

Acceptable Use Policy of BBMRI-ERIC Services

Version 1.0, 2017-08-23

1 Preamble

These usage conditions must be accepted by any authenticated User of any BBMRI-ERIC Service dealing with personal data or anonymized data (for example, but not limited to, BBMRI-ERIC Locator and BBMRI-ERIC Negotiator).

2 Definitions

BBMRI-ERIC Locator A service for searching preliminary availability information on samples and data sets. To be available in 2018.

BBMRI-ERIC Negotiator A service for facilitating access to BBMRI-ERIC partner biobanks, by orchestrating and simplifying the communications between researchers (requesters) and biobankers. <https://negotiator.bbmri-eric.eu/>.

Contributing Biobank Biobank which contributed the data or biological material via BBMRI-ERIC to the researcher.

Research Participant Patient or donor, who has consented to and contributed her/his data or biological material to be used in research.

3 Common Conditions of Use

- User agrees to be a bona fide researcher with (1) an intention to generate new knowledge and understanding using rigorous scientific methods, (2) an intention to publish the research findings and share the derived data in the scientific community, without restrictions and with minimal delay, for wider scientific and eventual public benefit, and where (3) the intended activities are not inconsistent with legal and ethical requirements or widely recognised good research practice.
- The User will avoid any attempts to reverse privacy enhancing technologies (i.e., pseudonymization, anonymization) applied to the data and/or to (re-)identify individual Research Participants contributing the data and/or donating the biological material.

- If possible,¹ any incidental findings will be reported back to the Contributing Biobanks, which in turn process the incidental findings based on their policy and based on the conditions specified in the informed consent.

4 Service-Specific Conditions of Use

- *BBMRI-ERIC Negotiator*: The User agrees to honor the BBMRI-ERIC Harmonized Access Procedure,² including data protection and confidentiality principles.

¹ Application of privacy-enhancing technologies may render reporting incidental findings back impossible, e.g., when found on anonymized data sets.

² <https://doi.org/10.5281/zenodo.823013>

Document Log

Version 1.1, 2017-08-24 Added Service-specific policy for Negotiator. Renamed from Terms and Conditions to Acceptable Use Policy. Added Document Log. Author: Petr Holub

Version 1.0, 2017-07-12 Initial version. Author: Petr Holub