of BBMRI-ERIC website to support education &amp; training activities</li> </ul>	
National Nodes	<b>In-kind feedback/information</b>	Q1-Q4

### 5.1.2 Communications and Outreach

A set of activities will be initiated to manage and monitor all internal and external communications of BBMRI-ERIC to all stakeholders in order to help explain the mission, vision and added value in a cohesive way, aiming at creating a favourable point of view.

We will identify topics in which we can demonstrate BBMRI-ERIC's expertise, such as quality assurance of samples (QM) and incidental findings (ELSI).

In order to help our member biobanks, we will initiate a quarterly communications call with our National Nodes (to which they can send a dedicated communications staff member or any representative) to coordinate our communication and outreach efforts, as well as to better highlight the strengths of each of the National Nodes and their biobanks. The original intention of highlighting particular collections of member biobanks in 2020 was not followed through due to the shift in focus to National Nodes and members biobanks doing COVID-19 research.

Our growing list of COVID-19-, Cancer-, and Rare Disease-related activities will be promoted further in 2021.

A focus of our outreach efforts will also be the gathering of COVID-19-, cancer-, and rare disease-relevant collections on our Directory. In doing so we will not only promote the (re-) use of samples and data for vital research but also promote BBMRI-ERIC to other RIs and associations – and place the BBMRI Directory as the one-stop-shop for finding samples and data relevant to COVID-19, cancer, and rare diseases. Exploiting this awareness-raising will in turn help raise awareness of the other collections within our member biobanks.

Responsible	Deliverable	Timing
Headquarters	<b>Outreach</b>	Q1
	• Define key messages for BBMRI-ERIC and articulate messages for all BBMRI activities	
	• Develop website and perform outreach activities for EU-funded projects in which BBMRI-ERIC is leading or co-leading the outreach WP, as well as for other collaborations (e.g. AMRI)	Q1-Q4
	• Continue to develop internal and external communications of the Life Science RI group, including the website	Q1-Q4
	• Continually improve social media network: Twitter, LinkedIn via social media management account with an emphasis on added followers beyond the RI community	Q1-Q4
	• Restructure monthly newsletter to better meet needs of National Nodes	Q1-Q2
	<b>Reporting</b>	Q1-Q2
	• Prepare Annual Report to better reflect the needs of the National Nodes	
Headquarters & National Nodes	<b>Dissemination Plan</b>	Q1-Q4
	• Coordinate with National Nodes to create a campaign targeting both biobanks and researchers, featuring Biobank/Collection of the Month, featured in newsletter and social media.	
	• Plan quarterly communications calls between Headquarters and National Nodes	Q1-Q4

## 5. Marketing & Communications

### 5.1.3 Marketing & Market Research

Communication, branding and environment research are instrumental in marketing the developed services that are offered by BBMRI-ERIC to the National Nodes. This shall truly increase the visibility and valorisation of their biobanks and samples. Special focus in 2021 will be on COVID-19, cancer, and rare diseases and related success/impact stories as a hook to gain interest in further biobanking services. Our standard message on sample access will be reinforced, combined with specific aspects of the Directory, ELSI Knowledge Base and QM activities in order to promote their use.

Working with the National Nodes, we will follow up on samples and data used for research projects in order to highlight academic publications resulting from samples/data provided by our network, and to write Impact/Success Stories based on research outcomes. These will demonstrate the added value of using samples/data within the BBMRI-ERIC network and serve to further promote our community.

