

Dialogue Summary

Developing a National Pain Strategy for Canada

14 December 2017



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**Dialogue Summary:
Developing a National Pain Strategy for Canada**

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The McMaster Health Forum's goal is to generate action on the pressing health-system issues of our time, based on the best available research evidence and systematically elicited citizen values and stakeholder insights. We aim to strengthen health systems – locally, nationally, and internationally – and get the right programs, services and drugs to the people who need them.

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Conflict of interest

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

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Dialogue

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SUMMARY OF THE DIALOGUE

Dialogue participants strongly agreed that chronic pain is not being effectively prevented or managed in Canada and agreed with the five features of the problem presented in the evidence brief. In their deliberations about the problem, participants focused in particular on five features of the problem:

- 1) hasty reactions to the opioid crisis have had unintended consequences for those with chronic pain;
- 2) uncertainty about how to best position chronic pain alongside the existing opioid crisis;
- 3) relatively few tools available to support the effective management of chronic pain;
- 4) little effort to capitalize on lessons from existing strategies; and
- 5) no widely endorsed leadership to champion change at the policy level.

These five features related directly to three of the five features of the problem presented in the evidence brief.

In deliberating about the development of a national pain strategy, most dialogue participants expressed support for the short- and medium-term milestones as presented in the four elements of the evidence brief:

- 1) improve primary-care-based chronic-pain management and create/expand interdisciplinary specialty-care teams;
 - 2) reduce the emergence of chronic pain and its sequelae (including opioid-use problems) once it has emerged;
 - 3) diagnose the causes of emerging challenges, test innovations to address the causes, and scale up successful efforts; and
 - 4) create a national coordinating body.
- While dialogue participants generally agreed with the milestones presented, for each element they noted a number of nuances that should be considered in the development of a national strategy. In addition, dialogue participants identified three cross-cutting themes that should be kept in mind when working through each element: 1) wherever possible capitalize on efficiencies and on lessons learned from others' experiences; 2) engage as many stakeholders as possible in the development of the strategy, including those from the private sector, to secure long-term support; and 3) balance the need to develop plans with the flexibility to adapt to unforeseen windows of opportunity.

In deliberating next steps for different constituencies, most dialogue participants agreed with four key next steps: 1) establish and then coalesce behind one group or organization that will act in a leadership role to coordinate efforts and push the strategy forward in the short term; 2) develop a clear set of next steps that both governments and chronic pain stakeholders; 3) actively engage all concerned stakeholders to create a coordinated effort (with extensive buy-in across the country) for implementing the next steps; and 4) pursue activities that can yield quick wins in the short term in parallel, such as public-awareness campaigns and developing processes to leverage existing data for insights about chronic pain, and identifying any challenges that require attention.

SUMMARIES OF THE FOUR DELIBERATIONS

DELIBERATION ABOUT THE PROBLEM

Dialogue participants strongly agreed that chronic pain is not being effectively prevented or managed in Canada and with the need to develop a national pain strategy (which is the primary focus of the next section). Most participants also agreed with the five features of the problem presented in the evidence brief: 1) many Canadians suffer from chronic pain, but it is not well understood; 2) the framing of chronic pain only in relation to the opioid crisis is not conducive to long-term solutions; 3) there are limitations in existing programs and services for effectively managing (and preventing) chronic pain; 4) gaps in health-system arrangements limit the reach and impact of chronic-pain programs and services; and 5) limited national coordination inhibits progress.

In their deliberations about the problem, participants focused in particular on five features of the problem:

- 1) hasty reactions to the opioid crisis have had unintended consequences for those with chronic pain;
- 2) uncertainty about how to best position chronic pain alongside the existing opioid crisis;
- 3) relatively few tools available to support the effective management of chronic pain;
- 4) little effort to capitalize on lessons from existing strategies; and
- 5) no widely endorsed leadership to champion change at the policy level.

The first two of these features relate to the second feature of the problem presented in the evidence brief, the third feature relates to the original third feature, and the fourth and fifth both relate to the original fifth feature.

