Canadians' preferences for receiving incidental findings from genetic testing

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Although many people value receiving information about incidental findings identified from genomic sequencing, not everyone wants to know about genetic conditions regardless of potential health implications, found a study of Canadian preferences in *CMAJ* (*Canadian Medical Association Journal*).

An incidental finding refers to discovery of a genetic condition that may cause a disease, but the finding is unrelated to why genomic testing was initially ordered by the physician. For example, a test to determine if there is a genetic cause of a patient's colon cancer may find that the patient is at risk of other diseases unrelated to the diagnosis. For some diseases identified incidentally, treatment may not be available.

Advances in technology and research indicate that individual genomic sequencing will soon be available to help provide individual-specific health care, although there is debate over whether people should be informed about incidental findings.

A survey of 1200 people set out to understand Canadians' preferences for hearing about incidental findings discovered during genetic testing that indicate possible risks for other diseases.

"We found that most participants valued receiving news of incidental findings, but that personal utility depended on the type of findings uncovered, and that not all participants wanted to receive results, regardless of potential health implications," states Dr. Dean Regier,

Canadian Centre for Applied Research in Cancer Control, BC Cancer Agency, and School of Population and Public Health, University of British Columbia.

People thought it useful to hear about diseases for which they were at risk (80%-90%) if there were lifestyle modifications or medical treatment available. If risk of diseases that had no treatment or those that had mild health effects were detected incidentally, the information was less useful to people and could negatively affect quality of life. However, preferences for receiving this information varied.

"We also found evidence of benefit related to offering participants a choice between receipt of incidental findings for both treatable and untreatable diseases or receipt of information about incidental findings for diseases with only medical intervention available."

The authors suggest that individuals should be offered an informed choice about the types of incidental findings from clinical genomic sequencing they prefer to be told about.

More information: *Canadian Medical Association Journal*, www.cmaj.ca/lookup/doi/10.1503/cmaj.140697

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