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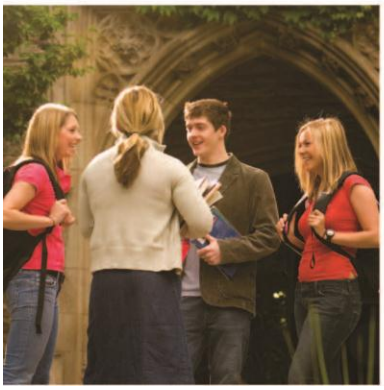
McMaster HEALTH FORUM

DIALOGUE SUMMARY

# COORDINATING THE USE OF GENETIC TESTS AND RELATED SERVICES IN BRITISH COLUMBIA

19 JUNE 2012

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

19 June 2012

McMaster Health Forum

For concerned citizens and influential thinkers and doers, the McMaster Health Forum strives to be a leading hub for improving health outcomes through collective problem solving. Operating at the regional/provincial level and at national levels, the Forum harnesses information, convenes stakeholders, and prepares action-oriented leaders to meet pressing health issues creatively. The Forum acts as an agent of change by empowering stakeholders to set agendas, take well-considered actions, and communicate the rationale for actions effectively.

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Conflict of interest

The authors declare that they have no professional or commercial interests relevant to the dialogue summary. The funder reviewed a draft dialogue summary but the authors had final decision-making authority about what appeared in the dialogue summary.

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# SUMMARY OF THE DIALOGUE

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) perhaps most pressingly, the rapid pace of technological change (e.g., whole genome sequencing) 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 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 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.

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 B.C., 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).

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 B.C.).

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# SUMMARIES OF THE FOUR DELIBERATIONS

## DELIBERATION ABOUT THE PROBLEM

Many dialogue participants agreed that key features of the problem in British Columbia (B.C.) 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. However, one dialogue participant argued that these features of the problem are common to many domains in healthcare and not unique to genetic tests and related services. This individual cautioned against "genetic exceptionalism."

A number of dialogue participants argued that certain features of the problem are, in fact, unique to genetic tests and related services. First, direct-to-consumer genetic testing was identified as a unique emerging feature of the problem. One dialogue participant noted, for instance, that the increased accessibility of genetic tests through direct-to-consumer genetic testing will create a number of challenges for publicly funded health systems, especially given the lack of regulation of direct-to-consumer genetic testing and the potential downstream costs arising from further investigations.

Second, the media coverage that portrays genetics and genomics as a medical panacea (which several dialogue participants called 'media hype') was also identified as a unique feature of the problem. One dialogue participant was worried that the media were not informing or educating the public in a balanced way (e.g., about the health benefits to be derived from tests and their ethical implications), which was contributing to a lack of public understanding of genetic issues and potentially driving increased demand for genetic tests and related services.

Third, and perhaps most pressingly, the rapid pace of technological change (e.g., whole genome sequencing), was identified as another unique feature. A number of dialogue participants noted that the changes are significantly affecting all areas of medicine in an unprecedented way and that this would pose a challenge in terms of how the level of genetic literacy could be increased and sustained among the public, healthcare providers and policymakers. As one dialogue participant noted, "there is a deluge of scientific discoveries." Many dialogue participants focused specifically on the challenge in relation to healthcare providers. A

**Box 1: Background to the stakeholder dialogue**

The stakeholder dialogue was convened in order to support a full discussion of relevant considerations (including research evidence) about a high-priority issue in order to inform action. Key features of the dialogue were:

1) it addressed an issue currently being faced in British Columbia, Canada;
2) it focused on different features of the problem, including (where possible) how it affects particular groups;
3) it focused on three elements of an approach (among many) for addressing the policy issue;
4) it was informed by a pre-circulated evidence brief that mobilized both global and local research evidence about the problem, three elements of an approach for addressing the problem, and key implementation considerations;
5) it was informed by a discussion about the full range of factors that can inform how to approach the problem and possible options for addressing it;
6) it brought together many parties who would be involved in or affected by future decisions related to the issue;
7) it ensured fair representation among policymakers, stakeholders and researchers;
8) it engaged a facilitator to assist with the deliberations;
9) it allowed for frank, off-the-record deliberations by following the Chatham House rule: "Participants are free to use the information received during the meeting, but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed"; and
10) it did not aim for consensus.