Hasty reactions to the opioid crisis have had unintended consequences for those with chronic pain

One participant described provincial reactions to the opioid crisis as being “knee-jerk” and noted that they did not give adequate consideration to the effects on chronic-pain patients who may be appropriately managing their pain using opioids. In particular, dialogue participants highlighted that policy changes such as calling out physicians with high prescription rates and restricting patient access has resulted in, for some chronic-pain patients, substitution with other legal and illegal drugs, painful withdrawal symptoms, or facing stigma when asking for or renewing opioid prescriptions. Participants

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 four elements of a potentially comprehensive approach to 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, four elements of an approach to 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 conceptualize the problem and possible elements of an approach to 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.

The dialogue did not aim for consensus because coming to agreement about commitments to a particular way forward can preclude identifying broad areas of agreement and understanding the reasons for and implications of specific points of disagreement, as well as because even senior health-system leaders typically need to engage elected officials, boards of directors and others on detailed commitments.

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.

also noted that the failure to combine these policy changes with public education about safe opioid use has led to a misunderstanding in the public about the safe use of opioids, opioid addiction and dependence more generally. The result of these reactive decisions has been, for the most part, additional barriers in the prevention and effective management of chronic pain.

Dialogue participants stressed that when developing a national pain strategy and any parallel guidelines to accompany its implementation, it is critical to think beyond the expected outcomes and to consider unintended consequences. In particular, one participant emphasized this point as it pertained to marijuana and recent findings that it may help in the management of chronic pain, stating “one lesson we can take from the opioid crisis is not to view any management option as a panacea. If we do, we risk having a cannabis problem in 10 years.”

Uncertainty about how to best position chronic pain alongside the existing opioid crisis

While most participants agreed that they thought the opioid crisis presented an opportunity to advance improvements in the prevention and effective management of chronic pain, participants were uncertain about how best to position chronic pain within the momentum that has been created by the opioid crisis. Participants described how the current narrative being used to advocate for a national pain strategy could be seen as combative rather than complementary to the opioid crisis, and described how this positioning is unlikely to gain traction with government or political stakeholders, as they will be looking for solutions able to address multiple health-system challenges.

Instead of continuing with this narrative, one participant suggested that stakeholders work on crafting a vision that shifts away from pitting chronic pain against other challenges (described by the participant as an ‘or narrative’) to one that more accurately describes the complex relationship between chronic pain and the health system (described as an ‘and narrative’). While there was no consensus on exactly how to position the issue or what the narrative should be, three possibilities emerged during the deliberations:

- 1) use a framing that positions chronic pain, and untreated or mismanaged pain, as underpinning many other health problems, including opioid overdoses, comorbid chronic conditions, and mental health and addictions challenges, to name a few;
- 2) use a framing that positions chronic pain as being at the intersection of a variety of health and social system challenges, including mental health and addictions, trauma and poverty; or
- 3) use a patient-centred positioning that focuses on leveraging personal stories and existing grassroots efforts to improve individuals’ well-being as a whole, rather than focused on treating or managing pain specifically.

While many participants generally agreed with at least one of these frames, some participants expressed concern that they would be too broad and not well positioned to achieve the quick wins that politicians and government stakeholders are looking for given the upcoming federal and (in some cases) provincial elections.

Relatively few tools available to support the effective management of chronic pain

Dialogue participants commented that from a clinical standpoint there were relatively few tools available to support the effective management of chronic pain. One participant compared “chronic pain to where cancer was 60 years ago,” while another noted that “unlike other conditions my toolbox to help patients is relatively shallow.” In deliberating about this dimension of the problem, dialogue participants focused on three key features: 1) there is a lack of data and research evidence about which prevention and management strategies are most effective; 2) healthcare providers and members of the public are provided with limited education about chronic pain and how it can be managed; and 3) services that can support chronic-pain prevention and management are not always publicly funded.

