Abstract: Ethics and Regulatory Frameworks for Biobanks

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The current rapid emergence of large biobanks – major collections of biological, genetic, environmental and health data – has raised some fascinating issues at the nexus of medical law and medical ethics. Since the controversies surrounding the Icelandic Health Sector Database (HSD), set up at the end of the last decade, there has been a growing awareness that such projects raise a novel set of ethical and legal issues, most obviously in relation to the nature of the consent gained, but also across a whole range of other social and moral concerns. In this paper I want to focus on what I regard as the two central ethical features of collections of this kind: their dependence on both altruism and trust from those who donate their samples and health data, and the corresponding duties which rest on the creators and custodians of biobanks to honour these commitments from the donors.