No expectation to share incidental findings in genomic research

Genomic sequencing studies can answer questions about the genetic contribution to complex medical disorders such as developmental disorders. Although findings relating to the disorder of interest will be communicated to patients along with appropriate counselling, there is pressure on researchers to return secondary or incidental findings (ie, additional health-related data unrelated to the research question).[1] But few studies have actually asked relevant stakeholders what their expectations are of researchers.[2]

Analysing and returning extensive data from genetic studies poses a particular dilemma simply because of the scale—with potentially hundreds of relevant variants that could be linked to future medical health. For many researchers, an exploration of such variants would have implications for time and resources that could compromise the ability to do research.

Incidental findings could be uncovered by accident while exploring a pertinent finding, or might be revealed through a deliberate search for particular genes linked, for example, to serious, life-threatening treatable disorders.[3] Whether to do such an opportunistic screen and what to do with incidental, health-related data, is subject to debate.[4]

With an online survey containing ten explanatory films, we gathered the attitudes of 6944 people from 75 different countries towards their expectations of genomic researchers with respect to sharing incidental findings.[5,6] These participants included four relevant stakeholder groups in sequencing research: members of the public (n=4961), genomic researchers (n=607), genetic health professionals (n=533), and other health professionals (eg, nurses, surgeons, paediatricians, and general physicians; n=843). We asked participants whether incidental findings from genome studies should be made available to research participants; and whether they expected researchers to deliberately do an opportunistic screen to look for incidental findings of particular health relevance. 5628 of 6370 respondees thought that incidental findings should be made available to research participants (figure). However, despite such a strong interest in having access to data, only 1741 of 5653 participants expected genomic researchers to actively search for incidental findings not relevant to their research. These results remained consistent even after adjustment for potential confounding effects.

When asked, stakeholders do not expect researchers to search actively for incidental findings in a research setting. The US Presidential Commission for the Study of Bioethical Issues also suggests that researchers do not have a duty to actively look for incidental findings.[4] Although researchers might choose to explore and share incidental findings, within an appropriate ethics framework, our survey supports a policy that does not obligate researchers to search for and then communicate incidental findings to research participants.

We declare no competing interests.

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1 Wolf SM. Introduction: The challenge of incidental findings. *J Law Med Ethics* 2008; **36:** 216–18.
2 Jackson L, Goldsmith L, O'Connor A, Skirton H. Incidental findings in genetic research and clinical diagnostic tests: a systematic review. *Am J Med Genet* 2012; **158A:** 3159–67.
3 Green RC, Berg JS, Grody WW, et al. ACMG recommendations for reporting of incidental findings in clinical exome and genome sequencing. *Genet Med* 2013; **15:** 565–74.
4 Presidential commission for the study of bioethical issues. Anticipate and communicate: the ethical management of incidental and secondary findings in the clinical, research and direct-to-consumer contexts. Washington, DC: United States Government, 2013.
5 Middleton A, Bragin E, Morley KI, Parker M. Online questionnaire development: using film to engage participants and then gather attitudes towards the sharing of genomic data. *Soc Sci Res* 2014; **44C:** 211–23.
6 Middleton A, Bragin E, Parker M. Finding people who will tell you their thoughts on genomics—recruitment strategies into social sciences research on genetics. *J Community Genet* 2014; **5:** 291–302.

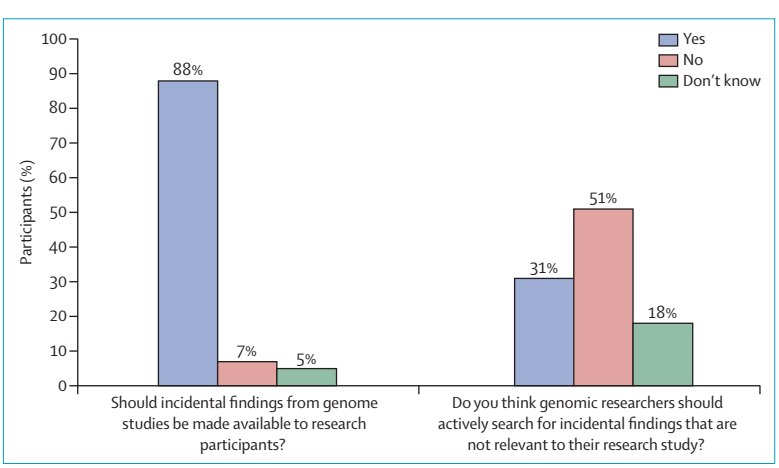

Figure: **Attitudes towards sharing of and active searching for incidental findings**

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