“This is a time of dramatic change in medicine. As we cross the threshold of the new millennium, we simultaneously cross a threshold into an era where the human genome sequence is largely known. We must commit ourselves to exploring application of these powerful tools to the alleviation of human suffering, a mandate that undergirds all of medicine.”

[Francis S. Collins & Victor A. McKusick, 2001]

In 2009, *Time Magazine* identified biobanks as one of the ten ideas changing the world (Parks, 2009). These organized collections of human biological samples and associated data are “vital research tools in the drive to uncover the consequences of human health and disease” (Chalmers and Nicol, 2008). Today, with many of these infrastructures gradually achieving their recruitment objectives, current initiatives are focusing on the orderly translation of research knowledge into beneficial clinical applications. Indeed, whether it is through international collaboration aimed at increasing statistical power (Burton et al., 2009), or broader access to comprehensive data meant to better understand the role of human genomic variation in “complex disease aetiology and treatment” (Knoppers et al., 2011), biobank researchers wish to realize the full benefits for which participants have provided their data and samples.

**This Special Issue “From Biobanks to the Clinic” examines the ways in which biobanks are facilitating this translation. In Rare Disease Research: Breaking the Privacy Barrier, Mascalzoni, Paradiso and Hanson discuss the effects of privacy on rare disease research and biobanking. Although the aggregation of health-related data has become a pressing need in these projects, the collection and use of large quantities of health information create challenges for patient privacy. The authors highlight some of these challenges, including the problem of specific informed consent procedures. They explain that genomics should also focus on the benefits for society as a whole. In order to improve researcher–patient relationships, researchers could consider patient partners as authors, and acknowledge them as valuable contributors to genetic research. In this way, the authors hope that biobanks will foster translational practices, while protecting individual rights.**

In turn, Brankovic, Malogajski and Morré discuss biobanking in the context of infectious disease research, using HIV. Chlamydia and Human Papillomavirus as case studies. Through an examination of various biobank consortia, including the Infectious Diseases Biobank at King’s College London and the Spanish HIV Biobank, the authors demonstrate how biobanks have successfully contributed to the translation of research data to clinics and patients. In each case study, the authors were able to demonstrate how biobank genomic research data can lead to a better understanding of infectious diseases in the clinical setting; for example, the translation of HPV research results is contributing to better diagnostics of cervical cancer and its intermittent stages. The authors also stress the importance of electronic health records in providing access to a more comprehensive set of data; vital for the future utilization of biobanks.

In P3G—10 Years of Toolbuilding: From the Population Biobank to the Clinic, Ouellette and Tassé discuss the evolution of the Public Population Project in Genomics and Society (P3G), a non-profit international consortium focusing on genomics and biobanking. From its inception, P3G has sought to develop tools for the conceptualization of biobanks, and has become key in fostering infrastructure research to facilitate the translation of biobank knowledge to clinical use. Biobank tools, support systems and networks help the international research community use health and social data for healthcare strategies aimed at disease prevention and tailored treatments. P3G’s comprehensive website describes its research programmes and also includes a TOOLKIT for epidemiological, ethical, statistical and IT tools for the access and use of biobanks, while its CATALOGUES provide easy access to information about large population-based biobanks.

In brief, the articles in this Special Issue cover a broad spectrum of critical issues and tools facilitating the clinical uptake of biobank research. Written by an international group of scientists, ethicists and jurists, they are a reflection of current efforts aimed at fostering the orderly translation of knowledge from the bench to the bedside. For biobanks, continuing on this path will not only ensure better healthcare planning for the health systems that will serve future generations, but hopefully also strengthen and sustain public trust for many years to come.

What this Special Issue illustrates above all, is the tension between “old” and “new” science and ethics since the launching of the Human Genome Project in the 1990s. The old, epitomized by the single “genius” researcher, is now giving way to international consortia with collaborative data sharing. The emphasis on personal autonomy and privacy at all costs, especially as concerns genetic research, is now giving way to broad consent for biobanks (populational or rare disease) serving as resources, that is, as infrastructures for specific disease research. The challenge for the next quarter century will be the sustainability of these biobank infrastructures for their clinical use in healthcare systems.

As a research participant, the modern citizen contributes to the solidarity ethos of research that creates generalizable knowledge for the public good; as a patient, however, choices as concern interventionism, clinical trials or medical care are intensely personal. Confusing the role of the quality and social needs of research and the need for individual choice in medical care can undermine the global need for research to scientifically underpin medical care. Biobanks and data sharing are a social enterprise that can and should undergird as well as sustain the viability of quality healthcare for all, including – as we have seen –
those with rare diseases and infectious diseases. Personal expressions of choice as concerns donating to infrastructure biobanks can always be expressed by non-participation (i.e. opt-out). Adding the slippery slope of multiple individual choice to such participation can only harm the quality of these biobanks that benefit all science without selection bias. Multiple consent options should remain in the context of clinical research and medical care.

Moreover, as the needs of the rare disease and infectious disease (public health) communities have demonstrated, there is now an even greater need to support the solidarity “citizen-like” nature of biobanks, built as they are on public trust, ongoing oversight and transparency. This contribution of citizens, especially as regards their confidence in the ethical governance of biobanks and in the international sharing of their data and samples, is distinct from the need to provide consent choices in either clinical research involving interventions or in personal medical care. The contents of this Special Issue are illustrative of these scientific policies, and, personal challenges. Note the words of caution of the legal scholars at the Mason Institute:

We do not support a dynamic consent approach on both principled and pragmatic grounds. First, as a matter of principle this re-enforces a highly individualistic (property-like) approach to data and its control which is likely to compromise solidarity interests in data uses for a range of purposes that can benefit both individual and public interests. Pragmatically, we question whether this is the best use of finite research resources to have to design such mechanisms when this will necessarily be at the expense of other research-focused expenditure (Laurie et al., 2013).

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