

Simell BA, Törnwall OM, Hämläinen I, Wichmann HE, Anton G, Brennan P, Bouvard L, Slimani N, Moskal A, Gunter M, Zatloukal K, Minion JT, Soini S, Mayrhofer MT, Murtagh MJ, van Ommen GJ, Johansson M, Perola M; BBMRI-LPC Consortium

Transnational access to large prospective cohorts in Europe: Current trends and unmet needs

New Biotechnology. 2019 Mar 25 (Epub 2018 Oct 17), 49:98-103. doi: 10.1016/j.nbt.2018.10.001.

ABSTRACT

Biobank samples and data from studies of large prospective cohorts (LPC) 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 (Biobanking and Biomolecular Research Infrastructure - Large Prospective Cohorts) assembled 21 LPCs from 10 countries and two EU-wide multinational cohort networks with a key objective to promote collaborative innovative transnational research proposed by external researchers on the broad field of common chronic diseases, and analyze the gaps and needs involved. BBMRI-LPC organized three 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. 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 in access provision.

KEYWORDS: Biobanks; Cohort studies; Collaborative research; GDPR; Transnational access

FOR MORE INFORMATION, CLICK [HERE](#)