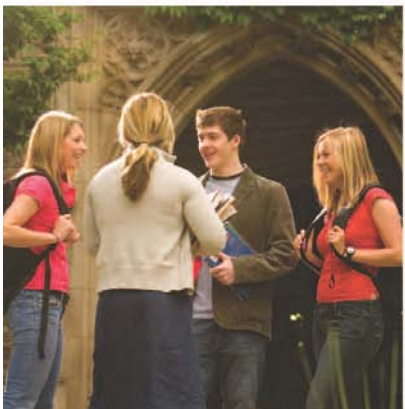




ENGAGING HEALTH SYSTEM DECISION-  
MAKERS IN SUPPORTING  
COMPREHENSIVE CHRONIC PAIN  
MANAGEMENT IN PROVINCIAL AND  
TERRITORIAL HEALTHCARE SYSTEMS IN  
CANADA



**Dialogue Summary:  
Engaging Health System Decision-makers in Supporting  
Comprehensive Chronic Pain Management in  
Provincial and Territorial Healthcare Systems in Canada**

11 April 2011

#### 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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The authors declare that they have no professional or commercial interests relevant to the dialogue summary. Members of the dialogue steering committee 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

Most dialogue participants noted that the lack of health system decision-maker engagement in supporting comprehensive chronic pain management in provincial and territorial health systems in Canada is largely the result of a lack of awareness of the problem. Several themes related to this lack of awareness emerged during the dialogue: 1) a lack of understanding of chronic pain (which in turn relates to a lack of consensus about what chronic pain actually is, and a lack of data and research evidence about its impact on Canadians and on health systems in Canada); 2) the limited education provided about chronic pain to patients, healthcare providers and health system decision-makers; and 3) a lack of a well documented case for why chronic pain is an issue that health system decision-makers need to focus on (which includes a lack of stories about how chronic pain affects patients' lives, a lack of documentation of the broader economic impact of chronic pain, and a lack of documentation of success stories in chronic pain management).

Most dialogue participants strongly endorsed the creation of a national multi-stakeholder network comprised of existing organizations and committed individuals who would work collaboratively to raise awareness about chronic pain, and increase support for and coordination in comprehensive chronic pain management. Several dialogue participants called for including in the network those involved in chronic disease management, primary healthcare and other domains that have already been prioritized, and that are highly relevant to those living with chronic pain. Most participants thought that an advocacy campaign would be an important function for this network. A number of dialogue participants also endorsed the idea of developing chronic pain policy portfolios within government, and strategic foci within regional health authorities, optimally nested within broader portfolios/foci such as chronic diseases, in order to ensure that there is a clear 'anchor' for chronic pain within health systems.

Five significant challenges related to implementation were identified by dialogue participants: 1) identifying a leadership model; 2) ensuring the capacity and willingness of existing organizations and individuals to engage in creating and sustaining the network; 3) weighing the advantages of working within a small group of provinces and territories to achieve some early wins, versus working across all provinces and territories simultaneously; 4) securing the resources to design, launch and operate the network and any advocacy campaign it develops; and 5) scaling up the efforts to identify and harness data and produce and synthesize research evidence that supports the work of the network and the content of any advocacy campaign.

Deliberations about next steps largely focused on the need to mobilize behind an effort to build a national network that would bring together existing organizations and committed individuals. Some early wins for the network could include the endorsement of a national pain strategy, which would include agreed upon definitions. Several dialogue participants emphasized the primacy being given to an 'evidence-based' and 'grass-roots' approach, and being certain not to lose these features in a rush to a 'big bang' solution.

## **SUMMARIES OF THE FOUR DELIBERATIONS**

### **DELIBERATION ABOUT THE PROBLEM**

Most dialogue participants noted that the lack of health system decision-maker engagement in supporting comprehensive chronic pain management in provincial and territorial health systems in Canada is largely the result of a lack of awareness of the problem. Several themes related to this lack of awareness emerged during the dialogue: 1) a lack of understanding of chronic pain; 2) the limited education provided about chronic pain; and 3) a lack of a well documented case for why chronic pain is an issue that health system decision-makers need to focus on.

The first theme – a lack of understanding of chronic pain by patients, healthcare providers, health system decision-makers and the broader public – was argued to have two antecedents: 1) a lack of consensus about what chronic pain actually is; and 2) a lack of data and research evidence about its impact on Canadians and on health systems in Canada.

