



ANNUAL REPORT 2016

BBMRI TURKEY

About:

Turkey has an observer status of BBMRI-ERIC. The national node BBMRI.tr is Dokuz Eylul University, this was established in 2014 with a joint protocol by the Ministry of Development and Dokuz Eylul University. In 2015, BBMRI-ERIC.tr became a partner in the ADOPT BBMRI-ERIC proposal that aims boosting and accelerating implementation of BBMRI-ERIC and its services. Dokuz Eylul University, Izmir International Biomedicine and Research Institute (iBG-izmir) is coordinator and Hacettepe University Center for Biobanking and Genomics (HUBİGEM) and Istanbul University (Institute of Experimental Medicine (DETAE) H. Behcet Life Science Center Biobank Facility are partners of the ADOPT BBMRI.ERIC project.

BBMRI-ERIC.tr has five main goals:

1. Play an advisory role in the establishment of biobanks in Turkey to create a harmonized and efficient biobanking infrastructure,
2. Increase awareness of biobanking among the public as well as the scientific community,
3. Create a coordination structure among biobanks,
4. Harmonizing the ethical and legal guidelines,
5. Sharing best practices acquired from BBMRI-ERIC and disseminating the knowledge in national biobanks, while contributing to the pan-European research infrastructure BBMRI-ERIC.

To achieve these aims BBMRI-ERIC .tr focuses on:

- 1- Harmonization and dissemination-of standard operating procedures (SOPs) for the collection, storage, quality control and access procedures to biological material and related data among biobanks,
- 2- Coordination of funding of an IT infrastructure for interoperability between biobanks for the use of patient registries and clinical data,
- 3- Organization of training activities to quality assurance of biobanks and registries and,
- 4- Educational activities to enhance awareness of biobanking to the general public, policymakers, and health-care providers.
- 5- Increase awareness of decision makers to develop tools to ensure sustainability of biobanks.

Web: <http://bbmri.ibg.edu.tr/>

National Node Director: Nese Atabey

Staff: 1,5 FTE/year

Partners:

- University Center for Biobanking and Genomics (HUBİGEM), Hacettepe, University, Ankara, TR
- Institute of Experimental Medicine (DETAE), H. Behcet Life Science Center Biobank Facility, Istanbul University, Istanbul.
- Izmir International Biomedicine and Research Institute (iBG-izmir), Dokuz Eylul University, Izmir.
- Medical Schools of Hacettepe University, Istanbul University and Dokuz Eylul University.
- Dokuz Eylul Technology Development Zone (DEPARK), Izmir.
- Istanbul Development Agency
- Ministry of Development
- The Scientific and Technological Research Council of Turkey (TUBITAK)
- Turkish Health Institutions (TÜSEB)

National Roadmap:

The National Roadmap of Research Infrastructures is currently under preparation. The ERIC regulation is also under preparation to facilitate multinational partnerships. In 2014, steps were taken at the national level to strengthen large-scale research infrastructures in Turkey. TUBITAK (Turkish Scientific and Technical Research Council) and the Ministry of Development are responsible for the regulatory processes regarding large-scale research infrastructures.

Turkey's research infrastructure development in its Tenth Development Plan (2014–2018) prioritizes nanotechnology, biotechnology, nuclear technologies, material sciences and environmental technologies. The 10th Development Plan foresees to increase the rate of R&D expenditures from 0.98% to 1.8% GDP by 2018. In addition, Turkish Health Institutions (TÜSEB) initiated The National Genome Project and support for disease/hospital based biobank infrastructures and establishment of a Population Biobank.

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BBMRI-ERIC.tr road maps includes:

- To map Turkish Biobanks in terms of quality levels by a self-assessment questionnaire.
- To encourage Turkish Biobanks to become member of BBMR-ERIC.tr.
- To improve BBMR-ERIC.tr web page (by creating interactive e-learning tools, information desk for common services and ongoing research projects etc.).
- To motivate creation of a Turkish National Biobanking Network.
- To support harmonization and standardization of SOPs.
- To stimulate involvement of stakeholders to BBMR-ERIC.tr structure.
- To organize hands on training courses for biobankers.
- To support certification and accreditation programs.

