Guidance for Providing Patient Input
The Role of Reimbursement Reviews

In Canada, our federal, provincial, and territorial governments manage their own health care budgets. These budgets are used to pay for hospitals, physicians, long-term care homes, drugs, and other necessities for health. In each jurisdiction, policy-makers must make difficult decisions about the management of these budgets to deliver, maintain, and improve health care. For example, if money is used to pay for a new drug, that money isn’t available to cover other drugs or health priorities.

How are these decisions made? How do policy-makers decide which drugs provide the greatest value? That’s where the CADTH Reimbursement Review comes in.

Health Canada

- Before a drug can be sold in Canada, it needs a Notice of Compliance (NOC) from Health Canada. A NOC does not mean that the drug is reimbursed by public drug plans.
- If a pharmaceutical company or recognized tumour group decides that they want the drug to be publicly reimbursed, they apply to CADTH.

CADTH

- CADTH evaluates clinical and economic evidence, guided by insights from clinicians and patients
- Expert committees review the evidence and insights, and recommend if and how a drug should be publicly reimbursed.

Public Drug Plans

- If CADTH recommends that a drug be reimbursed, the pan-Canadian Pharmaceutical Alliance negotiates the drug price.
- Canada’s federal, provincial, and territorial drug plans and cancer organizations, except for Quebec, make their reimbursement decisions based on CADTH’s recommendation and other factors.
Guidance for Providing Patient Input

The Role of Patient Input in Reimbursement Reviews

Reimbursement Reviews involve reviewing the clinical trials and economic model from the sponsor (typically, a pharmaceutical company), as well as studies identified by CADTH through a literature search. CADTH also seeks insight from clinical experts, clinician and patient groups, and the drug plans. We consult with clinical experts to make sure that our assessments reflect current practices and to identify any treatment gaps. We also invite clinician groups to provide input. Like patient input, clinician input is used by CADTH to help develop the review protocol and evaluate the evidence.

Patient perspectives help improve the quality of CADTH Reimbursement Reviews. The information that patient groups share with CADTH helps reviewers and expert review committee members understand the impact (both good and bad) that the treatment has on those taking it and on those caring for loved ones living with the disease. Here are some examples of how patient input is commonly used:

• to better understand the nature of the disease
• to identify health outcomes (e.g., symptom improvement, slowing symptom worsening, avoiding future illness, improving quality of life, avoidance of treatment-related side effects, ease of use) that are important to patients; understanding what outcomes really matter to those living with the disease helps CADTH question or confirm outcomes measured in the clinical trial and economic model
• to understand the diversity of needs among patients and health care settings across Canada and highlight needs that are specific to certain communities or subpopulations
• to identify potential issues around patients’ abilities to use and access the drug under review.

When expert committee members reflect on this information, they seek to find a balance between the patient and caregiver needs that may be met by a drug with the health resources that will be displaced if that drug is funded.

When people who are affected by CADTH recommendations participate in the reviews, it adds to the transparency, accountability, and credibility of the recommendations made.

Interested in becoming involved?

• **Register** to receive the CADTH Weekly Summary to learn of Open Calls for patient and clinician input, and stakeholder feedback.
• Watch for our CADTH Weekly Summary email every Thursday. Open calls will include the drug name (brand and generic names), disease area, and deadline for input. Please note that not every call will be relevant to your patient group.

Responding to a call for patient input

The information that patient groups share with us gives context to the evidence being assessed and helps reviewers and committee members better understand who will benefit most from the treatment under review. Patients and caregivers offer first-hand knowledge and understanding of what it means to live with the disease. We look to you to contribute those perspectives.
Any interested patient group can provide input to a review. We seek input from patient groups, rather than from individuals, to encourage diversity of voices and experiences.

If you are an individual patient or caregiver interested in providing input, please contact the Patient Engagement team (patientengagement@cadth.ca or 613-226-2553) and we can connect you with a relevant patient group. If you are a patient group and you are unsure of your eligibility to contribute, have a look at CADTH’s definition of a patient group.

Once a call for patient input is issued, it is open for 35 business days. If you would like to provide patient input, you have options to do so:

**Download and complete the** [Patient Input Template](#).
The template prompts are suggestions to help you organize your information. It can be especially helpful if this is your first time contributing or if the treatment under review is for a rare disease. You don’t have to answer every question.

