ADOPT BBMRI-ERIC
GRANT AGREEMENT NO. 676550

DELIVERABLE REPORT

Deliverable no	2.3
Deliverable Title	List of data, services technologies/technologic platforms for each Country
Contractual delivery month	M9
Responsible Partner	BBMRI.it/UNIMIB
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TITLE

List of data, services technologies/technologic platforms for each Country

Executive Summary

To establish what each National Node can offer in terms of samples and data and to acquire information about services and specific technologies/technological platforms at each National Node is essential in fulfill the ambition of BBMRI-ERIC to implement a world leading Research Infrastructure for biomedical research in Europe.

Validated accessibility of samples and data to address needs of precision medicine in colorectal cancer with the collection of 10 000 datasets from multiple biobanks is one of the major goal of ADOPT. The survey among the Nodes to select the biobanks that handle colorectal cancer samples has been performed and a list of qualified EU biobanks have been established. As second step, all National Nodes and the Biobanks who have already expressed their interest to become part of the European wide colon cancer (CRC) cohort, have been contacted and invited to partake the pilot phase of the CRC collection. A Data Protection Policy document containing the objectives of the CRC cohort, its legal framework and basic organizational aspects was developed. A list of biobanks contributing to the CRC collection with over 11 000 datasets has been established. A survey of the omics technology platforms (for genomics, transcriptomics, metabolomics and proteomics) in BBMRI-ERIC Member States has been performed and a list of relevant technology platforms has been established.

Background

The ambition of BBMRI-ERIC is to implement a world leading Research Infrastructure for biomedical research in Europe – a true gateway for health. A close collaboration between researchers, biobankers, patient advocacy groups, and the biotech and pharma industry is essential in addressing both common and rare diseases as well as societal concerns. Keeping in mind the need for better prevention, diagnostics, and therapy for all, we are aware that every single sample and its associated data impacts our ability to comprehend disease and, thus, achieve our goal for a healthier life. Well-characterised human samples and associated data are indeed unique resources for identification of new molecular features to be used as diagnostic and/or therapeutic targets.

Validated accessibility of samples and data to address needs of precision medicine in colorectal cancer is the goal of WP2. The collection of 10 000 datasets from multiple biobanks is one of the major tasks of ADOPT. The aim is to enable the existing, well-established biobanks in Europe to connect with BBMRI-ERIC to provide data sets and, later on, samples for future research use. The data sets are gathered, anonymized, and made available centrally for the research community to query and identify their specific research questions in colorectal cancer.

We collaborated with the BBMRI-ERIC National Nodes to establish what each National Node can offer in terms of samples and data and to acquire information about services and specific technologies/-omics technological platforms in BBMRI-ERIC Member States.

A list of 60 qualified EU biobanks was established (D2.2). The dataset for data associated with colorectal cancer samples was defined by an interdisciplinary group including biobankers, clinicians, disease registry experts, researchers, IT experts (D2.4).

For biobanks it is essential to know those technology platforms that are able to return quality defined analysis data back to biobanks. With the help of the National Nodes, we produced a survey of the omics technology platforms (for genomics, transcriptomics, metabolomics and proteomics) in BBMRI-ERIC Member States.

Approaches (Methods)

The task to establish what each National Node will precisely offer in terms of samples and data was performed in collaboration with WP3. The list of qualified EU biobanks was established in M8 consisting of 60 relevant biobanks in Europe (D2.2). Biobanks included in the list were the ones willing to collaborate in the context of ADOPT project at that moment but the mapping of biobanks is updated continuously throughout the project. A second wave of mapping the biobanks for the colorectal cancer collection have been performed and an updated list of qualified EU biobanks was established (**Appendix I**). The preparation work consisted of drafting and sending a letter to the biobanks with detailed information of process and writing a Data Protection Policy (DPP) while simultaneously maintaining the open discussion line with the biobanks. In March 2017, the letter (**Appendix II**) was sent to 76 different

biobanks in 17 countries: Austria, Belgium, Czech Republic, Cyprus, Estonia, Finland, France, Germany, Italy, Malta, the Netherlands, Norway, Sweden, Switzerland, Poland, Turkey and UK. The purpose was to inform the biobanks of the next steps, to collect the information on the availability and format of the data and therefore also to ensure the biobanks abilities to fulfil the inclusion criteria.

