Acceptable Use Policy of BBMRI-ERIC Services

Version 1.3, 2022-01-20

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 Finder A service for searching preliminary availability information on samples and data sets based on federated querying mechanisms..

BBMRI-ERIC Locator A service for searching preliminary availability information on samples and data sets based on federated querying mechanisms..

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.

- When querying or processing anonymized data, the User will avoid any attempts to infer additional data about any specific individual Research Participant.

- 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.

- User shall refrain from using data sets and services using SNOMED CT terminology[2] (and other terminologies based on it such as SNOMED CT based terms in OMOP[3]) unless having a license from SNOMED International or using the data set or service in a SNOMED International Member country or territory. BBMRI-ERIC Finder is an example of a service using SNOMED CT and OMOP.

4 Service-Specific Conditions of Use

- *BBMRI-ERIC Negotiator:* The User agrees to honor the BBMRI-ERIC Harmonized Access Procedure,[4] including data protection and confidentiality principles.

- *BBMRI-ERIC Locator* and *BBMRI-ERIC Finder*, comprising Federated Platform: These services are based on querying individual-level (pseudonymized) data hosted in the Contributing Biobanks (and possibly other service providers) and returning anonymized aggregated results back to the central BBMRI-ERIC Locator/BBMRI-ERIC Finder services. As these anonymized aggregated results bear non-zero risk of re-identification of individual, the user is forbidden to use these services to (re)identify any individuals, in compliance with the general principles stated above.

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

[2] https://www.snomed.org/snomed-ct/

[3] https://ohdsi.org/omop/

[4] https://doi.org/10.5281/zenodo.823013

Document Log

Version 1.3, 2022-01-20 Added policy for services using SNOMED-CT. Author: Petr Holub

Version 1.2, 2021-08-04 Added Service-specific policy for BBMRI-ERIC Locator and BBMRI-ERIC Finder. Author: Petr Holub

Version 1.1, 2017-08-24 Added Service-specific policy for BBMRI-ERIC 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