Industry involvement in publicly funded biobanks

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Increased private funding could add further to the ethical and legal complexities that are associated with biobanks.

> Policy development should be informed by further analyses

Jurisdictions throughout the world have supported the development of large-scale population biobank initiatives, which consist of collections of human biological samples and data for research purposes. Biobanks are viewed as a vital research platform that is necessary to support research that seeks, among other things, to understand the complex relationship between genes and the environment in the development of disease. Despite the substantial support from public funding entities and the development of multinational research infrastructure, concerns remain about the long-term financial sustainability of biobanks[1]. These initiatives are expensive and, hence, 'biobankers' are looking increasingly to private funding sources and links with industry. This strategy has the potential to add further ethical and legal complexities to the many policy challenges that are associated with biobanks.

One of the biggest dilemmas of obtaining funding from commercial entities is the adverse effect on public trust. A growing body of research suggests that the public supports the concept of biobanks and places a great deal of trust in the university researchers that use them[2]; however, that trust diminishes markedly if the research is funded by industry[3] — a phenomenon that occurs specifically in the context of biobanks[4]. Reasons for this loss in trust include, among others, the fear that public access to health benefits will be reduced owing to private interests. Also, the public seems more suspicious and less accepting of the outputs of research when industry is involved. Given the importance of public trust for the recruitment and continued involvement of much-needed participants, the obtainment and maintenance of public funding, and the implementation of any emerging health-related technologies, even a relatively small loss in public trust could have substantial ramifications for the viability and utility of biobank initiatives.

Industry involvement might also intensify the already complex issues associated with consent — an area that remains a divisive topic in the context of biobanking[5]. If the possibility of industry involvement is not addressed in the initial consent process when biobank participants are recruited, then some form of re-consent will probably be ethically and legally required. This could create substantial financial and practical dilemmas for the biobank community. Moreover, asking for re-consent that highlights industry involvement could result in the withdrawal of a portion of participants, thus diminishing the research value of the biobank. As not all issues can be adequately addressed by consent, a new or enhanced governance mechanism (including, for example, an oversight committee) may be required, thus necessitating further resources. Industry involvement could also increase the need to clarify issues that are associated with the ownership and control of samples, the regulations regarding access to samples and participant information, and what happens if a biobanking initiative loses funding or goes bankrupt[6].

Ideally, many of these and other issues would be anticipated and addressed — through consent and appropriate governance — when a biobanking initiative is commenced and participants first recruited. Unfortunately, this is often not the case and new strategies must therefore be devised. Policy development should be informed by further analyses that include an exploration of what the public finds most troubling about industry involvement, research on the role and possible impact of a return of benefits to the relevant community, and a consideration of governance and consent strategies that allow valuable research to proceed while still preserving the interests of both biobank participants and the public.

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The authors declare no competing interests.