

## Canadian Pain Taskforce submission – submitted online May 29, 2020

**Due: May 29, 2020**

This is a joint submission from the Canadian Psoriasis Network (CPN) and the Save Your Skin Foundation (SYSF). We appreciate the opportunity to share feedback from our communities through this consultation.

### **What challenges and barriers to understanding, preventing, or managing pain exist in your community and in Canada?**

CPN is a national, non-profit organization dedicated to enhancing the quality of life of people living with psoriasis and psoriatic arthritis. The most common form of psoriasis is plaque psoriasis, a non-communicable, chronic inflammatory condition that affects the regeneration of skin cells. Symptoms include flaking, itchiness, redness and pain. Having psoriasis increases the risk of developing other health conditions like psoriatic arthritis, metabolic syndrome, cardiovascular diseases and depression. Psoriasis can greatly affect quality of life, especially if symptoms are persistent and severe. Chronic pain is a common experience of people with psoriasis, particularly for the approximately one in three people who develop psoriatic arthritis.

SYSF is a national patient-led not-for-profit group dedicated to the fight against non-melanoma skin cancers, melanoma and ocular melanoma through nationwide education, advocacy, and awareness initiatives. Persistent pain related both to surgical procedures and to cancer stages is a prevalent and disabling melanoma-related symptom requiring early prevention and treatment ([https://www.scielo.br/scielo.php?script=sci\\_arttext&pid=S1806-00132016000100039&lng=pt&nrm=iso&tlng=en](https://www.scielo.br/scielo.php?script=sci_arttext&pid=S1806-00132016000100039&lng=pt&nrm=iso&tlng=en)).

Pain is particularly common in cancer patients in the advanced stage of disease when the prevalence is estimated to be more than 70% ([https://www.annalsofoncology.org/article/S0923-7534\(19\)31698-9/fulltext#bb0010](https://www.annalsofoncology.org/article/S0923-7534(19)31698-9/fulltext#bb0010)). In fact, over half of respondents in the Canadian Partnership Against Cancer's (CPAC) 2018 Cancer System Performance Report indicated pain as a symptom of patient distress, with 6% identifying a "high" level of distress in this category (<https://s22457.pcdn.co/wp-content/uploads/2019/01/2018-Cancer-System-Performance-Report-EN.pdf>).

The effect of pain related to these conditions can be profound, including fatigue, challenges with movement and resting, consuming the limited energy that people (and their families) have and preventing them from other daily activities.

In terms of challenges to *understanding* pain, gaps that are evident from our communities include inconsistencies in screening for pain by health care professionals and gaps in self-reporting.

In the case of psoriasis, it is well documented that there are screening and diagnosis gaps for psoriatic arthritis. Patients may not report symptoms of joint pain and discomfort associated with the condition, and dermatologists may not explore this risk. This is particularly problematic because delay in diagnosis of psoriatic arthritis can lead to more functional disability and worse outcomes, including chronic pain (<https://www.dermatologytimes.com/article/practice-gaps-psoriatic-arthritis>).

In the case of cancer, though nine provinces are using standardized tools to screen for symptoms of distress (including pain) in cancer centres (Canadian Partnership Against Cancer, 2018 Cancer System Performance Report), evidence suggests that many individuals living with cancer who have distressful pain and symptoms do not receive appropriate care, according to the McMaster 2015 Forum on Improving Pain and Symptom Management in Cancer Care in Ontario. Possible reasons for this identified through the Forum include the fact that providers do not consistently use pain and symptom management guidelines in practice settings; and that health systems have not been designed to promote the use of pain and symptom management guidelines in practice (<https://www.mcmasterforum.org/docs/default-source/product-documents/citizen-briefs/pain-symptom-management-in-ontario-cb.pdf?sfvrsn=20>).

Moreover, research has found that there are disparities between how symptoms of pain are perceived by patients and how they are perceived by their oncology teams. Oncology doctors and nurses may underestimate the prevalence and impact of symptoms like pain in their patients (<https://acsjournals.onlinelibrary.wiley.com/doi/epdf/10.3322/caac.21311>). This in turn has implications for how these symptoms are diagnosed and managed. This is particularly concerning in light of guidelines and practices related to the opioid crisis. The implications are that a clinician's assessment of a person's experience of pain may be increasingly cautious, putting the individual at risk of being under-diagnosed or under-treated for their pain.

We suspect that these gaps influence our overall understanding of pain among our patient communities. It is difficult to understand the full extent of the problem when it comes to chronic pain experienced by patients, as well as how well pain support and management is provided to patients because of inconsistencies in screening and measurement. This challenge is more pronounced when we consider people whose access to everything from screening to diagnosis to care is impacted by social determinants of health.

