

Publication

Reporting of secondary findings in genomic research: Stakeholders' attitudes and preferences

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When bioethics began to emerge as a distinct field in the 1960s and 1970s, it was a predominantly theoretical, normative endeavor. It was interdisciplinary from its very beginning, with academic disciplines such as medicine, law, philosophy, and theology presiding over “the birth of bioethics.” However, for a field concerned with very practical matters in medical research and clinical decision-making, it did take a surprisingly long time to incorporate empirical methods and findings into its discussions in a systematic way. Developing sound ways of integrating the views on bioethical issues of patients, health professionals, and the lay public into decision-making and policy was certainly not an early priority. When, however, this did start to happen increasingly (also against the background of a rise of the evidence-based medical paradigm), an intense debate ensued. True to bioethics' nature as a discipline asking whether, why and how something should be done, for roughly two decades in the 1990s and the 2000s, it was hotly contested if “the empirical turn” in bioethics was justified, problematic, or long overdue (to name just a few contributions from an extensive debate). Among many things, protagonists in these debates examined the reasons for including empirical data on stakeholder views and preferences; they discussed the quality of these initiatives within bioethics; they touched on potential methodological conflicts between bioethics and disciplines that had long pursued empirical research, such as the social sciences; and most importantly, they inquired about the proper place and function of empirical findings within the process of normative reasoning. How could simplistic “is/ought fallacies” be avoided? Was there a danger that referring to empirical data could replace normative analysis and argument? Conversely, was policy-making without hearing the views of those affected by a particular policy intrinsically paternalistic?

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