**Build on past input.**
If you or another patient group have provided input in the past for a treatment now being reviewed for a new indication or an expanded patient population, you may want to reference previous patient input. Highlight new information or anything specific to the requested reimbursement criteria that we should consider.

**Focus on your key concerns.**
If there is a key concern that is particularly significant to your membership, you can reduce your response burden by explaining that issue alone in a letter to CADTH. You’ll still need to upload the letter by the input deadline and complete a conflict of interest disclosure.

**Work with another patient group.**
If a lack of time and resources is a concern, you and one or more patient groups can work together and provide joint input. We ask that each group involved includes a conflict of interest disclosure.

**Ready to submit input?**
- If you’re not sure where to start, read through the “Advice for completing template” for some helpful tips.
- Review your input and remove any confidential information such as patients’ names.
- Make sure your input is accessible per The Accessibility for Ontarians with Disabilities Act.
- When you’re ready to submit your completed input, upload it using the “Submit” link on the Open Calls page. Please respect the deadline.
- Once submitted, you’ll receive an automated email acknowledging receipt of your input.
How can your input reach more people?

Your input is valuable to us and an important part of the CADTH Reimbursement Reviews. Because of that, we want to make sure that anyone who would like to read it can easily do so.

- As per *The Accessibility for Ontarians with Disabilities Act*, public documents must be compliant with accessibility guidelines.
- To ensure compliance, Word provides an “Accessibility Checker” for identifying and repairing accessibility issues that’s located under the “Review” tab and “Check Accessibility” sub-tab.

What can be done in 35 days?

- Describe the impact of the disease and identify often-used treatments using what you’ve learned from your regular interactions with your membership.
- We are not looking for a large sample of representative data. Include a range of perspectives that will provoke questions and challenge assumptions about the evidence we’re reviewing. A range might be two different views, or it might be quite diverse if the disease is experienced very differently by individuals.
- Describe what different patients would like to see in a new treatment that isn’t being accomplished by treatments commonly used by patients.
- Don’t worry about including information on the drug under review. We recognize that it might not be available to Canadians yet and/or that trials may not yet have been held in Canada.
- Add some quotes that illustrate the important ideas offered. You are welcome to reuse quotes from past input to CADTH.
- To reduce your response burden, reuse and build on past input unless there have been substantial shifts in the treatment landscape.

Reviewing the summary of patient input

The purpose of the patient input summary is to support the CADTH clinical and economic teams’ understanding of the disease, treatments used, and hopes for treatment improvement. To this end, reviewers read your input and write a summary to send to you, to make sure that they have a good understanding of the information you provided to us.

Sometimes only one group provides input; other times, multiple groups provide input. The summary combines all the input that we received for the drug under review. We send you the summary and any questions reviewers may have and ask that you comment within **five business days**.

Once you’ve confirmed we’ve understood your input, the summary is incorporated into the CADTH clinical report and is used to develop the review protocol.

Your original patient input in its entirety is shared with the committee and shared on the CADTH website. A few weeks before the committee meeting, committee members may have questions related to your input. In that case, we will connect with you to ask you those questions. A member of the expert committee will present your input during the committee’s deliberations.
Ready to review the summary?

• Read through the summary and consider whether the summary reflects the main issues of importance to your group.
• Reply to confirm the accuracy of the summary and share any feedback you may have with us.
• If we have any follow-up questions for you from reviewers and committee members, answer them to the best of your ability.

How do your insights help CADTH clinical and economic teams interpret the evidence?

• Clinical reviewers compare the helpful and harmful outcomes of the new drug with the beneficial and harmful outcomes of available treatments; for example, if outcomes that are important to patient groups were not measured in clinical trials. CADTH may highlight this in the review, with a suggestion that these outcomes be studied in future clinical trials.
• Clinical reviewers examine how well clinical trials were designed and conducted, and how well the results can be applied in a Canadian context. For example, the reviewers consider if the trial setting was representative of a typical Canadian hospital or community setting. They look at the types of patients included, or excluded, in the trial as compared with Canadian patients with the illness. They also look for sources of bias that may cause the trial results to be contrary to the true effect of the drug.
• CADTH health economists critically examine the economic assessments provided by the pharmaceutical company. The assessments estimate the differences between the cost and effects of the treatment options. Health economists use information you provided about the costs involved in preventing, managing, or treating the illness — and any difficulties accessing or using treatments — to appraise these assessments.