First, a handful of dialogue participants noted that there continues to be a lack of data and research evidence about which prevention and management strategies are most effective. Some participants pointed out that

compared to many other chronic conditions, chronic pain receives relatively less research funding, which in turn constrains the identification and advancement of approaches to effectively prevent and manage chronic pain. Participants described how this point underpins the following two points (limited education of healthcare providers and members of the public, and limited public coverage of services), as research evidence is a critical input to determine what patients and providers should be taught and can support decisions about what services to fund. Optimistically, some participants believed this was changing and that the opioid crisis had provided some impetus for investments in chronic-pain research. Those that held this perspective however, warned that any decisions taken prior to the publication of this research should be sufficiently flexible so as to incorporate the findings once published.

Second, participants described that healthcare providers and members of the public are provided with limited education about chronic pain and how it can be managed. Dialogue participants emphasized that despite numerous calls for increased chronic-pain-related training there remains relatively little time in healthcare providers' curriculum dedicated to diagnosing and managing chronic pain. Turning to members of the public, one participant stressed that this lack of awareness undermines prevention efforts, as patients are limited in their ability to recognize signs of emerging pain or acute pain that may be transitioning to chronic pain. Further, patients often do not know the types of services that are available to them, reducing their ability to act as advocates for their own care.

Finally, dialogue participants described how even with the necessary knowledge, effective chronic-pain management programs and services are not always available or accessible to all Canadians. They highlighted that patients may be restricted in what services can be accessed based on what is publicly covered. For instance, many of the approaches that have been found to be effective in the management of chronic pain are reliant on out-of-pocket payments or private insurance, including, among others, community-based rehabilitation, select mental health services, chiropractic services, or alternative approaches such as yoga and meditation.

Little effort to capitalize on lessons from existing strategies

Dialogue participants highlighted that in the past they have not consistently capitalized on learning from the experiences of others. One dialogue participant described that in the case of the Mental Health Strategy for Canada a 'made in Canada' approach led to Canada being seen as a world leader, with other jurisdictions having since adopted variations of the Canadian strategy. However, they described the process as being extremely resource- and time-intensive, taking multiple years to come to fruition.

Instead of starting from scratch, dialogue participants agreed that there was "no need to reinvent the wheel" and saw significant advantages in using the strategies that have worked elsewhere, such as the Australian Pain Strategy and forthcoming B.C. pain strategy. It was suggested that these elements could be adapted through consultations with stakeholders and the public to match the nuances of the national context. Dialogue participants highlighted that beginning with a strategy that has already shown success in other jurisdictions could save time and resources, as well as help to get stakeholders, particularly in government, to buy into the strategy.

In addition, two participants spoke of their experience in participating in the development of the Canadian Strategy for Cancer Control and the Mental Health Strategy for Canada. These two participants highlighted the following five lessons that should be taken forward to the development of a national pain strategy:

- 1) where possible create a business case for investments;
- 2) ensure there is broad consensus, through extensive consultations, about the changes that should be implemented (e.g., agree on what needs to be done);
- 3) know who your opponents are and who will oppose this work;
- 4) invest in partnerships and establish commitment for the initiative among engaged stakeholders; and
- 5) focus on securing quick wins to bring government to the table.

No widely endorsed leadership to champion change at the policy level

Throughout the deliberations about the problem, dialogue participants acknowledged that other efforts have been pursued with little progress towards establishing a national strategy. Participants suggested that these past efforts may have failed due to a lack of clear leadership within the area of chronic pain, and no one group championing the issue at the policy level or coordinating existing efforts across provinces and communities, despite previous calls for its establishment. Dialogue participants highlighted that since previous efforts to bring forward a national strategy there had been successes at the provincial levels, but that this work had not been scaled-up nationally, and that no one group was seen as the “go-to source for information and advocacy on chronic pain.”

Participants highlighted how this might be a result of no one agency or organization having the sufficient resources, skills or organizational sustainability needed to champion a national strategy. Other participants emphasized that the delay in coalescing behind one organization may have more to do with political challenges. Further, two participants, both of whom had experience in the development of previous national strategies (Canadian Strategy for Cancer Control and Mental Health Strategy for Canada) also emphasized that strong leadership is critical to gaining political traction and scaling up a strategy.