One major challenge to *preventing* pain in our patient communities is gaps that exist in access to care for one's primary condition. There are many treatments available to help people effectively manage symptoms of psoriasis and psoriatic arthritis, including pain, however access to these options can be limited. For some, treatment needs can change over the course of their condition and access to topical, systemic and biologic treatment options can vary depending on where in Canada people live, or what type of drug insurance policy they have. For those for whom phototherapy is the most appropriate

treatment option, there are barriers to accessing this treatment in an outpatient setting especially in rural or remote locations. There are few clinics that deliver this service across Canada and attending sessions during clinic hours several times a week can be burdensome or even unfeasible for some. Costs for transportation to and from appointments, missed school or work, and disruption of schedules for individuals and family members are some of the concerns that we hear about from our community.

In terms of cancer, though many new and effective medications are available in oral forms so that people can better manage their care in the community, without the added stress and physical requirements to attend appointments to receive intravenous treatments, some provinces do not publicly fund these options. Particularly for a person with chronic pain related to their condition, the difference between being able to access treatment at home versus going into a hospital or clinic can be significant on both a physical and an emotional level.

Evidence supports an individualized, holistic pain management approach including physical, psychological and pharmacological treatments as best practice for treating chronic pain. Yet, as described by the Task Force's June 2019 report, access to gold standard care in Canada is woefully inadequate and access to pain services in Canada is fragmented and limited, especially depending on where one lives. The Task Force report highlights the need for "increased availability of pain care, from wellness-oriented, community-based care for people with mild functional impairment due to pain, to specialized, multidisciplinary and interdisciplinary care for those experiencing moderate to severe pain and functional impairment. Many services are outside of the publicly funded health system and vary based on insurance coverage and geography."

From the psoriatic and cancer communities, lack of mental health treatments and supports and lack of multidisciplinary care (like occupational therapy and social work) are clear. What is more, there are major gaps in the referral process in current health care systems. Referrals from a primary care physician to a specialist or from one specialist to another can be fragmented, uncoordinated and therefore problematic for the patient. Even when resources are available in one's community, unless a person is overseen in a health care environment with wraparound care (e.g., diabetes clinics which include endocrinologist, dietician, diabetes nurse), access to other health professionals when a referral is made is fraught with wait times, problematic process and poor oversight.

Notably all of these challenges are intensified by the COVID-19 pandemic. Everything from screening to diagnosis to treatment to surgeries to interdisciplinary supports have been disrupted or suspended for many patients from our communities. This is not a short-term problem. These shortcomings in our system will persist beyond the pandemic as recovery measures will greatly focus on communicable diseases and public health rather than non-communicable diseases, like psoriasis, cancers and chronic pain. This makes the need to address chronic pain even more urgent. If health screening, diagnosis and interventions are delayed for chronic conditions and cancer, symptoms like pain must be appropriately managed in a timely way to avoid poorer outcomes for these patients.

**What needs to be done to respond to these challenges and barriers?**

In order to address the issues that we have identified as well as other challenges related to managing chronic pain in Canada, CPN and SYSF support the calls for the establishment of a comprehensive, pan-Canadian pain management strategy that incorporates the perspectives of chronic disease and cancer.

This strategy should be based on best practices and on priorities identified by the patient and caregiver communities, including those identified by The Arthritis Society's 2017 Pain Forum – enabling patient engagement, building research and surveillance, establishing standards of care and improving education for health care professionals, patients and caregivers.

To be effective, a feasible pan-Canadian pain strategy must include three major elements:

It must be fully integrated into overall treatment management approaches. A pain strategy will not be effective if it is not integrated into the existing structures that are working well for managing patients' primary conditions, like psoriasis and cancer.

It must recognize the role of the federal government to facilitate a coordinated approach to pain management that is co-developed and co-led by people with lived experience of chronic pain. The role of the federal government is to be a facilitator by bringing together provinces, territories, patients and other stakeholders and by supporting the creation of a coordinated approach to developing and implementing a feasible strategy across different jurisdictions and stakeholders.

It must further be developed and rolled out in alignment with, and concurrently with, other critical health strategies in Canada, including the Canadian Cancer Strategy, Canada's Mental Health Strategy and the national Rare Disease Strategy. An approach to addressing chronic pain in Canada must be part of these other strategies for improving the health and wellness of Canadians.