Participants' views and experiences and the tacit knowledge they brought to the issues at hand were key inputs to the dialogue. The dialogue was designed to spark insights – insights that can only come about when all of those who will be involved in or affected by future decisions about the issue can work through it together. The dialogue was also designed to generate action by those who participate in the dialogue, and by those who review the dialogue summary and the video interviews with dialogue participants.

number of participants emphasized that training in genetics is currently inadequate for all healthcare providers, and that there are too few training positions in genetics and insufficient emphasis on genetics in laboratory medicine and pathology. One participant observed that the primary care workforce is currently unprepared to integrate genetics into the regular practice of medicine: "[Sometimes] primary care practitioners know as little as the patient, but they need to respond like experts." A second participant pointed out, "as healthcare providers, we feel helpless and frustrated." A third participant argued that the challenges would not just be limited to education and training, and that technological changes will soon transform all aspects of medicine as it comes to be based, at least to some degree, on whole-genome sequencing: "That's the direction we are going."

Dialogue participants also highlighted several 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). First, the mix of funding and remuneration models for genetic tests and related services – the global budgets of hospitals and regional health authorities and the fee-for-service system for some genetic laboratory services – was singled out as a key feature of the problem. It was argued that each model brings its own set of complications. One dialogue participant argued that it was difficult for the Ministry of Health to obtain information about what tests have been performed and what protocols have been followed when genetic tests and related services are paid for through global budgets. Another participant argued that the fee-for-service system was also problematic because it created incentives to choose laboratory technologies based on the existence of a fee code for billing the Medical Service Plan for insured services. Both models also bring some common complications. One participant noted that both models made it difficult to leverage the wider genetic infrastructure in a coordinated way. Another participant argued that both funding models were not responsive to new and emerging genetic tests, especially for rare genetic diseases and conditions. A third dialogue participant noted that both funding models also delayed the implementation of technologies that could have saved money: "It doesn't make common sense. For Down syndrome detection, we are far behind Ontario. The whole system doesn't allow for good decision-making about what's cost-effective even when we have evidence… We should think forward, plan ahead."

Second, the lack of robust frameworks and processes to guide the evolution of genetic tests and related services was also singled out as a key feature of the problem. Several dialogue participants mentioned that the planning, funding, delivery and evaluation of genetic services are highly fragmented. One participant argued that, from the laboratory perspective, there is no infrastructure to help them define priorities in a context of scarce resources, to make choices on the "test menu" and to strengthen accountability or to define quality parameters and utilization guidelines. A second participant observed that there is no coordinated effort to support genetic counsellors who are struggling to expand the provision of counselling services in the community. A third participant noted that: "The policy on genetic testing is only two paragraphs and only covers treatment and management. Where do we go when [a new test] doesn't fit in the remit of current programs and services?" A fourth participant argued that the Ministry of Health has a difficult time making coverage decisions on discrete procedures. A fifth participant suggested that the development of a comprehensive framework would help them to know how to move forward: "(To understand) how to navigate the system to get us there."

Third, one dialogue participant argued that gaps in the research evidence regarding genetic tests (e.g., clinical validity, clinical utility, etc.), particularly "the kind [of research evidence] that is needed to make decisions," was a key feature of the problem. This individual went further: "We appear to have no will or capacity to review the evidence that will make [genetic tests and related services] valuable. How do we organize ourselves to sort out the evidence?"

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. This individual cited the following features of the problem in making this diagnosis of a 'complex problem': dynamic nature of the problem; the numerous drivers of the problem (e.g., the rapid pace of scientific discoveries, the increasing

public demand, the increasing number and types of genetic tests available, and the diverse health system arrangements – including incentive structures – and ethical considerations at play); and the interdependence among these drivers. This individual argued that the capacity of the individuals working in the health system appears to be overwhelmed by the complexity of the tasks they are being called on to provide.

