**CADTH Patient Submission Survey**

**NRBDO Template**

This survey is designed specifically to assist patient groups in completing the current CADTH Patient Submission Template (2016). It is not designed to collect additional data beyond that required for an effective patient submission.

(Consent Form template to be created by the NRBDO - consider plan for dissemination of data in the reporting design so that the consent form covers all your future plans.)

**Section 1 General**

Are you a [insert condition] patient?

Are you a [insert condition] caregiver?

Please select your province or territory. [Dropdown list]

[Insert any questions that you need the answer to regarding age, gender, etc., being careful not to ask for identifying information you do not actually need.]

**Section 2 Condition and Current Therapy Information**

**IMPACT OF CONDITION**

Questions from the CADTH template: *What are the condition-related symptoms and problems that impact the patients’ day-to-day life and quality of life? What aspects of this condition are more important than others? How does this condition affect day-to-day life? Are there activities that you are unable to do as a result of the condition?*

**Survey Question Bank:**

On a scale of 1 to 10, to what degree is your quality of life affected by the following, as a result of your condition:

Chronic pain

Crisis pain

Mobility issues

Financial hardships

Fatigue

Anxiety

Psychosocial issues

Other

Considering your answers above, tell a story of a time that the pain/anxiety/fatigue, etc. kept you from doing something.

[Consider giving condition-specific, non-leading examples]

What level of anxiety do you experience about sudden condition-related events?

How do sudden condition-related events affect your day to day life?

What does no one but you understand about this condition?

**PATIENTS’ EXPERIENCES WITH CURRENT THERAPY**

Questions from CADTH template: *How well are patients managing their condition with currently available treatments? Examples of the types of information that might be included are: What therapy are patients using for this condition? How effective is the current therapy in controlling the common aspects of this condition? Are there adverse effects that are more difficult to tolerate than others? Are there hardships in accessing current therapy? Are there needs, experienced by some or many patients, which are not being met by current therapy? What are these needs?*

[Give patient-group specific examples were applicable.]

What therapy are you currently using for your condition?

How well are you managing your condition with currently available treatments?

Really well Well Not well Really not well

How effective is the current therapy in controlling the common aspects of this condition?

Really effective Effective Not Effective Really not effective

Are there adverse effects that are more difficult to tolerate than others?

Yes No

If yes, explain.

Are there hardships in accessing current therapy?

Are there needs, which are not being met by current therapy?

Yes No

If yes, explain. [Consider stigma, polypharmacy, anxiety, if applicable.]

Any psychosocial effects?

Yes No

If yes, explain.

What access issues do you have with the current therapy and how does it affect you?

Is there another drug for your condition currently on the market that you have experience with, but that you are not taking yourself currently?

Yes No

If yes, please explain why. Does it not work as well for you, or is it an access issue?

**IMPACT ON CAREGIVERS**

Questions from CADTH template: *What challenges do caregivers face in caring for patients with this condition? What impact do treatments have on the caregivers’ daily routine or lifestyle? Are there challenges in dealing with adverse effects related to the current therapy?*

What challenges do caregivers face in caring for patients with [insert condition]?

What impact do treatments have on the caregivers’ daily routine and lifestyle?

Are there challenges in dealing with adverse effects related to the current therapy?

**Section 3 – Information about the Drug Being Reviewed**

**WHAT ARE THE EXPECTATIONS FOR THE NEW DRUG OR WHAT EXPERIENCES HAVE PATIENTS HAD WITH THE NEW DRUG?**

This is an opportunity to stress unmet needs. No cheerleading.

Did you participate in a clinical trial for this drug?

Yes No

If no, please complete section a. If yes, please complete section b.

**a) Based on no experience using the drug:**

Would you expect your life will be improved by this new drug?

Yes No

Is there a particular gap or unmet patient need in current therapy that this drug will help alleviate?

Would you be willing to experience serious adverse effects with the new therapy if they experienced other benefits from the drug?

Yes No

What other benefits might this drug have — for example, fewer hospital visits or less time off work?

How is the new drug expected to change a patient’s long-term health and well-being?

How likely would you be to take this drug to [insert improvement] if it didn’t [insert potential adverse effect]?

Very likely Likely Unlikely Very Unlikely

**b) Based on patients’ experiences with the new drug as part of a clinical trial or through a manufacturer’s compassionate supply:**

What positive and negative effects does [insert name of drug] have on [condition]?

Which symptoms does the new drug manage better than the existing therapy and which ones does it manage less effectively?

Does the new drug cause adverse effects?

Yes No

If yes, explain.

If yes, which adverse effects are acceptable and which ones are not?

Is the new drug easier to use?

Yes No

If yes, explain.

How is [insert name of drug] expected to change a patient’s long-term health and well-being?

**Section 4 – Additional Information**

In the absence of direct questions about cost and affordability, use this section if cost concerns are applicable.

What is the financial impact of your condition? Consider cost of the drug, dietary issues, social/economic costs, secondary/tertiary conditions, drug administration supplies.

Very high impact High impact Low impact Very low impact

Please explain.

Can we contact you for future survey research.

Yes No