A number of dialogue participants noted that there is no consensus on what chronic pain actually is. While there exist a number of definitions of chronic pain (including the two commonly used definitions that were highlighted in the issue brief), several dialogue participants argued that there are important disagreements about elements of these definitions (e.g., the amount of time that an individual needs to live with pain before being defined as having ‘chronic pain’). One participant also argued that ‘chronic pain is too big to grasp as a key issue’, and a second participant argued that chronic pain needs to be ‘broken down’ in such a way that decision-makers can see its importance. A third dialogue participant highlighted that there is a great deal of misunderstanding about chronic pain, observing that ‘pain is much more than just a symptom,’ yet in a disease-centred health system the focus is on treating the symptom.

A number of dialogue participants also noted that there is a lack of data and research evidence about chronic pain’s impact on Canadians and on health systems in Canada. Everything from the true prevalence of chronic pain in Canada through to its impact on Canadians’ finances and social networks is then poorly understood or contested. The lack of data and research evidence was attributed by some to a lack of targeted research funding from the Canadian Institutes of Health Research, and by others to (in most provinces) a lack of diagnostic codes and of billing codes

#### **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 Canada;
- 2) it focused on different features of the problem, including (where possible) how it affects particular groups;
- 3) it focused on three options (among many) for addressing the policy issue;
- 4) it was informed by a pre-circulated issue brief that mobilized both global and local research evidence about the problem, three options 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.

for chronic pain services delivered by physicians. The lack of diagnostic codes hinders assessments of prevalence, and the lack of billing codes (or the lack of diagnostic codes that can be linked to existing billing codes) hinders assessments of the services and costs attributable to chronic pain and the impacts and costs of chronic pain programs and services.

The second theme – the limited education provided about chronic pain to patients, healthcare providers and health system decision-makers – was discussed by several dialogue participants as a key contributor to the lack of awareness of chronic pain. One dialogue participant highlighted that patients often don't know about the types of services that should be included in their care, and more generally the options available to them. Turning to physicians, the lack of chronic pain-related training in medical school curricula was raised several times as a key contributor to the less-than-optimal diagnosis and management of chronic pain, and to the lack of physician-led advocacy for improvements to the supports available to those living with chronic pain.

The third theme –lack of a well documented case for why chronic pain is an issue that health system decision-makers need to focus on – emerged as having three dimensions to it: 1) a lack of stories about how chronic pain affects patients' lives; 2) a lack of documentation of the broader economic impact of chronic pain; and 3) a lack of documentation of success stories in chronic pain management.

First, a number of dialogue participants argued that there is a lack of stories about how chronic pain affects patient's lives. The lack of stories means that decision-makers, physicians and the public, among others, can't appreciate what people living with chronic pain go through and, given many will not 'get better,' the significant time periods that people live with pain. The lack of stories also means that many patients have to continue to live with the stigma associated with chronic pain, which can include the perception that it is the patient's fault, as opposed to a disease in its own right. One dialogue participant gave obesity as another example of a condition perceived as the patient's fault.

Second, several dialogue participants noted a lack of documentation of the broader economic impact of chronic pain on individuals, employers and governments. A few dialogue participants noted that at the level of individuals, the economic impacts included out-of-pocket costs and foregone income, among others. In terms of employers, the economic impacts can include absenteeism, a loss of productivity, higher extended-benefit program costs, and higher workers' compensation costs. One dialogue participant noted that much could be learned from how mental health champions have demonstrated the significant costs of depression for Canadian businesses. A number of dialogue participants argued that the situation facing individuals and employers is made more complicated by the lack of public financing for many types of care being used by those living with chronic pain (e.g., rehabilitation services), which has led to the emergence of a large and growing sector of for-profit providers marketing themselves as specialists in chronic pain management. One participant called this the 'elephant in the room', and another noted that what employers and insurance companies urgently need is help with identifying what to pay for and what not to pay for. A few dialogue participants noted that governments are affected by lower tax revenues from those living with chronic pain, and higher expenditures on health systems and on other social programs such as employment insurance.