## **PART C – WAYS TO BETTER UNDERSTAND, PREVENT AND MANAGE PAIN**

*Reminder: All questions are optional; please only respond to the extent you are comfortable and be mindful not to disclose any personal information about an identifiable 3<sup>rd</sup> party (e.g. your physician, a family member).*

**After reviewing the current state of pain in Canada we believe that there are many successes to build on. In pockets across the country, innovative clinical models, education, support programs, and research already exist. We would like to know more about what is already working well or showing promise of improving the health and wellbeing of people with pain.**

**We also hope to understand why some practices are successful, so we can begin to explore their use in new sites and settings.**

**We encourage you to share any experience and perspectives gained within Canada and elsewhere if this applies.**

**What is working to address pain in your community and in Canada? Please provide specific examples of practices and/or activities.**

A notable example from the cancer sector is the approach of Screening for Distress. According to the 2015 McMaster Forum report, this approach is a “widely accepted cancer pain and symptom management model that involves five steps, all of which are required to ensure people living with cancer receive patient-centred, comprehensive and evidence-based support for managing their pain and symptoms throughout the cancer journey”. According to the Forum report, these steps are: 1) screen for symptoms and distress (with the most widely accepted approach for achieving this known as the Edmonton Symptom Assessment System); 2) open a dialogue with the patient and initiate a therapeutic relationship; 3) assess risk factors, intensively assess problem(s) 4) ascertain patient perception of problem and negotiate a relevant plan of care; and 5) select appropriate interventions based on best evidence (*i.e.* symptom management guidelines) (<https://www.mcmasterforum.org/docs/default-source/product-documents/citizen-briefs/pain-symptom-management-in-ontario-cb.pdf?sfvrsn=2>).

This approach to screening for pain is ideal beyond cancer because it incorporates systemic screening for distress, including pain, and includes the perspectives and full engagement of patients. In fact, we would encourage the development and use of patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) as the benchmark for measuring the success of any health intervention, including screening for and managing pain.

To be most effective, any approach to screening for pain must also be used consistently, across the continuum of care, from screening and assessment to treatment and disease management to palliative and end of life care. It would also be imperative that this information be properly recorded to enable measurement and improvement at the individual and systemic levels.

Another example of how we can successfully address pain in our communities and in Canada is by using indicators that are identified by the patient community. One example comes from the Canadian Cancer Society that has identified three indicators that are appropriate for measuring and managing pain and other symptoms effectively in palliative care. These include: 1) Percentage of people who receive palliative care who have documented assessments of their pain and other symptoms in their medical record; 2) Percentage of people who receive palliative care (or their caregivers) who rate the level of support to relieve their pain and other symptoms as excellent; 3) Palliative care and hospice patients are screened for pain, shortness of breath, nausea and constipation during admission. These measures reflect the need to ensure timely, consistent screening for pain and other symptoms of distress and the importance of using patient-reported measures and patient-reported experiences to gauge what is important to measure and the success of different approaches and interventions used.

**What is it about these practices/activities that makes them successful?**

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**Canada is a world leader in pain research. Yet, there are many aspects of pain that we do not understand. More work is needed to apply knowledge from pain research in education, policymaking, clinical practice and elements of everyday life.**

**What should be the 3 top priorities for research in pain from your point of view?**

Though research is not within the scope of either CPN's or SYSF's mandates, we would add the following considerations for priorities for research in pain.

In order for research to effectively address the needs of people with pain, any research strategy or program must fully engage people with lived experience of chronic pain as well as people with chronic conditions, including people with psoriasis or with cancer for whom pain may be secondary to a primary condition. This means that patients, caregivers and the organizations that represent them should be involved in all aspects of research development, including cocreation of research programs, identifying research questions, developing research studies and conducting and reporting on research findings.

In terms of scope of research in pain for Canada, priorities must include pharmacological, psychological as well as psychosocial interventions and how various interventions interact.

Finally, one priority area that we would like to see explored in research is how we can better align patient and clinician understanding of pain and pain management so that awareness is improved, and interventions and healing are not delayed.

**What would help to better integrate research and new knowledge into education and training, policy, clinical practice, and everyday life?**

## **Part E – AN IMPROVED APPROACH TO PAIN**

***Reminder: All questions are optional; please only respond to questions to the extent you are comfortable and be mindful not to disclose any personal information about an identifiable 3<sup>rd</sup> party (e.g. your physician, a family member).***

**In the other sections of this questionnaire, we have asked you about:**

- **barriers to effective pain practices and how to address them (Part B)**
- **successful approaches to address pain and what makes them successful (Part C)**

- **priorities for research and what will help us to better integrate new learning and research into education, policy and practice (Part D)**

**What other strategies would help us to better understand, prevent, and/or manage pain in Canada?**

**If you have any additional comments or ideas on addressing pain in Canada, please include them here:**

Online sources:

<https://www.psoriasis.org/advance/psoriatic-arthritis-chronic-pain-management>

<https://www.psoriasis.org/advance/assessing-skin-pain-psoriasis-patients>  
(<https://www.tandfonline.com/doi/abs/10.1080/09546634.2018.1528330>)

<https://www.mcmasterforum.org/docs/default-source/product-documents/citizen-briefs/pain-symptom-management-in-ontario-cb.pdf?sfvrsn=2>

<https://www.mcmasterforum.org/docs/default-source/product-documents/evidence-briefs/pain-strategy-eb.pdf?sfvrsn=2>