

## Topic Overview

# Coordinating the Use of Genetic Tests and Related Services in British Columbia

## Stakeholder Dialogue 19 June 2012

The McMaster Health Forum convened a stakeholder dialogue on the subject of coordinating the use of genetic tests and related services in British Columbia. With the support of the Canadian Institutes of Health Research, the dialogue brought together 22 participants – three policymakers, five managers, four healthcare providers, one consumer, one researcher, and six individuals with experiences in four other provinces – to examine the problem, options for addressing it, and key implementation considerations.



The views expressed in the evidence brief and dialogue summary are the views of the authors and should not be taken to represent the views of the funders.

## Deliberation about the problem

Many dialogue participants agreed that key features of the problem included the exponential growth in demand for genetic tests and related services, the lack of coordination of existing programs and services, and a variety of gaps in the existing health system arrangements within which genetic tests and related services are provided. Dialogue participants identified three features of the problem that are unique to genetic tests and related services: 1) direct-to-consumer genetic testing; 2) ‘media hype’; and 3) the rapid pace of technological change that is significantly affecting all areas of medicine in an unprecedented way. Dialogue participants also highlighted three features of the problem that are not unique to genetic tests and related services (even if their consequences might be felt particularly acutely in this sector): 1) mix of funding and remuneration models; 2) lack of a robust frameworks and processes to guide the evolution of tests and related services; and 3) gaps in the research evidence regarding the clinical validity and utility of genetic tests. One dialogue participant emphasized the importance of recognizing that this is a ‘complex problem’ and that complex problems require particular approaches to understanding and addressing them.





Participants drawn from government and from government, stakeholder and research organizations gather during a McMaster Health Forum event on 19 June 2012

## Deliberation about an approach

Dialogue participants generally supported all three potential elements of a comprehensive approach to address this ‘complex problem:’ 1) a comprehensive policy framework for the ongoing planning, funding, delivery and evaluation of genetic tests and related services, particularly one that could guide decisions in BC regarding “who gets what, where and how, and who should pay” (although there were differences of opinion about whether to develop the framework so that it could address all genetic tests and related services immediately, or to build up the framework by working through the issues raised by a particular disease or test, whether the process for its development should involve few or many people and be a time-limited task force or a formalized body, and whether only experts or a broader array of stakeholders (including the public) should be involved in developing the framework); 2) a quality framework for genetic tests and related services (with a particular focus on education and training and a participatory process for guideline development, among other sub-elements); and 3) a framework to support consumer/patient/family decision-making about genetic tests and related services (with a particular emphasis on supporting patient self-education).

## Deliberation about next steps

Dialogue participants agreed that they needed to: 1) raise awareness about the urgency of the problem; 2) examine alignments between the elements of an approach to addressing the problem and existing provincial initiatives (e.g., clinical care management and health technology assessment) and their underlying goals (e.g., containing costs, increasing efficiency, improving quality); and/or 3) take advantage of both foreseeable and unforeseeable ‘windows of opportunity’ to pursue well-aligned elements of an approach to addressing the problem (e.g., the laboratory-reform process taking place and the establishment of a new health technology assessment infrastructure and process in BC).

## Dialogue deliverables

To learn more about this topic, consult the [evidence brief](#) that was presented to participants before the dialogue, the [summary](#) of the dialogue, and [view](#) or [listen](#) to the interviews with dialogue participants. For an electronic copy of the evidence brief or dialogue summary, or to view or listen to the interviews, visit our website [www.mcmasterhealthforum.com](http://www.mcmasterhealthforum.com) and click on ‘Products’ along the sidebar, or for direct access to our [YouTube](#) and [iTunes U](#) channels, simply click on the icons below.



### >> Contact us

1280 Main St. West, MML-417  
 McMaster University  
 Hamilton, ON Canada L8S 4L6  
 Tel: +1.905.525.9140 x 22121  
 Fax: +1.905.521.2721  
 Email: [mhf@mcmaster.ca](mailto:mhf@mcmaster.ca)

### >> Follow us

[mcmasterhealthforum.org](http://mcmasterhealthforum.org)  
[healthsystemsevidence.org](http://healthsystemsevidence.org)



[tinyurl.com/mhf-iTunesU](http://tinyurl.com/mhf-iTunesU)  
[tinyurl.com/mhf-YouTube](http://tinyurl.com/mhf-YouTube)  
[tinyurl.com/mhf-Facebook](http://tinyurl.com/mhf-Facebook)  
[tinyurl.com/mhf-Twitter](http://tinyurl.com/mhf-Twitter)

**EVIDENCE >> INSIGHT >> ACTION**