



I have a research idea that involves health data and/or biobank samples

Contact BRS, Umeå University, (info.brs@umu.se). Write 1-2 paragraphs about the study (disease area, method, research question) Answer from the Section of Biobank and Registry Support within 1 week

Overview and timeline – data/sample retrieval

Advisory meeting, discuss study design
Meeting within 2 weeks, follow-up meeting if needed

Submit application to the Expert group
Decision with recommendations 2-3 weeks after the meeting

Ethical application/amendment (if needed), reviewed by the Section of Biobank and Registry Support before submission to the Swedish Ethical Research Authority (EPM). Answer from EPM within 60 days

Study activation (e.g., after ethical approval and secured financial support)

Data management: 2-10 weeks

- Clarification of study details
- Exclusion criteria and matching of controls
- Number of sample aliquots and sample sorting criteria
- List of sample IDs for sample retrieval at the biobank
- Data withdrawal based on selected variable lists

Application for data withdrawal from other data registries (if needed) 3-12 months

Project administration: 3-6 months

- Biobank agreements (if applying for samples) – reviewed and approved by Biobank North (BBN), Region Västerbotten
- Third-party MTA (if samples are sent outside of Umeå University)
- Data Protection Impact Assessment and Standard Contractual Clauses (SCC) (If data/samples sent outside of EU/EES)

Glossary:

The Section of Biobank and Registry Support: Section under the Department of Public Health and Clinical Medicine, Umeå University. Administration of health data and samples in the Northern Sweden Health Disease Study (NSHDS) and other sample collections.

Biobank North (BBN): Organisational unit with legal responsibility for samples taken in health care at Region Västerbotten. Operational (laboratory) unit that manages sample handling during sample collection and sample retrieval.

Sample retrieval: 3-12 months (depending on queue at BBN)

- Sample retrieval from freezers, aliquoting, sorting, transport

Linking sample analysis data to other datasets: 1 week

- Delivery of complete pseudonymised dataset

Archiving of analysis data and publication guidelines