Expert committee deliberations

The CADTH Canadian Drug Expert Committee (CDEC) is composed of physicians, pharmacists, economists, and members of the public. The CADTH pan-Canadian Oncology Drug Review (pCODR) Expert Review Committee (pERC) is composed of oncologists, health economists, an ethicist, pharmacists, and patient members. These expert committees make drug reimbursement recommendations, based on CADTH assessments, as to whether a drug should be publicly funded.

You can learn more about the members of the expert committee and their backgrounds on the CADTH website here: Canadian Drug Expert Committee and pCODR Expert Review Committee.

At CDEC meetings, patient input allows committee members to hear what it is like to live with the illness and the treatment outcomes that are important to those with the illness. In its structured deliberations, CDEC considers clinical and economic evidence, as well as patient input. pERC develops its reimbursement recommendations by considering elements such as clinical benefits, patient values, economic evaluations, adoption, and feasibility. By identifying patient values, pERC considers what matters to patients and caregivers when receiving cancer treatment.
If ever CADTH needs to pause a review because the application from the sponsor is incomplete or the drug hasn’t yet received Health Canada market authorization, it will be tracked on the CADTH website. This can happen at any stage during a review.

If the review is delayed six months or longer, CADTH may re-post the call for patient input. This is to make sure that the patient input is relevant and up-to-date, and it gives other patient groups an opportunity to contribute to the review process.

**Ready to follow the progress of the review?**

- Search for the drug on the [CADTH Reports](#) page. When you click on the name, you’ll find:
  - your original patient input, which will be shared with the expert review committee and the public drug plans
  - the key milestones for the review; this includes the date that the expert review committee will be meeting to discuss the treatment and make a recommendation
  - when a review is scheduled to go to the expert committee.

**Providing feedback on the draft recommendation**

For each drug under review, an initial recommendation is made following the expert committee deliberations. If there is no good data to show that a new drug provides greater value than existing treatment options, the draft recommendation will recommend that it not be publicly funded. But if the data suggests that the drug provides added value for certain patients, the draft recommendation will recommend that it be publicly funded.

All draft recommendations are posted on the CADTH website for stakeholder feedback. The sponsor, the manufacturer of the drug under review (if not the sponsor), the drug programs, patient groups, and clinician groups have **10 business days** to review the draft recommendation and provide feedback using the CADTH template.

**What can be done in 10 days?**

- Read the recommendation and ask yourself:
  - What is surprising?
  - Can you see how the patient input was considered?
  - Is there anything that needs to be emphasized or explained?
- Your membership is welcome to read the recommendation but it is not necessary. CADTH does not expect you to canvas their support or feedback.
  - If lack of time and resources is a concern, just respond to the questions most important to you.
Patient groups who responded to the call for patient input can provide feedback on the draft recommendation. The feedback you provide will allow the expert review committee to further consider outcomes and issues that are important to patients and improve the clarity of the recommendation.

What does feedback on a draft recommendation look like?

Stakeholder agreement with the draft recommendation
Please indicate if the stakeholder agrees with the expert review committee’s recommendation.

Expert review committee consideration of the stakeholder input
Does the draft recommendation demonstrate that the expert review committee has considered the stakeholder input that your organization provided to CADTH?

Accuracy of the summary of stakeholder input
Does the draft recommendation accurately summarize the stakeholder’s input for the drug under review?

Clarity of the draft recommendation
- Are the reasons for the draft recommendation clearly stated in the draft recommendation?
- Have the implementation issues been clearly articulated and adequately addressed in the draft recommendation?
- If applicable, are the reimbursement conditions clearly stated and the rationale for the conditions provided in the draft recommendation?

Ready to submit feedback?

- Download the feedback form.
- Prepare your response. Please limit the number of responses to one per patient group.
- Review your feedback for confidential information.
- Make sure your feedback is accessible per The Accessibility for Ontarians with Disabilities Act.
- Upload your feedback by the deadline on the Open Calls page using the “Submit” link.
- Once submitted, you’ll receive an automated email acknowledging receipt of your feedback.
Understanding the final recommendation and next steps

After a Reimbursement Review is done, the final recommendation is posted on the CADTH website, together with the rationale for the recommendation and the information that contributed to the recommendation. It is also announced in the CADTH Weekly Summary.

