

Bioethicists contribute to consensus opinion on the responsibility of biobanks

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Bioethicists at the Johns Hopkins Berman Institute of Bioethics are coauthors on a consensus article placing "significant responsibility" on biobanks to report individual research results (IRRs) and incidental findings (IFs) to the contributors of genetic material.

"The <u>biobank</u> should set the rules for the overall process of recognizing (and subsequently analyzing and returning) IFs and IRRs," the authors write in *Genetics in Medicine*.

Biobanks should define and manage a system by which "findings that are analytically valid, reveal an established and substantial risk of a serious health condition, and are clinically actionable should generally be offered to consenting contributors," the authors write.

Jeffery Kahn, Ph.D., M.P.H, was co-investigator on the study and is Deputy Director for Policy and Administration at the Berman Institute. Co-author Joan Scott, MS, CGC, is a faculty member at the Berman Institute and Executive Director of the National Coalition for Health Professional Education in Genetics. Kahn and Scott were joined by 24 colleagues on the consensus report of a two-year study funded by the National Institutes of Health.

"This discussion of the ethical duty to research patients is extremely important and a preview of the questions we will face as genomic technologies such as whole genome sequencing move from the research setting to clinical care, and patients and providers are faced with an



increasing amount of genomic information," Scott says.

More information: *Genetics In Medicine:*

www.nature.com/gim/index.html

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