

Globalising the ‘Medical Gaze’: Research biobanks, epistemological imperialism and the pull of big data

Big Data

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Research biobanks house collections of biological samples from human populations. While biobanks have traditionally been contained within institutional walls and national borders, enthusiasm for “big data” is driving the formation of transnational biobank networks. The rationale for the global linkage of biobanks is that it increases their “big data” resources and affords opportunities for partnerships between institutions with commensurable ethical, regulatory and institutional structures. The global expansion of biobanks is, however, not entirely benign, as the local implementation of their operations in various country settings inevitably challenges, undermines or displaces local epistemologies and practices. Those countries that dominate the field are also (re)-setting the research agenda and establishing the financial foundations for bionetworks, thereby reconfiguring labour and human resources, technological capabilities, capital and finances, information and information technology, and ideologies and epistemologies. The consequences for (disempowered) local populations is often profound, as they must struggle to make sense of the idea that their tissue and data may be used for unspecified future research by transnational groups with no link or commitment to their community, must deal with divergent standards of research and institutional practice, and must accommodate ongoing uncertainty regarding how data will be analysed and interpreted, and results communicated and translated into policy and practice. Critical engagement with theories of globalisation can facilitate the necessary ethical reasoning required to address not only the “traditional” ethical issues raised by biobanking, such as consent, confidentiality and benefit sharing, but also broader socio-political concerns such as population surveillance and epistemological imperialism.