DELIBERATION ABOUT ELEMENTS OF A POTENTIALLY COMPREHENSIVE APPROACH TO ADDRESSING THE PROBLEM

The deliberations about approach elements centred on the milestones outlined for each of the elements and their implementation in the short (one year), medium (three years), and long (five years) term. While dialogue participants generally agreed with the milestones and timelines presented in the short and medium term, many participants expressed that it was too soon to plan for the long term. Participants warned about the need to plan with a degree of flexibility, noting the unpredictability of the current health and political landscape. In particular, one dialogue participant spoke about their experience moving forward with similar projects, stating “much of the growth and success we had was opportunistic, and while we can bang out a number of decisions and quick wins, there has to be enough flexibility to take advantage of windows of opportunity when they present themselves.” Other participants spoke of the need to iteratively revise plans based on the experience of the first few years, stakeholder support, new research evidence, and shifting political agendas and resources. Unique considerations were raised within discussions of each of the short- and medium-term milestones, which are outlined below before returning to participants’ assessment of a potential way forward.

Element 1 – Improve primary-care based chronic pain management and create/expand interdisciplinary specialty-care teams

With regards to element 1, all dialogue participants agreed that the existing non-pharmacological approaches for supporting chronic-pain management in primary-care settings were sub-optimal and needed additional attention. They generally agreed with many of the milestones that were outlined in the evidence brief in the short and medium term, however, they emphasized that the proposed milestones were often provider- rather than patient-centred (e.g., emphasis on supporting providers with resources such as best-practice guidelines, but relatively less emphasis on empowering patients), and advised that these be repositioned as patient-focused initiatives when developed as part of the national pain strategy. Specific deliberations on the proposed short- and medium-term milestones are summarized below.

Short term

In the deliberations on this element, dialogue participants particularly encouraged improving self-management supports over the short term, viewing this as one of the easier changes to put in place, compared to other features such as delivery-system design or health-system changes, which may take longer to realize. In discussing this, one dialogue participant stated, “there will never be enough care to help chronic-pain patients, so we really have to make sure they know how to help themselves and manage their own condition.”

Dialogue participants also emphasized the need to prioritize evidence-based practice, and in the short term, to do so by capitalizing on existing best-practice guidelines for non-pharmacological care and incorporating them into self-management supports.

Medium term

For the medium term, dialogue participants reiterated key components of milestones outlined in the brief by emphasizing the provision of comprehensive education and training in pain management to providers, with a particular focus on primary-care physicians, to ensure they have the necessary knowledge and resources to deliver care consistent with scientific evidence and patient preferences. In addition, participants suggested the development of routine mechanisms to support a ‘living systematic review and guideline’ model, so that best-practice guidelines, and any education and training in pain management that follows these guidelines, can evolve to reflect the latest knowledge.

Element 2 – Reduce the emergence of chronic pain and its sequelae (including opioid-use problems) once it has emerged

While dialogue participants generally endorsed the focus of this element’s milestones on developing public-education campaigns in the short and medium term, they also emphasized the need to explore ways in which the health system could prevent the onset of chronic pain, particularly from musculoskeletal injuries and in the transition of acute pain to chronic pain. Specific deliberations on the short- and medium-term milestones are summarized below.

Short term

The majority of dialogue participants supported developing a broad public-education campaign to generate public awareness, stressing that moving quickly on this campaign was important for two reasons: 1) it could help to educate existing chronic-pain patients on what supports and services they have access to; and 2) it could help to engender public support behind a national strategy, which may increase the chances for political support of a strategy in advance of the next federal election.

In deliberating on how such a campaign would be implemented, dialogue participants noted that the campaign should focus on explaining to patients and citizens what chronic pain is, the burden of chronic pain in Canada, and existing management options. One participant also stressed education of the public about the difference between safe opioid use for acute and chronic pain and more harmful substance use with opioids, expressing that the absence of such understanding is feeding some of the stigma associated with chronic pain and opioid use mentioned in the problem section.

