

Going Global: The Ethics of Biobanks in the Context of Globalisation

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Biobanks of human tissue and data have become an established part of the research landscape—enabling molecular research into the aetiology, course and therapy of many diseases. The extensively described ethical issues that surround biobanking include: 1) informed consent and right to withdraw; 2) confidentiality and protection from discrimination; 3) controlling data access; 4) equity, reciprocity and benefit sharing; 5) ownership, commercialization and intellectual property rights, 6) community engagement; and 7) respect for cultural diversity. Specialists broadly agree that addressing these issues is crucial to establishing and maintaining trust between biobanks and the general public, and fostering altruism among tissue donors.

The biobank landscape is, however, changing, as the pull of “big data” drives biobanks to “go global”. This amplifies the ethical issues that apply to localized biobanks, and introduces new and complex ethical considerations. For example, the heterogeneity of technical standards and practices across diverse settings challenges the validity and reliability of data analysis; the financial cost of maintaining biobank facilities can encourage commercial arrangements that impact upon benefit sharing; and the transfer of human biological samples across national boundaries can complicate the custodianship of tissue, return of results, and right to withdraw.

The ethicolegal, scientific and practical challenges of international biobank networks are heightened by the fact that there is more than one way for a biobank to “go global”. For example, biobanks can centralize their resources and collect samples from numerous countries; share data through virtual networks across several countries; or distribute and compartmentalize activities in different locations. The specific ways in which transnational biobank networks are formed can give rise to idiosyncratic ethical issues. We argue that it is critical that bioethicists engage with these complexities, and that theories of globalisation provide a valuable political frame through which the ethics of international bionetworks may be understood.