

July 17, 2018

To Whom It May Concern:

Re: Feedback on CADTH's Report on The Availability and Access to Non-Pharmacological Treatment of Chronic Non-Cancer Pain in Canada

Pain is pain whether it is related to cancer or not. The only exception is pain with the expectation to be short-term such as post-surgical pain. We provide you with this feedback from the perspective of people with lived experience in both short and long-term pain. Patients with long-term rheumatic disease experience pain as severe as cancer patients though often resigning themselves to coping with it for the rest of their lives.

The CADTH report does not convey the full impact of chronic pain on all aspects of an individual's life. Pain affects every aspect of daily life, including, but not limited to: sleep, activities of daily living and the ability to work. In the report, it appears that no patients were surveyed on their experience with availability and access to non-pharmacological treatments of chronic pain. The perspective provided in the report is provider-based only and it's important to realize that patients who live with pain everyday and for 24 hours a day may have a different view on the state of their care.

Cancer patients have, for the most part a health care system that meets their needs. They have cancer agencies and a national strategy that directs the treatments they receive. Chronic pain patients are left to navigate a health care system that has, in the case of many rheumatic disease patients, contributed to their pain by not having accessible care when it is needed and most required. There are significant unmet patient needs in terms of accessing non-pharmacological treatments, often because they are not reimbursed through provincial health care systems, the treatment options are not offered or there are lengthy wait lists delaying access to care.

It is extremely unfortunate that our patient community is not even considered in this report. While it is difficult to compare different disease states, it is important again to reiterate again that cancer patients have a national strategy, while others who live with pain are told to use "mindfulness" as an alternative treatment option for opioids. Treatments that pain patients report as being effective are not considered in the report, including: acupuncture, massage therapy and medical cannabis. These treatments are effective for many patients, making a huge difference in their ability to simply live somewhat of a normal life, are often economical, however, they are not even accessible in the public healthcare system. Physiotherapy is mentioned and sometimes covered by insurance but the wait times are often so long that patients give up on this form of therapy.

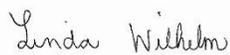
The report also gives the perception that pain patients' health care needs are not as important as patients living with other conditions. While we recognize that cancer is a life-threatening disease, it needs to be recognized that left untreated, or improperly treated, a number of chronic conditions are also life-threatening due to the poor mental health that these patients experience. The difference is that instead of their disease taking their life, they take their own lives- feeling little hope and that the system and

treatment paradigms have failed them completely or simply do not care enough for them. It is no wonder pain patients are angry and often experience depression, except when this occurs they cannot access the mental health services they require.

A major program for arthritis patients in Canada was not included. Good Life with Osteo Arthritis in Denmark (GLA:D) has been implemented in Canada but there is no mention of this program in the report. Furthermore, to exclude people with rheumatic disease from the report is a huge gap as many experience long-term pain, and quite frankly, reflects the state of how our system and government feel about us as an 'unimportant' disease class as arthritis is not perceived as needing urgent care.

The limitations of this report say more about the state of health care for chronic pain patients than anything else. The report provides only one perspective on treatment and access and must be completed with a lived experience perspective. We urge CADTH to include this perspective and to spend more time understanding all disease states that are associated with pain.

Sincerely

A handwritten signature in cursive script that reads "Linda Wilhelm".

Linda Wilhelm
President