

EU project identifies obstacles to transnational research access to large prospective cohorts

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BBMRI-LPC (Biobanking and Biomolecular Research Infrastructure—Large Prospective Cohorts) EU infrastructure project

was implemented during the years 2013-2017. The main findings of this work have now been published in the *New Biotechnology* journal.

Biobank samples and data from studies of large prospective cohorts represent an invaluable resource for [health research](#). Efficient sharing and pooling of samples and data is a central prerequisite for new advances in biomedical science. This requirement, however, is not compatible with the present scattered and traditional [access](#) governance structures, where legal and ethical frameworks often form an obstacle for effective sharing. Moreover, the EU General Data Protection Regulation (GDPR) is demanding increasingly rigorous administration from all those organisations processing personal data.

The BBMRI-LPC project, led by researchers from the University of Helsinki, Finland and Leiden University Medical Center (LUMC), the Netherlands, brought together more than 30 research organisations. The key objectives of the project were to promote collaborative innovative transnational research proposed by external researchers on the broad field of common chronic diseases, and analyse the gaps and needs involved in the access provision.

The BBMRI-LPC project assembled 21 large prospective cohorts from 10 countries and two EU-wide multinational cohort networks. BBMRI-LPC organised four scientific calls to offer European investigators an opportunity to gain free of charge transnational access to research material available in the participating cohorts. A total of 11 high-quality research proposals involving multiple prospective cohorts were granted, and the access process in the individual projects carefully monitored.

As a result, divergent access governance structures, complex legal and ethical frameworks and heterogeneous procedures were identified as currently constituting substantial obstacles for sample and data transfer in Europe. To optimize the scientific value and use of these research

resources, practical solutions for more streamlined access governance in collaborative projects are urgently needed. A number of infrastructure developments could be made to improve time-efficiency of access provision to the [cohort](#) research resources in Europe.

These observations have important relevance for promoting more harmonized and accessible biobanks, thereby envisaged to benefit entire biobanking and medical research community.

"The collaboration of biobanks is essential in the modern studies of diseases of public health interest. Now we know better how to further this collaboration," said Professor Markus Perola, the Coordinator of the study.

More information: Birgit A. Simell et al, Transnational access to large prospective cohorts in Europe: Current trends and unmet needs, *New Biotechnology* (2018). [DOI: 10.1016/j.nbt.2018.10.001](https://doi.org/10.1016/j.nbt.2018.10.001)

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