## DELIBERATION ABOUT POLICY AND PROGRAMMATIC OPTIONS

The deliberation focused primarily on developing a comprehensive policy framework for the ongoing planning, funding, delivery and evaluation of genetic tests and related services (potential element 1 of a comprehensive approach to address the problem), to a lesser extent on developing a quality framework for genetic tests and related services (element 2), and to a much lesser extent on developing a framework to support consumer/patient/family decision-making about genetic tests and related services. That said, a number of dialogue participants noted that the three elements were essential and could not be approached in isolation. Several dialogue participants argued that the quality framework and decision-making frameworks could be nested within the comprehensive policy framework.

### Element 1 - Develop a comprehensive policy framework for the ongoing planning, funding, delivery and evaluation of genetic tests and related services

The deliberation about the first element initially focused on the experiences of other Canadian provinces in developing policy frameworks for the ongoing planning, funding, delivery and evaluation of genetic tests and related services. A number of dialogue participants observed that smaller Canadian provinces have mostly ad hoc approaches to genetic tests and related services that are not guided by a policy framework. One participant shared the experience of one such province, noting that coverage decisions were not "very evidence-based," although provincial and regional decision-makers could occasionally use the reports from health technology advisory bodies in other jurisdictions. This individual admitted that decision-makers in this province often relied on a single individual who advised them about coverage decisions: "You just call this person. (…) It is not very formalized at all. We have a gatekeeper model, by default."

Several dialogue participants commented on the Ontario experience, observing that the Ontario policymakers appeared to have had a number of successes in coordinating the use of genetic tests and related services, even though the province has not yet formalized its comprehensive policy framework guiding their efforts. Two participants noted that the Ontario Ministry of Health and Long-Term Care had convened a steering committee to support its genetics services strategy initiative, with one subcommittee addressing each of oversight, evaluation of genetic testing, delivery of genetic services, and quality assurance/standards. The health technology assessment infrastructure in Ontario was also mentioned, with the Ontario Health Technology Advisory Committee providing evidence-based recommendations in this area. A few dialogue participants commented on the provinces' two efforts to develop a comprehensive framework, with one being optimistic that the second effort would culminate in the public release of a framework. Another participant noted that the strategy has been "a long time coming" and that the issue of genetic tests and related services has moved on and off the government agenda in relation to political considerations and the complexity of the issues and interests at stake.

The development of a "big policy framework" that could guide decisions in B.C. regarding "who gets what, where and how, and who should pay" was mentioned as a critical element of a comprehensive framework. One dialogue participant added to this list 'how infrastructure is renewed.' Another participant emphasized the importance of attending carefully to what is inside and outside the publicly financed system, and how the publicly financed system responds to tests done outside this system. There were differences of opinion about how to develop such a policy framework, as well as who should be involved in its development.

The first of two differences of opinion in how to develop a comprehensive policy framework was 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. An advocate for the former argued that it would avoid constantly 're-inventing the wheel' and would take much less time. An advocate for the latter emphasized the importance of understanding, with the input of key stakeholders, the different drivers for the numerous medical applications of particular genetic tests (e.g., diagnostic testing, predictive or susceptibility testing, companion testing and population screening), and then over time identifying the commonalities across medical applications and/or tests. Another dialogue participant argued a disease-based framework would be more helpful than a test-based framework: "The disease will stay the same, but the technologies will change." The advocate for the more inductive and iterative approach didn't care as much whether the starting point was diseases or tests, but argued: "You need to pick a disease [or genetic test] and look at the breadth of the population [potentially affected], the accessibility to the testing, and so on, working through problems…. There may be commonalities across domains, but you need to get the drivers right." This individual argued that these cycles of working through examples were akin to plan/do/study/act cycles in quality improvement, and could be done quite quickly. This inductive and iterative approach of working through examples in order to develop a comprehensive framework resonated with a number of participants. One said: "It encourages us to think about the individual elephants and the individual solutions."