Third, several dialogue participants lamented a lack of documentation of success stories in chronic pain management that can provide decision-makers with more confidence that something can be done. As one dialogue participant said: "A key element of problem framing is saying how a problem affects others and how addressing the problem provides benefits to many." Several dialogue participants gave examples of what they perceived as success stories, including the chronic pain self-management program in Ontario's Central East Local Health Integration Network, and the effort to address issues related to chronic pain along the continuum of care in Saskatchewan. However, dialogue participants observed that these success stories are not getting enough attention from health system decision-makers outside the jurisdiction where they take place.



One dialogue participant summed up the deliberation about the problem by saying that without consensus about what chronic pain is, its costs, and the desired outcomes or goals, it is difficult to reliably determine what the potential impacts and cost savings are going to be, which significantly limits the power of any proposal that can be made to a health minister or to a health system decision-maker.

## **DELIBERATION ABOUT POLICY AND PROGRAMMATIC OPTIONS**

Dialogue participants discussed three options that had been ‘worked up’ in the issue brief as concrete examples of what could be done differently. Most dialogue participants found elements of all of the options attractive, and most agreed that each could have a role to play in engaging health system decision-makers in supporting comprehensive chronic pain management.

### **Option 1 – Launch an advocacy campaign**

Most dialogue participants supported the idea that an advocacy campaign is an important part of a broader strategy, however, some participants thought that an advocacy campaign was the wrong place to start. Those who thought an advocacy campaign was the wrong place to start emphasized the importance of first doing more work on defining the problem (i.e., articulating ‘what are the real challenges’), developing concrete and fully costed proposals for action, and/or ‘laying the groundwork’ from a process perspective. Those with experience with advocacy campaigns emphasized the importance of: 1) identifying the target audiences for the campaign (which one individual argued should be politicians, but also the senior civil servants who advise them, whereas another individual argued they should include high-level health system decision-makers of many types, but also physicians who often have the ear of these decision-makers); 2) clarifying what will be communicated to these target audiences (which one individual argued should be supplemented by ‘getting the evidence out in an accessible way’); and 3) identifying and engaging one or more highly visible ‘champions’ to lead these communications (such as Michael Wilson, a former Canadian cabinet minister, and later Michael Kirby, a Canadian senator, did for mental health).

From a process perspective, several dialogue participants argued for establishing a Canadian network that can collaboratively develop the advocacy strategy, and for learning from past success stories. The network (which foreshadows the discussion about the next option) would ideally draw together all interested and committed parties while not, in the words of one participant, ‘assuming that an existing organization will be sufficiently free of the baggage needed to lead other organizations.’ One individual argued that the network needs to ensure it is headed by a small group of individuals who can work well together in a team, and that it always has a proposal ready for when a window of opportunity opens. An example of a window of opportunity might be the re-negotiation of the health accord between Canada’s federal and provincial governments, which is set to expire in 2014. The examples of past success stories that were offered include the advocacy campaigns related to mental health (which culminated in the creation of the Mental Health Commission of Canada) and cancer (which culminated in the creation of the Canadian Partnership Against Cancer).

Some dialogue participants noted the need to be aware of the competition for attention both from other diseases and from private for-profit interests, and the need to take advantage of strategic opportunities such as the national pain awareness week that was formally established in 2004 by the Canadian Senate and the activities of the Canadian Pain Society, Canadian Pain Coalition, and planned Canadian Pain Summit.

## **Option 2 - Create a multi-stakeholder provincial or national working group**

Most dialogue participants embraced the general idea of developing a national collaborative effort, such as a working group or network, to raise awareness about chronic pain and increase support for and coordination in comprehensive chronic pain management. The rationale offered by many dialogue participants for a national network was that it could act as a ‘big tent’ for existing organizations and committed individuals to work collaboratively. The focus of this work could include identifying and pushing to fill gaps in care and support, as well as advocacy. The word ‘network’ was preferred over the phrase ‘working group’ by one dialogue participant because it implied a potential for more coordinated efforts across organizations and individuals, and not just a potential for more coordinated efforts across individuals.

A number of dialogue participants emphasized the importance of collaboration, and by this most meant collaboration among those with expertise in chronic pain, including patients living with chronic pain, healthcare providers helping to manage chronic pain, health system decision-makers overseeing programs and services related to chronic pain, and researchers studying chronic pain. However, a small number of dialogue participants also emphasized the importance of collaboration with those involved in the funding, organization and delivery of healthcare programs and services that have already been prioritized, and that are highly relevant to those living with chronic pain, such as programs and services in the fields of chronic disease management and primary healthcare. As these participants noted, health system decision-makers in particular know how these programs can and should work, and they can more easily imagine how to incorporate chronic pain management into these programs than they can imagine starting something new to support chronic pain management. One participant argued for involving business people in the national network, given their vested interests in the topic and the substantial resources required to develop and sustain a long-term strategy and campaign.

