Volume 94, Issue 6, 5 June 2014, Pages 818-826

Article

Return of Genomic Results to Research Participants: The Floor, the Ceiling, and the Choices In Between

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https://doi.org/10.1016/j.ajhg.2014.04.009

As more research studies incorporate next-generation sequencing (including whole-genome or whole-exome sequencing), investigators and institutional review boards face difficult questions regarding which genomic results to return to research participants and how. An American College of Medical Genetics and Genomics 2013 policy paper suggesting that pathogenic mutations in 56 specified genes should be returned in the clinical setting has raised the question of whether comparable recommendations should be considered in research settings. The Clinical Sequencing Exploratory Research (CSER) Consortium and the Electronic Medical Records and Genomics (eMERGE) Network are multisite research programs that aim to develop practical strategies for addressing questions concerning the return of results in genomic research. CSER and eMERGE committees have identified areas of consensus regarding the return of genomic results

committees have identified areas of consensus regarding the return of genomic results to research participants. In most circumstances, if results meet an actionability threshold for return and the research participant has consented to return, genomic results, along with referral for appropriate clinical follow-up, should be offered to participants. However, participants have a right to decline the receipt of genomic results, even when doing so might be viewed as a threat to the participantsâ€™ health. Research investigators should be prepared to return research results and incidental findings discovered in the course of their research and meeting an actionability threshold, but they have no ethical obligation to actively search for such results. These positions are consistent with the recognition that clinical research is distinct from medical care in both its aims and its guiding moral principles.

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