

Patient Input Template for CADTH CDR and pCODR Programs

Name of the Drug and Indication	Tapentadol Hydrochloride, pain, severe
Name of the Patient Group	The Canadian Arthritis Patient Alliance (CAPA)
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Email	
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1. About Your Patient Group

If you have not yet registered with CADTH, describe the purpose of your organization. Include a link to your website.

CAPA is a grass-roots, patient-driven, volunteer, independent, national education, advocacy organization with members and supporters across Canada. CAPA creates links between Canadians with arthritis to assist them in becoming more effective advocates and to improve their quality of life. CAPA believes the first expert on arthritis is the person who lives with arthritis, and is an organization for patients run by patients. CAPA welcomes all Canadians with arthritis, and those who support CAPA's goals, to become members.

www.arthritispatient.ca

2. Information Gathering

CADTH is interested in hearing from a wide range of patients and caregivers in this patient input submission. Describe how you gathered the perspectives: for example, by interviews, focus groups, or survey; personal experience; or a combination of these. Where possible, include **when** the data were gathered; if data were gathered **in Canada** or elsewhere; demographics of the respondents; and **how many** patients, caregivers, and individuals with experience with the drug in review contributed insights. We will use this background to better understand the context of the perspectives shared.

CAPA gathers our input from our board members who are people living with daily pain from inflammatory arthritis. We have extensive experience with the healthcare system, the limitations of currently available treatments and current research in the area of pain through involvement with the Strategy for Patient Oriented Research Chronic Pain Network. In this instance a patient felt so strongly about her need to provide input she reached out to us before we put out a call on social media for patients to contact us with their experiences on nucynta.

3. Disease Experience

CADTH involves clinical experts in every review to explain disease progression and treatment goals. Here we are interested in understanding the illness from a patient's perspective. Describe how the disease impacts patients' and caregivers' day-to-day life and quality of life. Are there any aspects of the illness that are more important to control than others?

It is well documented that there are insufficient treatments available for chronic pain. For many patients' opioids are an important part of their treatment regime. Despite being a contributing factor to the current opioid crisis, many patients use these drugs safely, appropriately and effectively.

Beyond pharmaceutical options there are treatments available that can be helpful for patients but many of these; acupuncture, massage therapy, yoga, exercise programs, physiotherapy are either not available in the public health care system or the wait times are so long patients give up on them. The primary care environment, for the most part is ill equipped to treat chronic pain patients. Pain patients need access to specialized, multi-disciplinary treatment clinics but the wait time for the few clinics we have in Canada are measured in years. There is no magic bullet, patients must learn to be active self-managers and to use multiple treatments to achieve some quality of life. Some manage to accomplish this with little support from the healthcare system, others are not able to do this. Living a life with severe pain affects every aspect your day; getting out of bed in the morning can feel like climbing a mountain, then you must get dressed, bathe, perhaps care for children, make meals, do household tasks all while trying to remain employed and a functioning member of society. It becomes too much for many patients and they end up depressed and isolated.

Patient on nucynta reports to CAPA:

Pain has affected every part of my daily routine. I lost my career several years ago due to inflammatory arthritis and chronic pain, and have difficulties with daily activities such as cooking, housework and recreational activities.

While I am an active volunteer and patient advocate, I am very limited in terms of shoulder pain when on the keyboard. I am waiting for my third shoulder surgery and hope that this problem is improved with this intervention.

4. Experiences With Currently Available Treatments

CADTH examines the clinical benefit and cost-effectiveness of new drugs compared with currently available treatments. We can use this information to evaluate how well the drug under review might address gaps if current therapies fall short for patients and caregivers.

Describe how well patients and caregivers are managing their illnesses with currently available treatments (please specify treatments). Consider benefits seen, and side effects experienced and their management. Also consider any difficulties accessing treatment (cost, travel to clinic, time off work) and receiving treatment (swallowing pills, infusion lines).

It is well known that there are insufficient treatments for chronic pain. The pharmaceutical options, both prescription and non-prescription have the potential for serious risks with side effects that are often difficult to manage. The non-pharmacological, complementary treatments are difficult to access in the health care system with some not being available at all unless you have good private health insurance.