Responsible	Deliverable	Timing
Headquarters	<b>Marketing</b> <ul style="list-style-type: none"> <li>Coordinate the continuous marketing of materials we have produced that remain relevant (webinar recordings, published materials, videos, etc.)</li> </ul>	Q1-Q4
	<b>Market Research</b> <ul style="list-style-type: none"> <li>Conceptualize an overarching marketing strategy to be evaluated for execution in 2022</li> </ul>	Q3-Q4
Headquarters & National Nodes	<b>Marketing</b> <ul style="list-style-type: none"> <li>Write Success/Impact Stories and publicize academic publications on use of samples and data (or by biobank per se)</li> </ul>	Q1-Q4

### 5.1.4 Public Relations

In addition to the internally developed material, our regular media channels will also be used to get the overall message across. Press releases to media and posts on social media/blogs can support the communication with stakeholders and the general public in an effective way with relatively low investment. Central themes will be biobanking for COVID-19 research, mission for cancer, rare diseases, biobanking in general, GDPR, personalised medicine, etc. Here it is important to measure the effectiveness of press releases (where possible) and posts on a monthly basis.

Responsible	Deliverable	Timing
Headquarters	<b>Public Relations</b> <ul style="list-style-type: none"> <li>Liaise with Strategy &amp; Partnership Manager to produce content (social media post, newsletter, press releases, position papers, etc.) to highlight key challenges and increase visibility.</li> </ul>	Q1-Q4
	<ul style="list-style-type: none"> <li>Provide monthly measurements: social media, website, press where needed.</li> </ul>	Q1-Q4



### 5.1.5 Events and Promotions

The coronavirus pandemic drastically changed BBMRI-ERIC's approach to face-to-face meetings and events. Though we continue to value face-to-face contact to discuss and present the added value a Research Infrastructure can bring and its scientific achievements, it is essential that we seize online opportunities to promote the activities of the Headquarters and National Nodes. Resources previously used for travel to conferences and meetings will be reallocated to virtual events (webinars, online workshops, etc.) and online promotional opportunities (virtual poster sessions, virtual conference booths, etc.). Investments will be made in creating video content for use at virtual events and for general social media promotion, e.g., demonstrations of the Negotiator, summaries of ELSI-related research findings, or facility tours.

We will follow up on the successful online organization of Europe Biobank Week with outreach to participants and decide in light of the pandemic whether to continue in an online format in 2021.

Trainings (online for the time being) will be another focus of our events promotion – including the major QM training and upcoming ELSI and IT trainings.

The number of registrants, their background information and feedback scores will be measured per event/training and combined to analyse trends.

Responsible	Deliverable	Timing
Headquarters	<b>Events</b> <ul style="list-style-type: none"> <li>• Execute Europe Biobank Week 2021</li> <li>• Collaborate on events organised by/with other biobanking associations/National Nodes</li> <li>• Support other teams with (online) trainings</li> <li>• Execute IT Symposium together with in-kind contributions by National Nodes/CS IT</li> </ul>	Q3-Q4
National Nodes	<b>Events</b> <ul style="list-style-type: none"> <li>• Collaborate on the Europe Biobank Week with programme and booths</li> <li>• Open biobanks for stakeholders to visit</li> </ul> <b>Promotional Videos</b> <ul style="list-style-type: none"> <li>• Create video content together to highlight biobanks and the portfolio that National Nodes offer</li> </ul>	Q1-Q4  Q1-Q4

## 5. Marketing & Communications

### 5.1.6. Complementary Marketing and Communications Development in Projects

The following table provides an overview of how the funded projects are aligned with the overarching marketing, communications and event activities and as such are integrated in headquarter core services. More information on the distinct project goals is provided in the Appendix. Please note that of all MARCOM tasks, currently 38% are covered by BBMRI-ERIC core budget while 62% are based on grant funding.