Even though structural funds are limited due to Turkey not being a full member; talks are in progress to increase the usage of PreAccession Funds (IPA) for ESFRI projects. Turkey is committed to the BBMRI-ERIC project as an observer for the three years. It is believed that this will be followed by a full membership commitment

Specific strength:

- Hacettepe Rare Disease Biobank is already a member of the EuroBioBank network since 2014.
- There is an increasing public awareness and support for biobanks
- Ministry of Health and UNESCO Bioethics Committee have initiated an ethical reflection on biobanking in collaboration with the BBMRI-ERIC.tr national node and some local ethics committee members .
- Turkey is a partner in some other ESFRI projects (ECRIN, ELIXIR, EUROBIOIMAGING, INFRAFRONTIER).

Contribution to the joint efforts:

- **E-Infrastructure**

The inventory of existing biobanks in Turkey is collected. We have also studied the proposed standards on BBMRI-ERIC consortium and decided on the necessary infrastructure and personnel to carry out the project. We applied for funding from the Ministry of Development to fund this project.

Quality

Standart Operating Procedures (SOPs) based on OECD Guidelines, ISBER Recommendations and EuroBiobank have been followed by existing Biobanks. A workshop is organized to harmonize SOPs and to train biobankers on QMS systems in biobanks. The “SOPs and Quality in Biobanks” workshop will be held in April 6th, 2016.

Clinical Biobanks

We have been collecting the inventory of available clinical biobanks in Turkey.

- **Population-based Cohorts**

We are conducting follow up studies on sub-samples of the BHS (Balçova Heart Study) Cohort. These follow up studies include development of diabetes on the population with impaired glucose and a nested case control study of vit D and cancer. Additionally we are collaborating with the Greifswald Univ SHIP cohort, we held the first meeting in Germany in Jan 2015 and the second in Turkey in Sept 2015 to plan further Activities. We also joined the European Cohort Consortium which will apply to the call in Horizon 2020.

- **ELSI**

We organized a joint workshop with national stakeholders for standardization of informed consents forms and Ethical-Legal guidelines of biobanks, and a position paper is prepared. A workshop is organized to standardization of Biobanks informed consents and to train biobankers on Ethical and Legal issues. The “SOPs and Quality in Biobanks” workshop will be held in April 7th, 2016, in Istanbul.

- **Education & Training**
 - Curriculum proposal: ethics and biobanking as a topic at graduate level courses in medical schools and life science programs.
 - Two research courses called as “special study modules (SSM)” for 2nd grade medical students were opened in September 2015, in DEU Medical School. Ten MD students have been working on a survey to assess awareness of medical students and health professionals on clinical biobanks. The analysis of survey data is in progress. According to the results of survey, if necessary the MD students will train their peers about clinical biobanking.
 - A workshop for quality assurance of biobanks and for ELSI issues is organized. It will be held on 6-7 April.2016 in İstanbul.

- **Meetings (where you presented BBMRI-ERIC or which had a Pan-European focus)**
 - 12 .05. 2015, Ministry of Health and UNESCO Bioethics Committee, ECRIN.tr, BBMRI-ERIC.tr joint meeting on Biobank Ethics and Governance.
 - 28 .05. 2015, 1st BBMRI-ERIC.tr Management Committee Meeting, Izmir International Biomedicine and Genome Institute, Izmir, Turkey.
 - 23. 07. 2015, 2nd BBMRI-ERIC.tr Management Committee Meeting, Izmir International Biomedicine and Genome Institute, Izmir, Turkey.
 - 14. 10. 2015, Kick of Meeting of “*Investment in the Future: BIOBANK*” Project, Istanbul University, Institute of Experimental Medicine, Istanbul,Turkey.

- **Publications**

Ozguc M . Biobank Governance, (In Turkish)

http://www.unesco.org.tr/dokumanlar/biyoetik_komitesi/biyobanka_rapor.pdf

- **Other, please specify:**
 - The first national survey for self-evaluation of biobanks is prepared, and send to Biobanks in Turkey.
 - BBMRI-ERIC.tr working groups were established.
 - The project entitled "Investing in the Future: BIOBANK" has been accepted and awarded by a grant from Istanbul Development Agency (<http://en.biyobanka.org>)
 - A grant proposal was submitted to the Ministry of Development for the infrastructure and staff costs of BBMRI.ERIC.tr.