



ANNUAL REPORT 2017

BBMRI TURKEY

Country

Year joining BBMRI-ERIC: 2014- OBSERVER

GDP: € 774.5 Billion

Population: 79.8 Million

Number of biobanks and stand-alone collections as specified in the Directory 2.0: None

National Node

Start Date: 1 January 2014

Director: Safiye Nese Atabey (Since 2015), Kemal Baysal (until 2015)

Total staff (FTE/year and headcount): 1.5 FTE/year and 3

Total funding (period): € 0.2 million / year (2014-2017)

Funding body: Ministry of Development, Dokuz Eylul University, Istanbul Development Agency (ISTKA)

Legal entity of/hosting institution of National Node: Dokuz Eylul University, Izmir International Biomedicine and Genome Institute (IBG-izmir)

Partners (total 3): Hacettepe University Center for Biobanking and Genomics (HUBiGEM) and Istanbul University, Institute of Experimental Medicine (DETAE) H. Behcet Life Science Center Biobank Facility

Web: <http://biobank.gen.tr/>

National Catalogue: Not yet

About.

BBMRI.tr focuses on the establishment of a national biobanking infrastructure in Turkey to create a national registry and to increase harmonization between biobanks. These are very important to facilitate access of researchers to biobanks for improving research and innovation in life sciences. We have been organizing training activities to assure the quality of biobanks and registries as well as educational activities to enhance the awareness of biobanking in the general public, policymakers, and healthcare providers.

Specific Strengths

- Hacettepe University Center for Biobanking and Genomics (HUBiGEM) one of the largest Rare Disease Biobanks in Europe and a member of EuroBioBank network.
- Strong support of Turkish Health Institutions (TUSEB) to built a national biobank infrastructure.
- Support of TUSEB for establishment of population based biobanks and for sustainability of

disease based biobanks in Turkey.

- Clinical expertise on rare disease and repository of large consanguineous families.

National Expertise and Contributions to the Joint Efforts in BBMRI-ERIC

e-Infrastructure

BBMRI.tr actively participates in the creation of a National Biobank Registry and IT infrastructure for storage and processing of samples and related genomic data in Turkey within the scope of Turkish Genome Project.

Quality

- BBMRI.tr actively participates in BBMRI-ERIC QM Meetings with 5 experts, BBMRI-tr QM experts organized a quality workshop and prepared a guide for quality assurance ¹.

Clinical Biobanks

- To increase awareness and contribution to data set development on colon cancer collections (ADOPT BBMRI-ERIC), BBMRI.tr Clinical Biobanking Group and Turkish Pathology Societies Federation, Gastroenterology Working Group organized a workshop in November 2016.
- BBMRI.tr has involved development of a national network infrastructure for rare disease, common disease and tumor biobanks.

Population-based Cohorts

- No biobank is specialized in population-based cohorts within BBMRI.tr

ELSI

- The Turkish Law on the Protection of Personal Data, which is based on Directive 95/46/EC, published on April 2016. In addition, secondary legislation regarding protection of personal health data has been adopted on October 2016. This new law and regulation are a major step in aligning Turkey's legislative framework with the EU and largely reflects the requirements under the current EU Directive¹.
- A guide for "Ethical and Legal Regulations on Biobanks" was published².

Education & Training

Workshops

- A one-day workshop was organized to harmonize SOPs and to train biobankers on QMS Systems in biobanks: Protocols and Quality in Biobanks Workshop, April 6th, 2016,
- "Ethics and Legal Framework of Biobanks Workshop" was held in Istanbul, April 7th, 2016. During the workshop, ethical and legal issues in biobanks had been discussed in interdisciplinary participation such as lawyers, researchers and ethical committee members.
- Turkish Pathology Societies Federation, Gastroenterology Working Group organized a workshop to increase contribution to data set development on colon cancer collections (ADOPT BBMRI-ERIC- WP2), in 26th National Pathology Congress, which was held in Antalya on 2-6 November 2016.

Courses

- Workshop 1: "Pre-Analytical Sample Processing in Biobanking: A Practical Laboratory Course, May 27-28, 2016; Istanbul.
- Workshop 2: "Data Analysis Approaches and Processing Tools in Biobanks" course, May 30-31, 2016; Istanbul.

Publications 2016

1. Erbilgin Y, Ugur Iseri SA, Khodzhaev K, Haryanyan G. Protocols and Quality in Biobanks, ISBN: 978-605-4949-95-3.
2. Tuncel FN, Oztezel A, Kulahci S. Ethical and Legal Regulations In Biobanks, ISBN: 978-605-4949-94-6.