The second of two differences of opinion in how to develop a comprehensive policy framework was whether the process for its development should involve few or many people, and be a time-limited task force or a formalized body responsible both for developing the framework and for implementing it, monitoring its implementation, and evaluating its impact. One dialogue participant argued that a small group (of say three people) could rapidly draft a working document about how genetic tests and related services should be planned and funded in future. Another participant doubted that only three people could draft a framework that could address all the complex features of this problem: "[It is] hard to find two to three people who are knowledgeable enough and without vested interests." This individual argued for a larger, more inclusive task force. A third participant argued for a formalized advisory body: "We should think forward, plan ahead. I'm supportive about [developing a comprehensive policy framework], but a task force sounds too short term."

Turning to the differences of opinion in who should be involved in developing the framework, dialogue participants consistently argued for including experts who are knowledgeable about genetic tests and related services and who are credible in this domain, however, they differed in whether other stakeholders and particularly citizens should be involved. Some participants argued strongly for including members of the public right from the beginning. One participant commended the establishment of a citizen panel to provide public input regarding new technologies to the Ontario Health Technology Advisory Committee. A second participant acknowledged that public engagement can be time- and resource-intensive, but argued that "it can produce world-class documents." A third participant, while reflecting on the Oregon experience, was cautious about starting the process with a public forum. This participant preferred to start with a more expert-oriented process where the experts could critically examine different policy frameworks, and later work with stakeholders to fine-tune a draft framework: "A public forum is not a good place to start…. It should be more downstream."

**Element 2 - Develop a quality framework for genetic tests and related services**

Much of the deliberation about the second potential element of a comprehensive approach to address the problem focused on increasing opportunities for the education and training of health professionals in genetics. One dialogue participant expressed surprise about the framing of this sub-element in the evidence brief, and argued that it may be necessary to be more assertive: "I was shocked by this. It should be about mandating genetic education [and training]." Another participant emphasized the importance of focusing on:

1) the integration of new developments in genetic testing and related services into clinical practice, and not simply 'education;' 2) using research evidence to inform supporting this integration; and 3) using plan/do/study/act cycles to support integration in ways that are sensitive to local contexts. A third participant emphasized the need to focus on addressing overuse of genetic tests and related services. A fourth participant mentioned that existing efforts were focusing on continuing education (with a different participant noting CFPlus Gene Messenger being a good example of a continuing education approach), and suggested that basic education and training should also be improved. A fifth participant agreed with the need to change curriculums now, arguing that physicians in the next 10 years will use new tools that involve genetics and bioinformatics. A sixth participant noted that support from the College of Physicians and Surgeons of British Columbia would be very helpful for some of these activities. A seventh participant, invoking a 'systems approach' to this complex problem, called for developing the necessary capacity among healthcare providers to match the complexity of the problem they're facing.

Another focus of the deliberation about a quality framework was the potential role that genetic counsellors could play in supporting the education and training of other types of healthcare providers. One dialogue participant said: "[Genetic counsellors] are a resource to call. [They] get calls every day. [They are] a support system for healthcare providers." The mention of genetic counsellors playing this role raised a number of other issues regarding this group. One participant mentioned the need for an approach to evaluate how many genetic counsellors are needed and to support the credentialing process for genetic counsellors. This individual lamented that only six genetic counsellors are graduating every year in B.C., and that many are unable to find a job and often work as research coordinators. "We don't have a framework to look at how the resources that we currently have…. They are not properly utilized."

A third focus of the deliberation about a quality framework involved clinical practice guidelines. Several dialogue participants argued for developing simple guidelines about the "whens" and "whys" of ordering genetic tests and related services, which could be organized by disease or by medical application of genetic tests and targeted at different healthcare providers on the basis of their "need to know." One participant noted that the B.C. Guidelines initiative could be 'leveraged' for this purpose. A second participant noted that they had had bad experiences with guidelines that were developed without proper consultation with stakeholders, and that the process for developing guidelines needed to be improved. A third participant emphasized the importance of guidelines (and related quality-improvement supports) being "timely, responsive and relevant."