Beyond CADTH, the pan-Canadian Pharmaceutical Alliance negotiates the cost of the drug to achieve greater value for public drug programs and patients. At that point, federal, provincial, and territorial drug plans and cancer organizations can make their reimbursement decisions based on CADTH recommendations and other factors, such as drug plan mandates, jurisdictional priorities, and budget impact.

Meanwhile, we contact you and any other patient groups that contributed input to explain how it was used by CADTH reviewers and expert committee members. When it’s appropriate, we’ll provide suggestions should you want to submit patient input for future projects. This also gives you an opportunity to share any feedback you might have on the process with CADTH.

Please remember that CADTH Reimbursement Reviews follow strict processes to evaluate evidence in a way that is fair. We ask that you refrain from directly contacting CADTH’s executive staff and expert review committee members. If you have any comments or feedback that you would like to share with CADTH, we would love to hear from you. You can contact the Patient Engagement team at patientengagement@cadth.ca or 613-226-2553.
Opportunities for Patient Engagement in Reimbursement Reviews

CADTH submissions fall under three main categories:

- **Standard review** — Submissions for new drugs, drugs with new indications, and selected new combination products.
- **Tailored review** — Submissions for new combination products or new formulations of existing drugs that CADTH has selected as tailored reviews. Submissions for subsequent-entry, non-biologic complex drugs.
- **Cell and gene therapy review** — Submissions for cell and gene therapies. Cell therapies treat diseases by using cells from a patient or from a donor and transferring them into a patient. Gene therapies treat diseases by using genes to change a patient's cells. Some therapies are both cell and gene therapies.

Patient engagement is part of all three categories of reviews but is most useful for standard reviews and cell and gene therapy reviews. The following are the stages of the reviews during which patients can be involved.

### Key Milestones for Patient Group Engagement

<table>
<thead>
<tr>
<th>Milestone</th>
<th>Description</th>
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<tbody>
<tr>
<td>Call for patient input opens</td>
<td>The call for patient input is issued and stays open for 35 business days.</td>
</tr>
<tr>
<td>Patient input is posted on the CADTH website</td>
<td>Approximately two weeks after the call for patient input closes, the patient input CADTH received is accessible on the website.</td>
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<tr>
<td>Patient group(s) review(s) the CADTH summary</td>
<td>CADTH prepares a summary of the patient input. Patient groups have 5 business days to review and validate the summary.</td>
</tr>
<tr>
<td>Call for feedback on draft recommendation opens</td>
<td>Patient group(s) have 10 business days to review and comment on the draft recommendation during the stakeholder feedback period.</td>
</tr>
<tr>
<td>Follow-up correspondence</td>
<td>When the review is complete, CADTH contacts the group(s) that contributed input to provide feedback.</td>
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Learn More

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

• You can search Reimbursement Review Reports for examples of patient group input from previously completed reviews.
• Our Procedures for CADTH Reimbursement Reviews outlines the process in detail, including the patient group input procedure.
• List of acronyms.
• If you are using surveys or interviews to collect information, Strengthening Your pCODR Submission: Collecting and Presenting Information offers tips on conducting surveys and collecting and reporting findings.
• 2020 CADTH Virtual Symposium: How Patient Input is Used by CADTH: Insights From Feedback Letters discusses ideas that CADTH reviewers and expert committee members have identified as helpful in patient input, as well as approaches for sharing information that is useful.

Need Help? If you have questions or need advice about patient input to the CADTH Reimbursement Review process, contact the Patient Engagement team at patientengagement@cadth.ca or 613 226 2553.

Questions or comments about CADTH or this tool?

Online: cadth.ca

Email: patientengagement@cadth.ca

New at CADTH Newsletter: cadth.ca/subscribe
Advice for Completing the Patient Input Template

You can report some or all of the information that follows, depending on what is most relevant to you and what is most important for your membership to share with CADTH.

Information about your patient group

How is it used by CADTH?
• Understand your group’s perspective. For example, a group focused on treatment access might emphasize different information than a group focused on patient safety.

Guidance
• All groups contributing input should complete this section.
• Tell us what your group is and what your group does (e.g., your membership or audience base, geographic reach).
• We suggest 50 to 100 words for completing this section.

