

Instructions for Providing Patient Input to the CADTH Common Drug Review

Patients are important participants in Canada's drug reimbursement recommendations processes. By providing input to the CADTH Common Drug Review (CDR), patients ensure that their perspectives and experiences inform drug reimbursement recommendations. Patient perspectives are considered by: CADTH; the CADTH Canadian Drug Expert Committee, or CDEC; Canada's federal, provincial, and territorial drug plans; and the pan-Canadian Pharmaceutical Alliance, or pCPA.

Following are instructions for providing patient input to the CADTH CDR:

1. **Sign up to receive CADTH E-Alerts** at www.cadth.ca/subscribe. Make sure you select the CADTH e-Alert box and give your consent to receiving emails from CADTH.
2. **Watch for our CADTH e-Alert "Call For Patient Input"** emails. Our e-Alerts include the drug's name (both the brand and generic names), disease area, and deadline for receipt of patient input. As well, [Open Calls for Patient Input](#) are posted on our website and shared via our social media channels. Not every e-Alert will be relevant to your patient group.
3. **Download** the CDR Patient Input Template when you've identified a "Call for Patient Input" that's relevant to your patient group. For most reviews, the standard template "[Patient Input Template for CADTH CDR and pCODR Programs](#)" is the one to use. Occasionally, the drug under review is a biosimilar (as indicated on the CADTH website along with details of the project number, project status and submission type) For biosimilar reviews, use the template with prompts on awareness of biosimilars and accessibility considerations titled: "[Biosimilar Patient Input Template for CADTH CDR and pCODR Programs](#)"
4. **Gather the perspectives and experiences** of those living with the disease. Some patient groups interview some of their members who have diverse experiences and perspectives representative of those living with the disease; others ask their entire membership to complete a questionnaire. We're most interested in hearing about the diversity in patients' and family members' experiences that represent those living with the disease, rather than receiving information on clinical trials or views from medical specialists.
5. **Complete the Patient Input Template.** The template explains how your input will be used, and provides prompts to help you organize your submission. Be specific and concise, and respect the eight-page word limit. You may need to remove the prompts to stay within the page limit.
6. **Review your submission for confidential information.** Remove any information that could be used to identify individual patients or their family members. Your submission (with your group's contact details removed) will be shared with our expert committee members and the public drug plans. It will also be posted on our website.
7. **Submit your completed Patient Input Template** using the "Submit Feedback" link on the [Open Calls for Patient Input](#) page. The online form will allow you to upload your completed file. Once submitted, you will receive an automated email acknowledging receipt of your input.
8. **Confirm the accuracy** of our patient input summary. A summary of the patient input received is included in our clinical report. Sometimes you will be the only group to provide input; other times multiple groups will provide input. You will be asked to review our draft version of the summary before it is published in the CADTH clinical report.
9. **Follow the progress of our drug review** using the "Submission Status Report" found by locating the drug on the [CADTH CDR Reports](#) page, clicking on the drug name, and looking for the report on the top right-hand side of the drug plan submission page.
10. **Respond to our questions.** During the review, if we have questions about your input, a CADTH Patient Engagement Officer will contact your group's primary contact.

- 11. Consider the feedback** in our follow-up letter. Once the review has been completed, we will highlight the areas from your input that we, and our expert committee members, found especially useful, and offer suggestions for future submissions. We will also invite you to share your feedback on the process

Eligibility

Any interested patient group can provide input. We seek input from patient groups, rather than from individuals, to encourage diversity of voices and experiences.

For CDR, a patient group is defined as an organized group that represents patients with a specific disease or condition, or collection of diseases or conditions. A group will typically have members that are patients, family members, or both, and have a public face such as a website or social media presence. Groups are requested to provide information about their organizations in the input template.

Individual patients and caregivers are encouraged to work directly with a patient group so that their experiences are included in the group's submission. However, if no Canadian patient group exists, individual patient and caregiver input will be accepted. Before submitting input, individual patients and caregivers should contact requests@cadth.ca to confirm the absence of a relevant patient group.

International patient groups may submit patient input, and Canadian patient groups may include perspectives and experiences from patients outside of Canada. Please indicate where perspectives come from to help us better understand their context and the health care setting in which the treatment was received.

Advice to Complete the Template

You are welcome to refer us to previous patient input submissions if this helps reduce your response burden. If you build on previous submissions, we'd like to hear if there is anything specific for certain types of patients that we should consider.