A fourth focus of the deliberation was quality assurance in laboratories, which was noted to be mandatory in B.C., but did not fully include proficiency testing for genetic testing and related services. One individual noted that issues related to quality assurance in laboratories were intertwined with issues related to their funding and service volumes.

A fifth and final focus of the deliberation was the need for a unifying quality framework and the high likelihood that one could be developed given key stakeholders' willingness to cooperate. One dialogue participant noted that a unifying quality framework would be particularly helpful given how genetic resources and initiatives are currently scattered and fragmented. A number of dialogue participants argued that a variety of healthcare providers would be willing to come together around a quality framework. One participant said: "I don't see a lot of turf issues in town… there is a lot of cooperation. It's not too 'Balkanized'…." Another said: "Cooperation… is remarkable in this community. To have pathologists cooperate is amazing." A third participant cited the example of the Family Practice Oncology Network as an example of a willingness to work together. A fourth participant cautioned, however, that a similar willingness to work together diminished significantly when laboratories in B.C.'s lower mainland were required to consolidate services.

**Element 3 - Develop a framework to support consumer/patient/family decision-making about genetic tests and related services**

Many dialogue participants argued that the third potential element of a comprehensive approach – developing a framework to support decision-making – was critical, especially in a context of direct-to-consumer genetic testing and 'media hype.' One participant noted that if provincial policymakers and stakeholders cannot provide a framework to support decision-making, it will be done by others: "Most information in the media is incorrect. It must be done properly. (We) must provide access to accurate information."

One dialogue participant suggested that any initiative to develop such a framework should not be done in isolation from healthcare providers, including genetic counsellors whose role is to promote informed choices regarding genetic testing. A second dialogue participant agreed that genetic counsellors could contribute to the framework's development, which would be more realistic than involving them in every decision regarding genetic tests and related services: "You can't have genetic counsellors in every discussion."

A number of dialogue participants emphasized the need to support patient self-education, and many of them suggested guiding people to existing, highly rated supports. One participant mentioned the need to develop web-based interventions to support consumer/patient/family decision-making. Another participant mentioned the use of social networks, like www.patientslikeme.com, where members can share experiences and learn from each other. A third participant also highlighted the need for a public version of the physician-targeted CFPlus Gene Messenger education program. A fourth participant mentioned the need to draw lessons from international initiatives, such as the work of the U.S. National Council on Patient Information and Education. A fifth participant noted that these efforts could help both to address the high demand for genetic tests and related services and the uncertainty associated with them.

A few dialogue participants mentioned the importance of national collaboration to develop a framework to support consumer/patient/family decision-making. One participant believed that it would be useful to have a single Canadian portal to support public and patient education about genetic tests and related services, as well as a single Canadian portal for physicians or perhaps all healthcare providers. However, this individual was skeptical about the feasibility of such an initiative given the federal/provincial dynamics in the country. Another participant regretted that federalism has resulted in a fragmented community and that it was difficult to learn from and collaborate with each other.

**Considering the full array of options**

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 B.C. regarding "who gets what, where and how, and who should pay" (although there were differences of opinion about how the framework should be developed and who should be involved in its development) 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). Dialogue participants did not identify additional potential elements of a comprehensive approach.

## DELIBERATION ABOUT IMPLEMENTATION CONSIDERATIONS

Dialogue participants identified two barriers to implementing the key elements of a comprehensive approach to coordinating the use of genetic tests and related services in B.C.: 1) the perception that the issue is not on the government agenda; and 2) the degree to which B.C. and Canadian experts who could contribute to the process are over-committed.

