



Biobanks and Electronic Health Records: Ethical and Policy Challenges in the Genomic Age

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Abstract:

In this paper we discuss the ethical and policy challenges presented by the construction and use of biobanks and electronic health records systems, with a particular focus on how these resources implicate certain types of security concerns for patients, families, health care providers and institutions. These two technology platforms are selected for special emphasis in this paper for two reasons. First and foremost, there is a close connection between them. Indeed, of the many accepted

definitions, this one from the German National Bioethics Commission provides a sense of this close connection and the great power and reflects the great power these two separate platforms provide to probe more deeply the connection between genotype and phenotype: "...[B]iobanks are defined as collections of samples of human bodily substances (e.g., cells, tissues, blood or DNA as the physical medium of genetic information) that are or can be associated with personal data and information on their donors." Second, these two topics implicate both clinical ethics issues (those arising at the bedside for health care providers and patients), and human research ethics issues (issues arising for scientists, research subjects, ethics review bodies and regulatory authorities). Both of these sub-specialty areas confront similar and complementary ethical issues; for example, issues arising from the nature and adequacy of informed consent, the sufficiency of systems to protect personal privacy and confidentiality, or the need to balance concerns relating to data security and the need to know. A growing research base supports calls for more attention to these issues, and yet current professional ethics frameworks and policy consultation methods are poorly organized and ill-equipped to anticipate and fully address ethical issues in health information technology generally, or to provide adequate ethical assessment of the tools that elicit these issues. Our strategy is to orient readers to the history and context of these issues, to frame several key challenges for researchers and policy makers, and then to close with several recommendations for next steps.

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