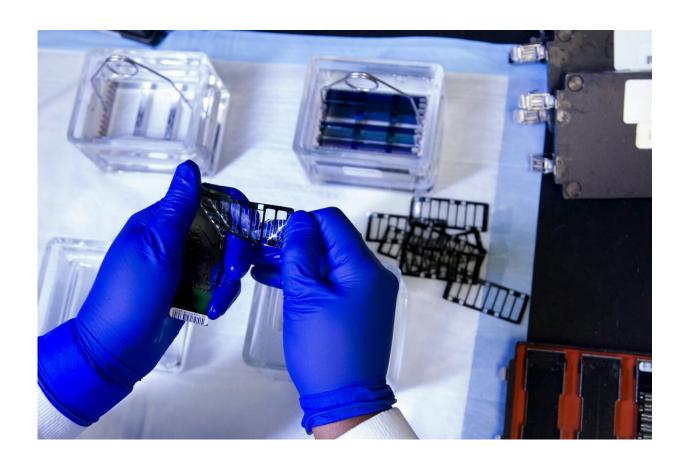


## Is free genetic testing really free?

July 29 2024



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Free genetic testing, offered partially or fully subsidized by industry, may have trade-offs, and health systems in Canada must carefully weigh potential clinical, ethical, and legal considerations to protect patient data, authors argue in a *Canadian Medical Association Journal* commentary.



"Near- and long-term expansion in no-cost testing and industry partnership in genetics, with <u>patient data</u> as the commodity, is likely," writes Kirsten Bartels, a genetic counselor at Providence Health Care Heart Centre, St. Paul's Hospital, Vancouver, British Columbia, with coauthors. "Commodification of data is not the norm in health care systems in Canada and should not be introduced without due consideration."

Sponsored genetic testing is available for a variety of conditions, from neuromuscular to eye conditions, and must be ordered by a medical professional, like provincially funded genetic tests. Most of these sponsored tests are performed in the United States, and technologies and testing methods may differ from those used in Canada, with potentially different or incomplete results. Sponsored genetic testing can also include a wider range of genes for testing, which may cause additional harm.

As well, Canada has stringent privacy laws to protect patients, but these laws may not apply in countries where testing is conducted, which could leave patients vulnerable to being identified.

To help guide health care providers in Canada about using sponsored genetic testing, the commentary authors, as members of the Canadian College of Medical Geneticists and Canadian Association of Genetic Counsellors, recently published a <u>position statement</u>.

They end with a call to action for government and health organizations.

"We call on health care jurisdictions to consider this important issue urgently and to support the development of comprehensive guidance to help practitioners navigate this next generation of genetic testing and data sharing."



**More information:** Free genetic testing is not free of clinical and ethical considerations, *Canadian Medical Association Journal* (2024). DOI: 10.1503/cmaj.231588.

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