Based on the availability of the data and the feedback from the biobanks, the biobanks were divided into three groups resting on their method of participation: manual collection of data sets, semi-automated collection of datasets and automated data collection. For each group, a 2nd letter was prepared and sent in July 2017 informing them of the next steps together with a Data Protection Policy document (**Appendix III**), which was a major collaborative effort driven by WP2 and WP3. It gathers the objectives of the CRC cohort, its legal framework and basic organizational aspects. It describes the data collection and integration process, together with measures for quality checking and assurance. Access modes for the data set are also discussed and an overview of tools on which the implementation of the CRC-Cohort relies is provided. More in-depth discussion of combination of technical and organizational measures to ensure data security and protect privacy of the persons contributing their data to CRC-Cohort is included with any other relevant BBMRI-ERIC documents.

Systematic teleconferences were initiated in August with the biobanks interviewing them one by one on their legal and ethical landscape in terms of the collection, the data items in detail and timelines in general.

The task to acquire information about services and specific technologies/technological platforms at each National Node was performed together with WP6.

The planning of the work was initiated in autumn 2016 in collaboration with WP6. A core working group consisting of National Node directors from BBMRI.it, BBMRI.fr, BBMRI.fi, BBMRI.at and BBMRI.nl was established and teleconferences between the core working group were organized. Four questionnaires (see D6.4) were planned in collaboration with ADOPT BBMRI-ERIC WP6 in spring 2017. The questionnaires were sent to the directors of BBMRI National Nodes in July 2017 with a cover letter, where they were asked to circulate the questionnaires to all relevant technology platforms in their country. The answers were received between July and September 2017. In October the questionnaire was sent a second time and the answers were received in November 2017.

Results

83 qualified biobanks were interviewed on the availability of data, the results are summarized in **Appendix IV**: 30 biobanks' (from 12 countries: Austria, Belgium, Cyprus, Czech Republic, Finland Germany, Italy, Malta, Poland, Sweden, Switzerland, UK) involvement was verified together contributing to the CRC collection with over 11 000 datasets (**Appendix V**).

We received answers from 13 National Nodes about services and specific technologies/technological platforms:

1. Austria (1 facility)
2. Estonia (1 facility)
3. Finland (4 facilities)
4. France (16 facilities)
5. Germany (2 facilities)
6. Italy (18 facilities)
7. Latvia (1 facility)

8. Malta (1 facility)
9. Netherlands (7 facilities)
10. Norway (2 facilities)
11. Poland (1 facility)
12. Sweden (5 facilities)
13. Turkey (1 facility)

In total we received 60 answers to the 4 questionnaires.
We received
- 22 answers to the genomics-questionnaire,
- 14 to the transcriptomics-questionnaire,
- 7 answers to the metabolomics-questionnaire
- 17 answers to the proteomics-questionnaire

The list of services/specific technologies/technological platforms can be found in Appendix VI.

Discussion and Conclusions

To establish what each National Node can offer in terms of samples and data and to acquire information about services and specific technologies/technological platforms at each National Node is essential in fulfill the ambition of BBMRI-ERIC to implement a world leading Research Infrastructure for biomedical research in Europe.
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The aim of the survey on platforms/services available for biobanks and researchers was to produce a list of facilities providing -omics technologies. The current results of the -omics survey can support the biobankers and researchers to find -omics technology platforms that have open access, operate under defined quality conditions and have been utilized to analyze high quality samples of BBMRI-ERIC biobanks or researchers utilizing biobank samples.

Next Steps

The effort of forming a cohort with existing 10,000 colorectal cancer cases with detailed pathological and clinical data and available tissue samples should demonstrate the feasibility of large scale collaboration within BBMRI-ERIC and generate a yet unprecedented resource for medical research.

It would be important to identify a BBMRI-ERIC National node that would have interest in hosting the database of the omics technology platforms.

Appendices

Appendix I: CRC-biobanks list

Appendix II: BBs Information Letter

Appendix III: CRC-Data-Protection Policy

Appendix IV: Interview results of qualified Biobanks_Countries

Appendix V: Dataset_Qualified Biobanks_Countries

Appendix VI: List of Technological platforms_Services