Table: Interdependencies between core and project tasks and budget

		Manage website, social media	Outreach activities	Newsletter	Marketing	Produce PR content	Support trainings & events (e.g., EBW)
<b>Core</b> 38% (1,3 FTE)	<b>Tasks</b>	Coor	Coor	Coor	Coor	Coor	Coor
		Ops	Ops	Ops	Ops	Ops	Ops
		Dev	Dev	Dev	Dev	Dev	Dev
<b>Projects</b> 62%	RI-VIS	-	Coor/Ops /Dev	-	Ops	-	Coor/Ops /Dev
	EOSC-Life	Coor/Ops /Dev	Coor/Ops /Dev	Coor/Ops /Dev	Coor/Ops /Dev	Coor/Ops /Dev-	Dev
	ERIC Forum	-	Coor	-	Ops	-	Coor/Dev
	CY-Biobank	-	Dev	-	-	-	Coor/Dev
	EUCAN-Connect	-	Dev	-	-	-	-
	euCanSHare	-	Ops	-	-	Dev	-
	EJP RD	-	Ops	-	-	-	Coor/Ops /Dev
	CETOCOEN II	-	Ops	-	-	-	-
	euCanImage	-	-	-	-	-	-
	CINECA	-	Ops	-	-	-	Dev
	and others to come	-	-	-	-	-	-

Abbreviations: Coor = Coordination; Ops = Operations; Dev = Development; FTE = Fulltime Employee

Beyond tasks and deliverables clearly described in EU projects' grant agreements, we are also involved in daily basic outreach and dissemination actions for each single project granted by the European Commission.

#### **5.1.7. Milestone and Key Performance Indicator by Headquarters\*\***

Milestone Q2/2021: Landing page for IT on website active

Key Performance Indicator: Number of success/impact stories published  
(current in 2020 – prospect in 2021: 0 - 3)

\*\* To define and agree on BBMRI-ERIC's overarching KPIs for Headquarters and National Nodes in alignment with member states and EU expectations (ESFRI guidance) will be a specific task of the Work Programme 2021 (see 4.1.1).

## 6. Funding

While COVID-19 brought on many challenges, there are also significant financial implications, some of which are already felt throughout the biobanking community and some are yet to come. Moving a large number of tasks and activities online has also prompted us to reassess our expenses and redistribute resources to new ways of communication, new tools and platforms and new ways of supporting the community, whether through digital knowledge bases, virtual workshops, webinars and meetings, IT tools or online networks of expertise and support.

To fulfil its commitments and deliver all the activities as described in this work programme, BBMRI-ERIC relies on the yearly contributions of its members and observers. In addition, BBMRI-ERIC also relies on other income generated from the annual conference Europe Biobank Week, small amounts of income generated from the delivery of services and subcontracting office space and the host country contribution of Austria.

The 2021 core budget was created with the sole purpose of ensuring the successful implementation of this work programme. The expenses and income we forecast for the year to come are presented below.

### 6.1 Expenses

#### Operational costs

Operational costs	2021	2022	2023
Rent, maintenance, equipment, consumables	181.000,00	181.250,00	195.500,00
Consulting, subcontracting, legal advice	111.000,00	113.000,00	115.000,00
Annual conference (EBW)	200.000,00	400.000,00	400.000,00
Business trips and meetings	39.500,00	69.000,00	69.000,00
Federated search IT software	60.000,00	60.000,00	60.000,00
total:	<b>591.500,00</b>	<b>823.250,00</b>	<b>839.500,00</b>

### Staff costs

In addition to the full-time employees (FTE) specified in chapters 2 to 5 of this Work Programme, five additional positions in the central office are covered by the core budget: 0,6 FTE office administration, 1,45 FTE IT administration, 1,8 FTE finances, 0,6 FTE Director General. The central office oversees/supports currently all together 29 employees working either full- or part-time based on core and/or project budget.

