

ANNUAL REPORT 2015

BBMRI TURKEY



About:

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

BBMRI.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 the awareness of biobanking among the public as well as the scientific community,
3. Create a coordination structure among biobanks,
4. Harmonize the ethical and legal guidelines,
5. Share 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.tr focuses on:

1. Harmonization and dissemination of standard operating procedures (SOPs) for the collection, storage, quality control and access procedures of biological material and related data among biobanks,
2. Coordination of the 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,
4. Educational activities to enhance the awareness of biobanking in the general public, policymakers, and health-care providers,
5. Increase the awareness of decision makers to develop tools to ensure the sustainability of biobanks.

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

National Node Director: Nese Atabey

Staff: 1,5 FTE/year

Partners:

- ✓ 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), DEU, Izmir.
- ✓ Dokuz Eylul Technology Development Zone (DEPARK), Izmir.
- ✓ Ministry of Development.
- ✓ Turkish National Commission for UNESCO Bioethics Committee
- ✓ The Scientific and Technological Research Council of Turkey (TUBITAK)
- ✓ Turkish Health Institutions (TUSEB)

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 and the Ministry of Development are responsible for the regulatory processes regarding large-scale research infrastructures. Turkey's research infrastructure development in its 10th 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 (TUSEB) initiated The Turkish Genome Project and support for disease/hospital based biobank infrastructures and established of a Population Biobank. BBMRI.tr focuses on the dissemination of standard operating procedures for the collection, storage, quality control and access procedures of biological material and related data, the coordination of the funding of an IT infrastructure for interoperability between biobanks for the use of patient registries and clinical data, the organization of training activities to assure the quality of biobanks and registries and, educational activities to enhance the awareness of biobanking in the general public, policymakers, and health-care providers.

BBMRI.tr road maps include:

- ✓ Mapping Turkish Biobanks in terms of quality levels by a self-assessment questionnaire.
- ✓ Encouraging Turkish Biobanks to become members of BBMR.tr.
- ✓ Improving the BBMR.tr web page (by creating interactive e-learning tools and an information desk for common services and ongoing research projects etc.)
- ✓ Motivating the creation of a Turkish National Biobanking Network.
- ✓ Supporting the harmonization and standardization of SOPs.
- ✓ Stimulating the involvement of stakeholders in the BBMR.tr structure.
- ✓ Organizing hands-on training courses for biobankers.
- ✓ Supporting certification and accreditation programs.

Specific strengths

- ✓ 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.tr national node and some local ethics committee members.
- ✓ Turkey is a partner in some other ESFRI projects (ECRIN, ELIXIR, EUROBIOMAGING, bINFRAFRONTIER).

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:** Standard 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 on April 6th, 2016.
- **Clinical Biobanks:** We have been collecting the inventory of available clinical biobanks in Turkey. Turkish Gastrointestinal Pathology Working Group has been informed about the BBMRI-ERIC-ADOPT project. Main centers are sent a questionnaire about colorectal carcinoma cases with follow up information and/or formalin fixed-paraffin embedded and/or material stored at -80°C.
- **Population-based Cohorts:** We are conducting follow-up studies on subsamples of the BHS (Balçova Heart Study) Cohort. These follow up studies include the 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, and the first meeting was held 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 the standardization of informed consent forms and Ethical-Legal guidelines of biobanks, and a position paper has been prepared. A workshop has been organized to standardize Biobanks’ informed consents and to train biobankers on Ethical and Legal issues. The “SOPs and Quality in Biobanks” workshop will be held on April 6th, 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 “special study modules (SSM)” for 2nd grade medical students have been opened in September 2015 at DEU Medical School. Ten MD students have been working on a survey to assess the awareness of medical students and health professionals on clinical biobanks. The analysis of the survey data is in progress. According to the results of the survey, if necessary the MD students will train their peers on clinical biobanking.
 - ✓ A workshop for the quality assurance of biobanks and ELSI issues has been organized. It will be held on April 7, 2016 in Istanbul.
- **Meetings**
 - ✓ 12.05.2015, Ministry of Health and UNESCO Bioethics Committee, ECRIN.tr, BBMRI.tr joint meeting on Biobank Ethics and Governance.
 - ✓ 28.05.2015, 1st BBMRI.tr Management Committee Meeting, Izmir International Biomedicine and Genome Institute, Izmir, Turkey.
 - ✓ 23.07.2015, 2nd BBMRI.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 the self-evaluation of biobanks has been prepared and sent to Biobanks in Turkey.
 - ✓ BBMRI.tr working groups were established.
 - ✓ The project entitled "Investing in the Future: BIOBANK" has been accepted and awarded 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.tr.