One dialogue participant outlined what past experience suggested were four requirements for success in multi-stakeholder networks: 1) developing a vision and goals that will be used to guide the activities of the network; 2) developing an understanding of the values of each network member (as the dialogue participant called it, ‘getting everything on the table’); 3) agreeing to share in the financial, legal and reputational risks associated with the network’s activities; and 4) agreeing to share in the credit that accrues from the network’s activities. Another dialogue participant argued that champions are also important to the success of networks, however, engaging one to focus on chronic pain could be difficult given the stigma associated with the condition.

Several dialogue participants again called for learning from past success stories, but in this case with network creation, development and sustainability. The examples of past success stories that were offered include the network that came together to develop the Canadian Strategy for Cancer Control, and later to secure funding for the Canadian Partnership Against Cancer, as well as the network of four expert centres based within Quebec universities (Laval, McGill, Montreal and Sherbrooke) and anchored in the Réseaux Universitaires Intégrés de Santé (RUIS – Integrated University Health Network) that came together to support improvements to chronic pain management in Quebec. As noted in the issue brief, each centre has a specific mandate in terms of tertiary-level clinical services, training, research and support related to chronic pain for a defined region of the province.

During the dialogue, a dialogue participant described the stages involved in the development of the Quebec network, which might be germane to those developing a national network:

- developing awareness about the issue;
- convening a series of meetings to work through the issue;
- establishing a vision for addressing the issue (which included framing the vision from the patient, physician and system perspective);
- setting specific goals; and

- initiating a participatory process to identify and define a set of organizations to be involved, and a set of functions to be undertaken.

The dialogue participant noted that the well respected Québec government agency responsible for health services and technology assessment (AETMIS - the Agence d'évaluation des technologies et des modes d'intervention en santé) was engaged to mobilize the best available research evidence, using a rigorous approach, to support the work.

The final step in the development of the Quebec network was the preparation of a proposal to the deputy minister and the relevant assistant deputy minister. Each of the steps that had been followed in getting to the proposal stage was thought to have given the proposal 'the added weight and respectability' needed to make the case convincingly. Key elements of the case included: 1) chronic pain 'clients' are already in the healthcare system and the proposed program would cost less than the status quo; 2) the proposal built on what is already in place (e.g., by designating four existing centres as expert centres for chronic pain); and 3) this type of approach had been used successfully in other domains. Interestingly, the expert centres now create pressure on the system from within to continually improve what is being done for patients living with chronic pain.

### **Option 3 - Develop chronic pain policy portfolios and strategic foci**

A number of dialogue participants endorsed the idea of developing chronic pain policy portfolios within government and strategic foci within regional health authorities, in order to ensure that there is a clear 'anchor' for chronic pain with health systems. Most of these dialogue participants agreed that this portfolio/focus would need to be integrated within other broader portfolios/foci in order to make it viable and sustainable. In Quebec's provincial government, chronic pain was nested within the neuroscience portfolio. Several dialogue participants suggested that the most logical fit for chronic pain in their provinces would be to nest it within chronic disease portfolios/foci. However, one participant argued that additional work would still be needed to address the unique features of chronic pain. A second participant gave the example of chronic obstructive pulmonary disease (COPD) that also required significant additional work to address its unique features. Another dialogue participant gave the example of the work done on obesity in Alberta as an example of where a provincial strategy had been developed in part by leveraging capacity across portfolios.

Two dialogue participants argued for a more stand-alone approach to addressing chronic pain. One noted that lessons could be learned from the development and implementation of the regional geriatric model in Ontario, which also required a significant effort to organize and integrate care for a defined population. The second noted that lessons could also be learned from Cancer Care Ontario, which has much more independence and a greater degree of authority (in this case over the design of the cancer care sub-sector, the purchasing of cancer care services, and the performance monitoring and management system used in cancer care, among other domains).