- 1. About Your Patient Group:** All groups contributing to CDR should complete this section, as the registration of groups is relevant only to the pCODR process. In this section, we're looking to understand what your group is and what your group does. You might describe your group's membership or audience base and geographic reach. We suggest 50 to 100 words for completing this section.
- 2. Information Gathering:** Please describe how you gathered the patient perspectives shared in the input submission. Many different types of methods are appropriate. Depending on resources, groups might use one method or multiple methods. Groups can:
 - interview patients, caregivers, or both
 - draw on previous interviews, conversations, or comments from patients
 - draw from blog posts, online forums, and chat rooms
 - prepare, promote, and gather survey data from the patient community in Canada, or internationally
 - draw from past surveys and reports prepared by the patient group or others
 - share personal experiences of the submission's author(s)
 - share experiences of patient group staff or advisory board members.
- 3. Disease Experience:** We understand that delaying death and reducing pain are important outcomes; but they might not be the only outcomes important to patients and their families. Consider:
 - physical impacts
 - limitations on activities (such as work, school, sports, hobbies)
 - stigma or embarrassment
 - impact on relationships with family members
 - impact on relationships with friends and colleagues
 - emotional impact (such as self-esteem).

We understand that each individual's experience with an illness is unique, and that experience might vary from day to day. Reading about different individual's best days and worst days offers a greater understanding of that variability than a focus on the worst days alone.

Direct quotations can powerfully communicate a patient's or caregiver's story and illustrate an idea, although too many direct quotations can take away from your summary of the disease experience. We suggest one or two direct quotations, and 300 to 1,000 words overall for this section.

- 4. Experience With Currently Available Treatments:** Current treatments are those that patients in Canada are already using to prevent, manage, or treat their illness. Please be specific in linking benefits, side effects, and any difficulties to named treatments. We suggest between 300 to 1,000 words for this section.
- 5. Improved Outcomes:** Improvements might be small — less nausea, greater predictability of length of effectiveness, fewer appointments to receive treatment — and make a tremendous difference to patients' and their families' lives. We imagine that patient views of the same disease area will not change substantially from review to review unless the treatment landscape changed dramatically. Groups or individuals do not need to know anything about the drug in review to comment in this section. We suggest 300 to 500 words for this section.
- 6. Experience With Drug Under Review:** To find patients with experience, some groups contact the clinical trial investigators; others speak with patients outside of Canada. We'd like to hear patient feedback when improvements were slight or substantial, when patients experienced problems of any kind, or when they saw mixed results. We suggest up to 1,000 words for this section.
- 7. Companion Diagnostic Test:** If the drug in review has a companion diagnostic test, it will be indicated on CADTH's website. Only complete this section if there is a companion diagnostic test.
- 8. Anything Else:** Share your comments here, or contact CADTH's patient engagement team directly.
- 9. Appendix: Patient Group Conflict of Interest Declarations:** A conflict of interest (COI) is when professional judgment about one activity may be, or may be perceived to be, influenced by another interest or activity. A potential COI may be intellectual, financial, or personal.

The purpose of asking patient groups to disclose any COIs is to inform CADTH, our committees, and other readers, of any competing interests the group may have. CADTH staff, experts involved in the review, and committee members all complete COI declarations.

We recognize it is resource-intensive to run surveys, hold interviews, and gather data. It is OK to receive help. When groups use material prepared with the support of other organizations, please cite who was involved in collecting, analyzing, and presenting the data. If you have received help from a consultant, or a contact from outside of your group, to write or review your patient input, please also include this information.

Learn More

CADTH has a number of resources to help patients better understand our drug review processes and the value of patient input:

- To hear how patient input is used with CDR and CDEC, see the [CADTH video series](#).
- If you are using surveys or interviews to collect information, [A Guide for Patient Advocacy Groups: How to provide patient and caregiver input for a pCODR drug review](#) offers tips on conducting surveys and collecting and reporting findings.
- You can search the [CDR Drug Table](#) for examples of patient group submissions from previously completed CDR reviews.
- Our [Procedure for the CADTH Common Drug Review](#) outlines the CDR process in detail, including the Patient Group Input Procedure.

Need Help?

If you have questions or need advice about patient input to the CADTH CDR or the CADTH pCODR programs, contact Sarah Berglas (sarahb@cadth.ca) or Tamara Rader (tamarar@cadth.ca) at 613 226 2553.