Information gathering

How is it used by CADTH?
• Learn from a diversity of viewpoints while recognizing that your input cannot be representative of the entire Canadian patient population. For example, seniors’ perspectives differ from youths’ perspectives; those in urban centres who live in proximity to clinical trials differ from those living in remote or rural Canada who cannot access them.

Guidance
• Describe how you gathered the perspectives shared in your input. Many different types of methods are appropriate. Depending on resources, groups might use one method or multiple methods. Here are some suggestions:
  • Interview patients, caregivers, or both, with diverse experiences and perspectives of those living with the disease.
  • Ask your membership to complete a questionnaire.
  • 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 the input author’s or authors’ personal experiences.
  • Share experiences of patient group staff or advisory board members.
  • If you are aware of disease burden surveys that have been reported in the literature, you can reference these and explain what it means to Canadians and what challenges they face.

Disease experience

How is it used by CADTH?
• Support the understanding of disease from the perspective of those impacted by it.
• Encourage reviewers to consider the physical, emotional, and social impacts of disease.

Guidance
• 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
• the impact on relationships with family members
• the impact on relationships with friends and colleagues
• the emotional impact (such as self-esteem).

• We understand that everyone’s experience with a disease is unique and that experiences might vary from day to day. Reading about different individuals’ best days and worst days offers a greater understanding of that variability than a focus on the worst days alone.

• Direct quotes can powerfully communicate a patient’s or caregiver’s story and illustrate an idea, although too many direct quotes can take away from your summary of the disease experience. We suggest including one or two direct quotes.

• We suggest 300 to 1,000 words overall for this section.

Example of its use in a CADTH report

"Patient input for this review described the diagnosis of a child with SMA [spinal muscular atrophy] as having a devastating effect. The feeling of hopelessness and despair in the face of a progressive and severe illness is especially pronounced, considering the absence of effective therapies. Young patients miss out on typical childhood experiences such as using the playground. In more severe cases, patients cannot execute basic movements such as sitting up and require help with needs such as transfers as well as positioning in wheelchair and in bed. In the most severe cases, an infant’s condition worsens over time and passes away before reaching their second birthday."

— Disease Prevalence and Incidence, Clinical Report

Experiences with currently available treatments

How is it used by CADTH?
• Support the understanding of how patients are preventing, managing, or treating their illnesses, including benefits, side effects, and any difficulties with treatments.
• Reflect on any barriers preventing the use or access to treatments that might lead to patients stopping treatment (e.g., patient preferences around methods of delivery and frequency of administration).
• Explain out-of-pocket costs that patients incur.

Guidance
• Please keep in mind that current treatments are those that patients in Canada are already using to prevent, manage, or treat their illnesses.
• When discussing specific benefits, side effects, and any difficulties with treatments, name the treatments you are referring to, when possible.
• We suggest between 300 to 1,000 words for this section.

Examples of its use in CADTH reports

“There is currently only one approved therapy for PBC [primary biliary cholangitis] in Canada — ursodeoxycholic acid (UDCA) — and more than 80% of patients with PBC receive UDCA. In their input to CADTH, patient groups described gastrointestinal symptoms (diarrhea), weight gain, alopecia, dizziness, and flu-like adverse effects while on UDCA, in addition to PBC-related symptoms such as pruritus and fatigue.”

— Standard of Therapy, Clinical Report
“The input received from patient groups has identified patients who might not have been eligible for surgery as usually including anemic patients, patients suffering from obesity, and patients with bleeding abnormalities. These patients have experienced significant relief from long-term intermittent therapy with [drug]. In addition, there is an unmet need to be addressed in patients who wish to maintain fertility, are ineligible for surgery, wish to avoid surgery, or wish to reduce symptoms until reaching menopause. No available alternative medical therapy exists that can be administered in the long term and for which evidence suggests reduced fibroid size.”

— Discussion of Clinical Evidence, Clinical Report

**Improved outcomes**

**How is it used by CADTH?**

- Learn what outcomes are important to patients and understand how these outcomes affect a patient’s quality of life and day-to-day life.
- Identify what outcomes are important to be explored in our assessment; and what assumptions about effectiveness, harms, unmet need, ease of use, willingness to endure harms, and delivery challenges we need to explore, challenge, or confirm.
- Identify research gaps by flagging outcomes that were identified as important by patients that were not considered in clinical trials.

