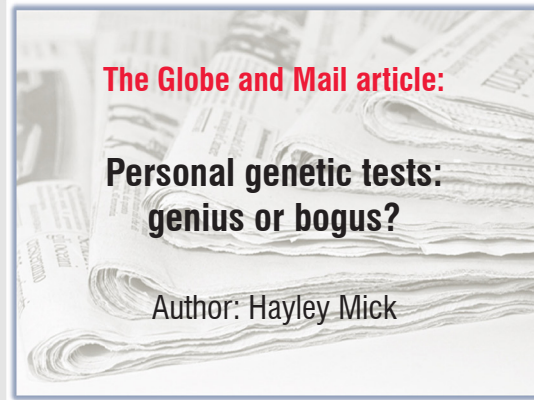




7.2.2 Genetic Tests Sold Directly to Consumers

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To view this article by Hayley Mick, please click [here](#).

Private commercial companies are advertising and selling kits via the internet that allow people to send biological samples for DNA analysis. This is called “direct-to-consumer genetic testing.” Consumers receive information about their likelihood of developing certain condition(s) linked to particular genes. Many of these companies conduct genetic testing in children and youth,¹ and the tests are often offered without medical supervision.

Companies use promotional statements such as “let your DNA help you plan for the important things in life” or “our goal is to empower you with genetic insights to help motivate you to improve your health.”²

While some genetic tests are well validated, some have not been validated or are considered inappropriate for the public.

In Canada, Cepmed (Centre for Excellence in Personalized Medicine) and DNA Direct have developed a [Personalized Medicine Portal](#) that provides tools to help patients understand how genetic testing can be used in making treatment decisions and promotes communication between patients and healthcare providers. The Portal provides information about access to specific genetic tests in each province.³

1 Howard HC, Avard D, Borry P. Are the kids really all right? Direct-to-consumer genetic testing in children: Are company policies for testing minors clashing with professional norms? *European Society of Human Genetics*. 2011;19(11):1122–6

2 Kolor K, et al. Health care provider and consumer awareness, perceptions, and use of direct-to-consumer personal genomic tests, United States, 2008. *Genetics in Medicine*. 2009;11:85–95

See, for example, Navigenics' Terms and Conditions: “you should not interpret Your Report or any other Content as recommending any specific treatment plan, product or course of action. You should always consult your physician or other qualified health provider before starting any new treatment.”

http://www.navigenics.com/visitor/what_we_offer/our_policies/terms_conditions/ Accessed August 17, 2011

3 Cepmed launches online personalized medicine portal. Marketwire. February 22, 2012. <http://finance.yahoo.com/news/cepmed-launches-online-personalized-medicine-204000631.html>

Implications

Direct-to-consumer genetic testing for children may provide useful genetic information, though without the benefit of appropriate genetic and clinical counselling. The Canadian College of Medical Genetics and the Canadian Pediatric Society have established professional norms concerning genetic testing of children. They state that for genetic conditions that will not present until adulthood (susceptibility or predictive testing), testing should be deferred until the child is competent to decide whether they want the information. Many argue that testing children using direct-to-consumer services deprives them of the right to decide for themselves whether they want to receive this genetic information. Therefore, it is not in keeping with these norms.