Medium term

In discussing the medium-term milestones, dialogue participants turned their attention to preventing the onset of chronic pain. Specifically, a few participants highlighted how sub-optimal recovery from musculoskeletal injuries or from other types of acute pain can lead to transitions into chronic pain, and that these upstream factors, many of which are known, are not being sufficiently well managed by current

supports and services. Dialogue participants also highlighted that emphasizing approaches to prevent the onset of chronic pain may be a key point to getting private insurers to buy into the strategy, given that in many cases they are paying for pain-management services.

Element 3 – Diagnose the causes of emerging challenges, test innovations to address the causes, and scale up successful efforts

Dialogue participants generally agreed with the focus of element three, especially the need to improve data collection as a means of diagnosing emerging challenges in preventing and managing chronic pain. While this element was not the focus of much deliberation during the dialogue, where applicable specific points of deliberations on the short- and medium-term milestones are summarized below.

Short term

Dialogue participants generally agreed that current efforts to collect data were insufficient, and therefore they supported the design and implementation of registries and/or treatment-monitoring systems to contribute towards a national picture of the burden and treatment of chronic pain in Canada. In order to complement these efforts, a few participants called for the development of national indicators and benchmarks to monitor the implementation of new approaches and the evaluation of their impacts. Dialogue participants described how increased monitoring could in the long-term support the evaluation of new approaches to chronic-pain management, and in the short term would help to gather additional data to better document the case for a national strategy.

Medium term

In deliberating about the medium-term milestones, one participant in particular highlighted the need to determine efficient mechanisms to support the scale up of successful non-pharmacologic approaches to the management of chronic pain, stating that “medicines have a clear advantage as they can be easily scaled [up] and consistently implemented across jurisdictions... we need to mimic these qualities in the scale up of other approaches.” In addition, dialogue participants reiterated the need for national alignment in patient registries and treatment-monitoring systems, as well as in chosen outcome indicators, both to flesh out the case for a national strategy and to support cross-jurisdictional learning.

Element 4 – Create a national coordinating body

Dialogue participants engaged most extensively about this element, focusing on two parallel but interrelated issues: 1) what group or agency in the short term could coordinate efforts and help build momentum among existing stakeholders; and 2) what group or agency could take this role forward to coordinate the development and implementation of the strategy in the medium to long term. Specific reactions to the proposed short- and medium-term milestones are presented below.

Short term

In the short term, most dialogue participants agreed that a national coordinating body is necessary for the development of a national pain strategy, with one participant noting the advantage of speaking with a common voice rather than having the narrative split across agencies and organizations. However, dialogue participants were divided on whether a new body should be created or whether an existing body could be adapted, with the involvement of additional stakeholders, to fit this role. While many dialogue participants saw merit in an existing network or organization taking the lead (with some participants advocating for the Canadian Pain Network to take on this role), others worried that an existing group may bring select priorities

or perspectives that are not endorsed by the entire chronic-pain community, and that creating a new national coordinating body may result in a more inclusive approach.

While participants did not come to a conclusion about who specifically should lead the development of the national strategy, they did agree that an important first step, once established, would be to identify well-connected political champions who would be willing to work with the coordinating body to identify funds and take the strategy forward within the federal government. Simultaneously, dialogue participants thought it would be important to identify specific individuals within the coordinating body who could take responsibility for identifying possibilities for and achieving quick wins within the first year. It was suggested that demonstrating initial success would contribute towards gaining traction and support among uncertain stakeholders, as well as to reassure those stakeholders who have already bought into the strategy.

Finally, whereas the evidence brief suggested drafting a national strategy using a participatory approach, within the first year, dialogue participants suggested first running a consultation with the key players involved in the development of the Australian Pain Strategy and existing (or developing) provincial strategies (such as the one in B.C.), to determine what has worked and why. They proposed using this information to adapt a strategy to fit the Canadian context and to use this as a basis for consultations once a national coordinating body is up and running.