<b>Staff costs (4,5 FTE) brutto-brutto costs</b>	<b>2021</b>	<b>2022</b>	<b>2023</b>
Salaries, social security contributions, insurances	<b>436.731,45</b>	<b>444.155,89</b>	<b>451.262,38</b>

### Services

<b>Services (incl. Personnel and development costs)</b>	<b>2021</b>	<b>2022</b>	<b>2023</b>
QM (including 1,85 FTE)	193.828,07	197.123,15	200.277,12
ELSI (including 2,25 FTE)	317.342,20	317.217,01	317.904,49
CS IT (including 4,3 FTE)	409.932,11	412.902,00	419.508,43
SHF and Public Affairs (including 1,5 FTE)	174.057,00	176.794,97	181.415,69
Marketing and Communications (including 1,3 FTE)	155.605,00	162.964,94	165.332,37
total:	<b>1.250.764,38</b>	<b>1.267.002,07</b>	<b>1.284.438,10</b>

## 6. Funding

### 6.2 Income

Membership contributions	2021	2022	2023
Austria	68.361,14	69.528,97	70.874,25
Belgium	76.768,44	78.162,71	79.768,82
Bulgaria	31.349,03	31.520,03	31.717,01
Cyprus	6.711,10	6.730,25	6.752,32
Czech Republic	48.619,22	49.255,35	49.988,13
Estonia	22.925,60	23.004,40	23.095,17
Finland	51.292,24	52.000,36	52.816,07
Lithuania	7.531,75	7.573,01	7.620,53
Germany	402.974,75	413.154,67	424.881,29
Greece	45.743,36	46.302,04	46.945,60
Italy	223.667,02	229.017,68	235.181,30
Latvia	23.241,88	23.329,19	23.429,77
Malta	21.408,91	21.446,85	21.490,57
Netherlands	112.210,44	114.559,26	117.264,96
Norway	65.613,10	66.706,92	67.966,94
Poland	81.100,42	82.611,36	84.351,87
Sweden	78.507,82	79.948,93	81.609,01
Switzerland	28.086,67	28.641,13	29.279,83
United Kingdom	299.579,28	306.974,47	315.493,26
Turkey	31.140,66	31.777,37	32.510,82
IARC	6.000,00	6.000,00	6.000,00
total	1.732.832,83	1.768.244,96	1.809.037,48
Host country contribution	100.000,00	100.000,00	100.000,00
Other earnings (including EBW):	296.163,00	466.163,00	466.163,00
EU projects overheads	150.000,00	200.000,00	200.000,00
Total other income:	546.163,00	766.163,00	766.163,00
	2021	2022	2023
<b>Total income:</b>	<b>2.278.995,83</b>	<b>2.534.407,96</b>	<b>2.575.200,48</b>



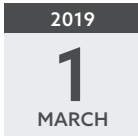
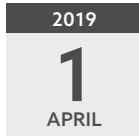




# 7. Appendix

Table: BBMRI-ERIC's European projects involvement in 2021

<b>SPIDIA4P</b>	<b>CLINIMARK</b>	<b>EDIREX</b>	<b>EOSC-Hub</b>
BBMRI-ERIC Budget* <b>€ 100.673,75</b>	BBMRI-ERIC Budget -	BBMRI-ERIC Budget <b>€ 70.558,75</b>	BBMRI-ERIC Budget <b>€ 25.625,00</b>
Start Date <b>2017</b> <b>1</b> JANUARY	Start Date <b>2017</b> <b>14</b> MARCH	Start Date <b>2018</b> <b>1</b> FEBRUARY	Start Date <b>2018</b> <b>1</b> FEBRUARY
To generate and implement a comprehensive portfolio of 22 pan-European pre-analytical CEN/TS and ISO/IS, addressing the important pre-analytical workflows applied to personalized medicine.	Experts contributing to the establishment of best biomarker practices, networking	Development of Levels of Assurance for authentication suitable for biomedical research applications	Development of policies for sensitive human data to be hosted or processed in the European Open Science Cloud
<b>euCanSHare</b>	<b>CINECA</b>	<b>EJP RD</b>	<b>ERIC Forum</b>
BBMRI-ERIC Budget* <b>€ 104.675,00</b>	BBMRI-ERIC Budget <b>€ 314.682,50</b>	BBMRI-ERIC Budget* <b>€ 1.620.071,26</b>	BBMRI-ERIC Budget <b>€ 181.250,00</b>
Start Date <b>2018</b> <b>1</b> DECEMBER	Start Date <b>2019</b> <b>1</b> JANUARY	Start Date <b>2019</b> <b>1</b> JANUARY	Start Date <b>2019</b> <b>1</b> JANUARY
An EU-Canada joint infrastructure for next-generation multi-Study Heart research	International flagship collaboration with Canada and Africa for human data storage, integration and sharing to enable personalised medicine approaches	European Joint Programme on Rare Diseases creates a comprehensive, sustainable ecosystem allowing a virtuous circle between research, care and medical innovation	Policy and international cooperation measures for research infrastructures