Reported to CAPA by patient on nucynta

I go to our community- based therapy pool every second day, walk 10,000 steps most days, and closely follow the recommendations made by my medical team.

My pain is not well managed without my current medication regimen, and when pain management becomes poor, I get discouraged and have trouble staying active. This leads to more pain.

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I often run out of private funding for Physiotherapy and would love to have access to a Psychologist periodically to help with relaxation techniques for pain. Wait times for the only Pain specialist in my region is five years and waiting time to access Orthopaedic Specialist care and surgery is measured in years.

We currently have a private drug plan, but this is expensive for our family. My husband is retired so the premium has gone up markedly.

Chronic pain has been part of our family life now for almost 20 years. It has affected every element of our family in terms of finances, activities and relationships. Our children are now grown so it is easier for us to manage.

5. Improved Outcomes

CADTH is interested in patients' views on what outcomes we should consider when evaluating new therapies. What improvements would patients and caregivers like to see in a new treatment that is not achieved in currently available treatments? How might daily life and quality of life for patients, caregivers, and families be different if the new treatment provided those desired improvements? What trade-offs do patients, families, and caregivers consider when choosing therapy?

With few treatment options for pain every new therapy is important and can return some quality of life to a patient allowing them to resume daily activities that healthy individuals take for granted.

Patient on nucynta reports to CAPA

I have experienced far fewer side effects with Nucynta versus other pain medications. In addition to Nucynta, I take Lyrica, low-dose Amitriptyline, Humira and a small dose of Cannabis oil at night.

The treatment goal for me when taking Nucynta is to manage pain well enough to carry-on with every day activities At home and in the community.

I have been taking this medication for several years and it is the first opioid that I have been able to tolerate. It has given me my life back

6. Experience With Drug Under Review

CADTH will carefully review the relevant scientific literature and clinical studies. We would like to hear from patients about their individual experiences with the new drug. This can help reviewers better understand how the drug under review meets the needs and preferences of patients, caregivers, and families.

How did patients have access to the drug under review (for example, clinical trials, private insurance)? Compared to any previous therapies patients have used, what were the benefits experienced? What were the disadvantages? How did the benefits and disadvantages impact the lives of patients, caregivers, and families? Consider side effects and if they were tolerated or how they were managed. Was the drug easier to use than previous therapies? If so, how? Are there subgroups of patients within this disease state for whom this drug is particularly helpful? In what ways?

Patient on Nucynta Reports

Without Nucynta, I have no doubt that I would not have been able to stay active and this would have had a profound impact on my life and the life of my family members

Before starting Nucynta, I had tried several other opioids. All had intolerable side effects in terms of severe constipation. I had to take laxatives and other treatments for the constipation and this was a real problem for me. My doctor told me that Nucynta has fewer G.I. side effects than other opioids and this has made the world of difference for me in terms of my ability to take this medication And stay active.

7. Companion Diagnostic Test

If the drug in review has a companion diagnostic, please comment. Companion diagnostics are laboratory tests that provide information essential for the safe and effective use of particular therapeutic drugs. They work by detecting specific biomarkers that predict more favourable responses to certain drugs. In practice, companion diagnostics can identify patients who are likely to benefit or experience harms from particular therapies, or monitor clinical responses to optimally guide treatment adjustments.

What are patient and caregiver experiences with the biomarker testing (companion diagnostic) associated with regarding the drug under review?

Consider:

- Access to testing: for example, proximity to testing facility, availability of appointment.
- Testing: for example, how was the test done? Did testing delay the treatment from beginning? Were there any adverse effects associated with testing?
- Cost of testing: Who paid for testing? If the cost was out of pocket, what was the impact of having to pay? Were there travel costs involved?
- How patients and caregivers feel about testing: for example, understanding why the test happened, coping with anxiety while waiting for the test result, uncertainty about making a decision given the test result.

N/A

8. Anything Else?

Is there anything else specifically related to this drug review that CADTH reviewers or the expert committee should know?