Medium term

Dialogue participants suggested that public consultations on the strategy could begin in the first year, but experience with previous strategies led a few dialogue participants to suggest that it is a lengthy process and would likely continue into the second year. One participant in particular suggested that throughout the public consultations, the national coordinating body, once established, should work with professional advocates to engage stakeholders rather than trying to take on the role themselves. The dialogue participant explained that this had to do both with the necessary skills and time required, stating that “engaging stakeholders is a full-time job and I don’t think anyone in this room has the time to take this on.”

Considering the full array of approach elements

As noted in the introduction to this section, dialogue participants generally embraced the short- and medium-term milestones of all four elements of a potentially comprehensive approach to developing a national pain strategy, although for each element they noted a number of nuances that deserved more emphasis, particularly with regards to element four. Dialogue participants also identified three cross-cutting themes that should be kept in mind when working through each element:

- wherever possible capitalize on efficiencies and on lessons learned from others’ experiences;
- engage as many stakeholders as possible in the development of the strategy, including those from the private sector, to secure long-term support; and
- balance the need to develop plans with the flexibility to adapt to unforeseen windows of opportunity.

DELIBERATION ABOUT IMPLEMENTATION CONSIDERATIONS

Discussion about the barriers to moving forward with a national pain strategy generally focused on four challenges: 1) accessing the financial resources needed to support a national strategy; 2) developing the ‘ask’; 3) securing widespread support for the ‘ask’ and the leadership team to bring it forward; and 4) potential for limited traction due to the legacy of past failures.

Dialogue participants identified one challenge in developing a national pain strategy to be accessing the financial resources needed to support the strategy, with one participant stating, “there is no money for anything until you can prove that it will save money somewhere else.” While most participants believed there were clear efficiency gains to be made in the system, they noted that the value case for investment in a national strategy needed further development.

Participants identified a second challenge to be developing the ‘ask’ going to federal, provincial and territorial governments. Dialogue participants discussed how the existing opioid crisis can act as “a blessing or a curse” based on how the issue is framed. Importantly, it was stated that a pain strategy should be positioned to complement recent investments to combat the opioid crisis.

The third challenge that participants identified was securing widespread support for the ‘ask’ and for the leadership team to bring it forward. Participants emphasized that some groups may have significant personal interest in what elements are included in the strategy and, as a result, may resist the leadership efforts of particular organizations. While by no means a panacea, participants suggested three strategies that may help mitigate some of these challenges: 1) define clear actionable priorities for the strategy that can be broadly supported; 2) engage all relevant stakeholders early and often; and 3) know your opponents early on and anticipate what may be needed to bring their support behind the strategy.

As the final challenge dialogue participants identified the potential for limited traction given the legacy of previous attempts at developing a national strategy. Dialogue participants were concerned that repeating efforts may result in fatigue on the part of stakeholders and politicians to act on the issue. Similarly, one dialogue participant expressed that they anticipated some hesitation from federal politicians due to the historical funding relationship between the pain community and pharmaceutical companies.

DELIBERATION ABOUT NEXT STEPS FOR DIFFERENT CONSTITUENCIES

In deliberating on next steps for different constituencies, most dialogue participants agreed with four key steps to take the development of a national pain strategy forward:

- 1) establish and then coalesce behind one group or organization that will act in a leadership role to coordinate efforts and push the strategy forward in the short term (and simultaneously determine whether a new group needs to be created or whether the existing organization could continue this role in the medium and long term);
- 2) develop a clear set of next steps that both governments and chronic-pain stakeholders, including members of the public, can sign on to support;
- 3) actively engage all concerned stakeholders to create a coordinated effort (with extensive buy-in across the country) for implementing the next steps, including undertaking stakeholder mapping to clearly identify who needs to be involved and in what capacity, as well as developing a ‘living’ environmental scan to keep track of the policies and politics related to the issue across the country; and
- 4) pursue activities that can yield quick wins in the short term in parallel, such as public-awareness campaigns and developing processes to leverage existing data for insights about chronic pain, and identifying any challenges that require attention.



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