# Patients should have right to control genomic health information

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Doctors should not have the right or responsibility to force-feed their patients with genomic information about their future health risks, according to bioethicists writing on May 9 in *Trends in Biotechnology*, a Cell Press publication. They write in response to controversial recommendations from the American College of Medical Genetics and Genomics (ACMG) on the reporting of incidental findings in clinical genome sequencing.

"A lot of people in this field would agree that no one has a right to withhold your health information from you," said Megan Allyse from the Stanford University Center for Biomedical Ethics. "But it's problematic to suggest the inverse: that the medical system should give you information you didn't ask for and don't want. No one should be able to interfere with your ability to accept or decline access. We think that's where these recommendations are problematic, because they do suggest that your physician should interfere in that decision by essentially saying, 'You have to accept this information.' And there is certainly evidence that some people do not want information about long-term health risks, especially in children."

The ACMG recommendations were prompted by the increasing use of genome sequencing in medical care. A challenge in sequencing whole genomes or exomes (protein-coding sequences only) is the sheer quantity of information that results. For instance, a patient may undergo sequencing in an effort to individualize their cancer therapy, but their genome sequence might contain information about their risk of

developing Alzheimer's disease in old age. The questions are these: Should patients receive those "incidental findings" or not? And who decides?

The ACMG recommends that anyone undergoing genome sequencing for any reason should be tested for a list of clinically actionable conditions, including predispositions to various forms of cancer and to cardiomyopathy (but not to Alzheimer's disease). Furthermore, the recommendations are that physicians have a duty to then pass that information on to the patient, like it or not.

Not only would such an approach to medicine be a challenge for patient autonomy, but it would also be costly, the bioethicists say.

"It's not clear how those costs would be passed along, either to insurers or to patients themselves," Allyse said. "For the moment, from a patient perspective, the affected population is pretty small, because few people currently undergo whole-genome sequencing. But there are definitely signs that this practice is growing, especially in cancer diagnosis, and so we can envision that this issue of how to define and report incidental findings is likely to affect more and more people in the future. The issue of cost will of course affect any patient who has limited resources—along with the hospitals, insurance companies, and government programs that pay for much of the care patients receive."

**More information:** *Trends in Biotechnology*, Allyse et al.: "Not-so-incidental findings: the ACMG recommendations on the reporting of incidental findings in clinical whole genome and whole exome sequencing."

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