\*Budget figure includes funding for BBMRI-ERIC headquarters and linked third parties

## 7. Appendix

<b>EUCAN-Connect</b>	<b>RI-VIS</b>	<b>EOSC-Life</b>	<b>ConcePTION</b>
BBMRI-ERIC Budget <b>€ 399.326,25</b>	BBMRI-ERIC Budget <b>€ 248.500,00</b>	BBMRI-ERIC Budget* <b>€ 1.961.488,75</b>	BBMRI-ERIC Budget* <b>€ 328.420,00</b>
Start Date 	Start Date 	Start Date 	Start Date 
A federated FAIR platform enabling large-scale analysis of high-value cohort data connecting Europe and Canada in personalized health	Expanding research infrastructure visibility to strengthen strategic partnerships	Providing an open collaborative space for digital biology in Europe	Building an ecosystem for better monitoring and communicating of medication safety in pregnancy and breastfeeding: validated and regulatory endorsed workflows for fast, optimised evidence generation
<b>CY-Biobank</b>	<b>CETOCOEN II</b>	<b>Diamonds</b>	<b>IC2PerMed</b>
BBMRI-ERIC Budget <b>€ 1.285.815,00</b>	BBMRI-ERIC Budget* <b>€ 600.000,00</b>	BBMRI-ERIC Budget* <b>€ 130.000,00</b>	BBMRI-ERIC Budget* <b>€ 219.687,50</b>
Start Date 	Start Date 	Start Date 	Start Date 
Center of Excellence in Biobanking and Biomedical Research and the Cyprus human genome project: Expanding research infrastructure visibility to strengthen strategic partnerships	Establishing the European Centre of Excellence in Environmental Health Sciences	To bring personalised medicine into routine use in EU healthcare systems for diagnosis and treatment of common infectious and inflammatory diseases	Integrating China in the International Consortium for Personalised Medicine






<b>EuCanImage</b>	<b>B1MG</b>	<b>BigPicture</b>	
BBMRI-ERIC Budget** <b>€ 310.425,00</b>	BBMRI-ERIC Budget* <b>€ 157.190,13</b>	BBMRI-ERIC Budget* <b>€ 380.000,00</b>	
Start Date <div style="text-align: center;"> <div style="background-color: #333; color: white; padding: 2px;">2020</div> <div style="font-size: 2em; font-weight: bold; margin: 5px 0;">1</div> <div style="text-align: center;">OCTOBER</div> </div>	Start Date <div style="text-align: center;"> <div style="background-color: #333; color: white; padding: 2px;">2020</div> <div style="font-size: 2em; font-weight: bold; margin: 5px 0;">1</div> <div style="text-align: center;">JUNE</div> </div>	Start Date <div style="text-align: center;"> <div style="background-color: #333; color: white; padding: 2px;">2021</div> <div style="font-size: 2em; font-weight: bold; margin: 5px 0;">1</div> <div style="text-align: center;">FEBRUARY</div> </div>	
Building a secure and federated imaging platform for next-generation artificial intelligence in oncology	Towards access to at least 1 million sequenced genomes in the EU by 2022	Central repository of digital pathology slides to support the development of artificial intelligence tools	

\* Budget figure includes funding for BBMRI-ERIC headquarters and linked third parties

\*\* Budget figure doesn't include linked third parties



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