### **Considering the full array of options**

Most dialogue participants strongly endorsed the creation of a national multi-stakeholder network comprised of existing organizations and committed individuals who would work collaboratively to raise awareness about chronic pain and increase support for and coordination in comprehensive chronic pain management. Several dialogue participants called for including in the network those involved in chronic disease management, primary healthcare and other domains that have already been prioritized, and that are highly relevant to those living with chronic pain. Most participants thought that an advocacy campaign would be an important function for this network. A number of dialogue participants also endorsed the idea of developing chronic pain policy portfolios within government and strategic foci within regional health authorities, optimally nested

within broader portfolios/foci such as chronic diseases, in order to ensure that there is a clear ‘anchor’ for chronic pain with health systems.

Over the course of the deliberations about options, dialogue participants raised new option elements or increased the attention given to existing option elements. First, several dialogue participants expressed the urgent need for a national strategy that can be used to engage health system decision-makers and a broad array of stakeholders from across the country, which is something that the organizers of the Canadian Pain Summit are already developing. Second, a few dialogue participants argued for better engaging physicians and other health professionals as champions for improved chronic pain management. Physicians in particular were noted as ‘having the ear’ of many health system decision-makers. Third, several dialogue participants emphasized the importance of effectively packaging and presenting research evidence to health system decision-makers.

### **DELIBERATION ABOUT IMPLEMENTATION CONSIDERATIONS**

Five significant challenges were identified related to implementation:

- identifying a leadership model, which might require identifying different types of leaders, including one with formidable motivational and organizational skills to engage existing organizations and individuals in the creation of a national network, a number who are well placed within existing organizations (including government) and can contribute their own time and staff time to the effort, and one or several highly visible champions in the media who can give a face to chronic pain;
- ensuring the capacity and willingness of existing organizations and individuals to engage in creating and sustaining the network;
- weighing the advantages of working within a small group of provinces and territories to achieve some early wins versus working across all provinces and territories simultaneously;
- securing the resources to design, launch, and operate the network and any advocacy campaign it develops; and
- scaling up the efforts to identify and harness data and produce and synthesize research evidence that supports the work of the network and the content of any advocacy campaign (as well as address data ownership issues, possibly by working with the Canadian Institute of Health Information to collect standardized data from across the country).

The second of these challenges, particularly the challenge of ensuring the willingness of existing organizations to engage in creating and sustaining a network, was the focus of some disagreement. Some dialogue participants worried about creating ‘another’ organization on top of those that already exist, such as the Canadian Pain Society, Canadian Pain Coalition, and related provincial organizations, as well as about reconciling their competing interests. One dialogue participant argued that the credibility that would accrue from being able to speak with one voice would be worth the effort, and that this was a significant motivator for organizations like the Canadian Cancer Society joining forces with other groups to form the network that lobbied successfully for the creation of the Canadian Partnership Against Cancer. Another dialogue participant noted that the challenges weren’t as significant in the creation of the Quebec network for chronic pain because each of the participating centres was sufficiently pleased to receive the designation and to have a clear mandate to focus on its part of the province.

### **DELIBERATION ABOUT NEXT STEPS FOR DIFFERENT CONSTITUENCIES**

Most dialogue participants expressed strong support for mobilizing behind an effort to build a national network that would bring together existing organizations and committed individuals. One dialogue participant emphasized the importance of any network being a ‘value’ network, meaning that it has to add value continuously in its own work and to the work of others in order to ensure its relevance and survival. For example, the network should enable those organizations and individuals already working in the area to strategize and communicate more effectively. Some early wins could include the endorsement of a national pain strategy, which would include agreed upon definitions. Several dialogue participants emphasized the importance of working together. One participant gave the example of how a network could facilitate even small-scale improvements, such as negotiating agreements between smaller and larger provinces to provide smaller provinces with access to the specialty programs and services available in larger provinces. A few participants extended the idea of ‘working together’ to include learning from one another, which includes building on the successes in other provinces and not ‘reinventing the wheel.’ One participant cautioned that working together needed to include working with those in complementary domains such as chronic disease management and primary healthcare. Otherwise the network would be creating additional silos and slowing coordination and integration efforts in the health system. Finally, several dialogue participants argued for primacy being given to an ‘evidence-based’ and ‘grass-roots’ approach, and being certain not to lose these features in a rush to a ‘big bang’ solution.