Starting with the first of the two barriers, several dialogue participants argued that the problem was not currently on the government agenda and that the ministry needed to either participate in developing an approach to addressing the problem or to lead it (although they disagreed about which was preferable). A few participants stated that the government's role needed to include not just publicly financed genetic tests and related services, but also a stewardship role with respect to privately financed tests and services. One participant noted that the development of the yet-to-be-released policy framework for genetics in Ontario was led by the Ministry of Health and Long-Term Care. 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. Regarding alignment with current government priorities, one participant noted that "if there is a cost-containment or cost-saving dimension, it's likely to have more traction for the ministry." A second participant observed that it could be "very palatable to the Ministry of Health" if it was clearly explained that addressing the problem would increase the returns to existing investments (i.e., increase efficiency). A third participant argued that quality assurance was the most helpful way to align with existing priorities: "There has never been a better time for quality assurance. There is a real opportunity here." In terms of taking advantage of windows of opportunity, dialogue participants gave the examples of a quality-improvement initiative led by two Canadian premiers, the laboratory-reform process taking place and the establishment of a new health technology assessment infrastructure and process in B.C., and a provincial election in 2013. One dialogue participant, drawing from the Ontario experience, argued for undertaking the work rapidly in order to have the right information ready: "Having the information available at the right time is critical."

Turning now to the second of the two barriers, a few dialogue participants commented on the degree to which B.C. and Canadian experts who could contribute to the process are over-committed. One dialogue participant noted that "freeing up people to do this is a challenge." Several dialogue participants noted that some elements of the framework-development process would benefit from having experts from other provinces participate, both to bring experiences from these other provinces and to learn from the B.C. experience in order to support similar work in their own provinces. One dialogue participant said: "Although it needs to be B.C. specific, it cries out for a national or pan-Canadian approach." The same participant said that the Canadian Institutes of Health Research (CIHR) Institute of Genetics could play a convening role for a pan-Canadian approach if there was a desire to proceed in this direction. Another participant agreed, noting that there are a number of successful cross-provincial collaborations in healthcare (e.g., accreditation of medical schools). A third participant agreed: "You need to act locally, connect regionally, and think globally." However, a fourth dialogue participant cautioned that: "We can't wait for another province to sort this out [although we] need to connect with efforts in other provinces." A fifth dialogue participant noted that there has been "[s]ome interest expressed in other jurisdictions, but I'm less confident if we could get this under an FPT [federal, provincial, territorial] initiative."

## DELIBERATION ABOUT NEXT STEPS FOR DIFFERENT CONSTITUENCIES

Dialogue participants agreed that each of them as individuals could undertake a number of steps given their respective roles, but many argued that it would be very helpful if the ministry could convene senior staff (such as the five assistant deputy ministers) to discuss potential next steps (including the part of the ministry best positioned to lead or be the point of contact for this work, as well as the parts that need to play other roles), and to update dialogue participants about these potential next steps so that their individual efforts could support and add value to these next steps. Several dialogue participants also noted that in circumstances such as these the ministry tends to prefer to use a collaborative (or consensus-based) approach rather than a prescriptive approach (even though eventually there may be a regulatory component to the work ahead and, ultimately, the ministry will have to set policy).

Examples of individuals' potential contributions, given their organizational roles, include: 1) playing an impartial convenor role (in the case of the Michael Smith Foundation for Health Research for provincial discussions and the CIHR Institute of Genetics for national discussions); 2) identifying potential participants in the framework-development process (e.g., existing medical genetics programs) and encouraging them to avoid turf wars and the creation or perpetuation of silos; 3) identifying those who will be involved in or affected by this work so they can be engaged early on in the process (including B.C. College of Physicians and Surgeons, B.C. Guidelines, the B.C. Medical Association's Tariff Committee, and the Canadian Association of Genetic Counsellors); 4) raising awareness among funders (e.g., CIHR, Genome B.C.) about the need to support this work; 5) supporting education and training initiatives, include medical curriculum and resident training program design (e.g., getting family-practice residents to give presentations about the implications of genetics for primary care); and 6) identify individuals from other provinces who could support the process and learn from it.

The views of one dialogue participant were summed up at the end of the deliberations in a particularly galvanizing way: "I think B.C. has everything it needs, including a collegial environment and the will and dedication to move this forward. [It could be] a real showcase for other jurisdictions."