What will it take to create a national approach to chronic pain?

**Background and the Need**

Chronic pain is a complex illness with a profound impact on the individuals who experience it, their capacity to participate in their communities, and on the healthcare system. Current estimates indicate that about seven million Canadians (including children and the elderly) live with chronic pain, with a $7.2 billion direct cost to the healthcare system. Each patient accrues an additional annual cost of approximately $15,000 in treatment expenses and lost wages; these hard costs are frequently compounded by mental health issues, social isolation and severe loss of quality of life. For many people with acute pain, the experience begins to completely dominate their existence.

Clinicians, health researchers and public policy decision-makers recognize pain as a significant public health problem in Canada, with action in multiple provinces, research supported by CIHR, the establishment of provincial and national chronic pain networks, and links to the solutions sought in the opioid crisis. Patients are also mobilizing themselves into organizations that provide support and reduce isolation of people with chronic pain conditions. At the same time, chronic pain resists clear pathways to meaningful action. While chronic pain is a systemic illness with often devastating consequences for those who experience it, its causes and manifestations are incredibly varied. Persistent pain has many sources, including injury, genetic, life history and neural conditions, and is associated with natural aging and degeneration processes and almost any human disease from osteo-arthritis to gall bladder disease, post-chemotherapy and post-op conditions, and. This broad spectrum of conditions and aetiologies reveals that pain pathways in the human system are complex and different for everyone. Individual perception and experience of chronic pain is widely varied, with people with apparently similar conditions having significantly different experiences or impact on function. Chronic pain is both physical and emotional, and many people with physical pain have comorbidities with mental health conditions. Gender, culture, socio-economic conditions and environment are additional factors in the complexity of pain perception and function with chronic pain. Some groups such as Aboriginal people, poor and rural people, the young and the old and those with comorbidities such as mental illness and developmental challenges may be at highest risk of pain and poor pain care. Against this landscape, health professionals are frequently significantly unprepared to respond to their patients’ needs: pharmacological approaches to pain management are insufficient, ineffective and often lead to dependence; there are few alternative approaches in wide use; and the opportunities of e-health approaches to overcoming barriers to care have not been widely used.

Researchers have made great strides in understanding the physiology of pain and pain perception, and have developed scales and resources to measure the dysregulation of the “pain matrix,” the full detection, transmission and processing of neural information related to pain, and have established useful findings.
related to the efficacy and appropriateness of treatment. Current research is focused on expanding evidence about the causes, assessment and treatment of abnormal pain, which is critical to develop proper therapeutic approaches. For much too long, chronic pain was considered a mere side effect of other conditions, delaying development of treatments targeting pathological pain. In parallel, researchers are exploring solutions for better access to pain care and better pain education for healthcare professionals.

Across the country, everyone involved in pain research, treatment and advocacy recognizes that we must develop a national, shared approach to developing solutions for chronic pain. At the CAHS Major Forum on Chronic Pain on September 13, 2018, more than 120 health scientists, clinicians and policy developers came together to explore how CAHS can contribute to this national approach.

Overview of Recommendations

Across all of the speakers’ presentations and table discussions, key needs emerged:

- Better understanding of the causes, physiology and experience of pain
- A map of the current realities for living with and treating pain in Canada
- A full picture of the socio-economic cost of pain in Canada
- Better knowledge translation
- A full mapping of evidence-based treatments and solutions
- Recommendations for developing more evidence for promising solutions

A summary question that reflects much of the Forum’s discussion would be:

What would a national, evidence-based, equity and outcome-driven, coordinated pain strategy look like?
- What interventions are needed to address social, structural, organizational and clinical issues?

Overview of the Forum

The Forum was opened by Linda Rabeneck, President of the Canadian Academy of Health Sciences and Gavin Stuart, the Chair of the Forum planning Committee. Dr. Stuart welcomed Yves De Koninck and Patrick McGrath, the Forum Co-Chairs, who outlined their aspirations for convening this conversation at this time: to bring the wisdom and multiple perspectives of the CAHS together to explore the multi-dimensional topic of chronic pain, which has a huge economic and psychological burden on Canadians but which does not receive concerted national attention.

The Co-Chairs introduced Cate Creede, the moderator for the Forum, who outlined the process of engaging Forum participants in discussion each panel with the aim of working together in the final session to make recommendations for ongoing work, such as a Major Assessment.

The foundational context focused on the theme “From Patient to National Strategy,” with insights from keynote speakers, Maria Hudspith, Executive Director of Pain BC, and Linda Porter, the Director of the Office of Pain Policy at the National Institutes of Health. Both focused on chronic pain as an overwhelming journey, unique to each patient, with a huge impact and burden on their ability to participate in social life, work life and personal meaning. Experiencing chronic pain often create a spiral of consequences that may include job loss, isolation, anxiety and other mental health issues, and a tremendous loss of hope and social connection. The individual experience has an equally significant impact on the economic wellbeing of Canada and the US.
and on the healthcare system. The complexity of finding effective treatment is compounded by the opioid crisis, which has increased stigma on people using pharmacological solutions for pain, and limited access to those therapies.