**Guidance**

- 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 don’t need to know anything about the drug, plasma product, or cell and gene therapy in review to comment in this section.
- We suggest 300 to 500 words for this section.

**Examples of its use in CADTH reports**

Questions re the drug’s ability to meet patient needs: “As stated in the patient group input, CF [cystic fibrosis] has a major impact on the quality of life of patients and their caregivers. Treatment with [drug in review] did not demonstrate statistically significant improvements in health-related quality of life (i.e., CFQ-R or EQ-5D-3L) in either [trial 1] or [trial 2].”

— Interpretation of Results, Clinical Report

Identifies limitation of clinical trial: “One limitation of the study was the fact that treatment response was assessed using change in BMD [bone mass density] rather than the incidence of fractures, which is the most important outcome for patients according to the patient input received by CADTH; consequently, there is no direct evidence regarding the effects of [drug] on reducing the incidence of fractures in men.”

— Critical Appraisal, Clinical Report

Contributes to the understanding of clinical significance: “In their input for this review, the Multiple Sclerosis Society of Canada highlighted the importance of mobility in preserving the independence of well-being of MS patients. The clinical expert consulted by CADTH also indicate that, based on clinical observation, a treatment that is able to delay deterioration in walking ability is meaningful to patients.”

— Interpretation of Results, Clinical Report
Clinical trials meet patients needs: “pERC deliberated the input received from one patient advocacy group, Ovarian Cancer Canada (OCC), and noted that patients value new treatments that lengthen the time to recurrence, prolong survival, and improve QoL [quality of life]. Based on the evidence from the [trial 1], pERC agreed that niraparib aligns with patient values because it delays disease recurrence and fulfills a need for a new treatment option, particularly for patients with BRCA wild type who don’t currently have a funded maintenance treatment option.”

— Final Recommendation

Experience with drug under review

How is it used by CADTH?

• Further understand the impact of the benefits (and harms) experienced.

Guidance

• We understand it may not be possible or practical to gather any lived experiences if the drug is not yet widely available in Canada. Many patient groups don’t find individuals with experience.
• 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.

Examples of its use in CADTH reports

“Patients also emphasized the impact of RCC [renal cell carcinoma] on their quality of life particularly as their disease progresses. Of the seven patients and one caregiver that had direct experience with [drug], pERC noted that the patients experienced delayed disease progression and a generally well-tolerated side effect profile with [drug].”

— Final Recommendation

“Patients on [drug] have reported beneficial cognitive impacts, improved academic performance, improved executive functioning and focus, improved energy, and increased confidence in their futures. In many cases, the thought of returning to the strict Phe-restricted diet should [drug] be unattainable is devastating.”

— Final Recommendation

Companion diagnostic test

How is it used by CADTH?

• Further understand patients’ treatment journeys and standard of care; for example, if tests are used to match a patient to a specific drug or therapy, to track serious side effects from treatment, or to see how well treatment is working.

Advice

• If the drug, plasma product, or cell and gene therapy 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.

Example of its use in a CADTH report

“Lung Cancer Canada noted that diagnostic testing for the NTRK gene fusion is currently not available or funded in Canada. With the increasing importance of genomic profile testing and personalised medicine, this form of testing is needed. Sarcoma Cancer Foundation Canada also noted that patient respondents were proponents of these tests being made widely available.”

— Clinical Report
Anything else

Advice
• Share your comments here or contact CADTH’s Patient Engagement team directly.

Conflict of interest declaration

How is it used by CADTH?
• Build trust and demonstrate openness. To maintain the objectivity and credibility of CADTH’s processes, all participants in the drug review process must disclose any conflicts of interest (COI).

Advice
What should you include in your COI?

• We understand that patient groups and clinician associations must rely on donations to run their organizations and that they have a strict code of conduct about the management of donations.

• We ask that you please list all companies or organizations that provided your group with financial payment over the past two years who could have interest in the drug under review (i.e., the drug manufacturer and its competitors).

• Most groups will receive donations from more than one source. Ideally, you want to list ALL companies or organizations who have provided funding to you over the last two years. This information is requested for transparency — it does not affect the use of your input.

• We recognize it is resource-intensive to run surveys, hold interviews, and gather data. If you 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.