Both speakers outlined foundational work done to date, including provincial strategies in Canada and the IOM report in the US, and noted that while much is known about the impact and issues related to chronic pain, making a meaningful difference will require national strategies. Both speakers argued for the need for multi-faceted, collective strategies that incorporate prevention, public policy, comprehensive research, evidence-based approaches to treatment including alternatives to pharmacology, and access to often-chaotic health services. Both speakers underlined the paradox that pain is a chronic disease and needs to be recognized as such, but each person experiences pain in a highly individual manner, and health professionals are mostly ill-equipped to offer meaningful treatment and support plans.

Across the rest of the day, 13 additional presenters, including scientists, clinician-researchers and patient-advocates, outlined evidence, their work and key questions, in four panels: 1) Is chronic pain a bonafide disease? 2) The Complex Chronic Pain Ecosystem: From Comorbidities to Drug Therapeutics; 3) Paths to Solutions: Non-Pharmacological Approaches; and 4) Paths to Solutions: Societal Approaches. These panels further illuminated the key ideas set out by the keynote speakers, simultaneously detailing the physiology of pain and potential solutions, while consistently humanizing the issue with patient-centred perspectives and calling on patient voices in forming solutions.

Throughout the day, all 120 participants in the room held table discussions to distill their key insights from each panel, and at the end of the day, made recommendations for priorities and how to inform the Major Assessment. These table recommendations are captured below.

**Detailed Table Insights**

The overwhelming message from the participant discussions was that CAHS needs to collaborate with other key stakeholders such as the Federal Ministry of Health, provincial bodies like Pain BC, Canadian Pain Care Forum, workers’ compensation bodies and provincial and national Chronic Pain Research Networks to ensure it is making a unique, needed contribution to movement toward a pan-Canadian solution. Many voices asserted that the most powerful role for CAHS could be in gathering and synthesizing evidence, identifying gaps and providing a map for the knowledge and knowledge translation that is most needed.

Specific areas that require either more evidence or synthesis of existing evidence include:

1. **Understanding chronic pain**
   - The reasons underlying chronic pain
   - Scale for measuring and categorizing pain
   - The effects of non-medical factors on how we categorize and understand pain (socio-economic, gender, cultural, life stage, etc.); pain and addiction
   - Value of framing and building understanding of chronic pain as a disease

2. **Mapping out the current realities for living with and treating pain in Canada**
   - The full socio-economic cost of pain
   - Gaps in service provision and clear pathways for accessing services
   - The role of stigma
   - The role of socio-economic factors in outcomes
   - The experience of accessing treatment and care for pain today
3. Knowledge translation and mobilizing change
   - Building knowledge and uptake about existing evidence among health professionals, policy-makers and health services
   - Pain education among health professional, both learners and those in practice ("vets receive more pain education:"")
   - Existing leadership and effectiveness in system change around pain
   - The role of e-health in knowledge translation and change
   - Health literacy, prevention and self-care management of chronic pain

4. Mapping out evidence-based treatments and solutions
   - Economic models for treating pain
   - Measuring successful outcomes, including return to participation in life roles, that are useful for health professionals
   - Use of alternatives to pharmacology (acupuncture, physical rehabilitation, cognitive behaviour therapy, etc)
   - The role of interdisciplinary pain management teams
   - Bringing non-addictive medications to market
   - Best approaches for self-management
   - How can the health system incentivize effective pain management and optimize outcomes for the value per dollar spent
   - Pathways for treatment for different pain phenotypes

Possible Major Assessment Questions

Participants agreed that a primary role for CAHS is to synthesize existing evidence, connect with existing efforts, and to map out a Canadian approach that incorporates proven treatments, promising pathways for health services, and access to treatment for everyone across Canada, including vulnerable populations. Several tables underlined the need for collaboration with other stakeholders and with patient partners in this assessment.

The group identified two possible broad assessment questions based on these needs.

What are the best practices and strategies for assessing and treating chronic pain and how can these strategies be implemented in a comprehensive, pan-Canadian way?

This would incorporate the following topics:
   - What is the breadth and scope of chronic pain across Canada now?
   - What is the most effective assessment and diagnostic model?
   - What are the most effective treatment pathways, and how could these be implemented in Canada?
   - What are the best intervention points and treatments, and how do these differ for different groups?
   - How do we maximize agency for people with chronic pain?
   - What outcomes should we be measuring and striving for?
   - What economic models can we apply for the best value for outcomes?
   - What education, knowledge translation and policies are most meaningful?
   - What new research could be most meaningful?
A simpler variation would be:

*What would a national, evidence-based, equity and outcome-driven, coordinated pain strategy look like?*

- What interventions are needed to address social, structural and clinical issues?