A Guide for Patient Advocacy Groups: How to provide patient and caregiver input for a pCODR drug review
# TABLE OF CONTENTS

**Introduction**  

**Part 1: The pCODR Process and Input Template**  

1.1 How do patient and caregiver experiences add value to the review process?  
1.2 What is involved in contributing to the pCODR review process?  
1.3 What information should you include in your submission?  
1.4 What information is not necessary?  

**Part 2: Planning for Your Submission**  

2.1 Steps to complete the input template  
2.2 What types of information should you collect?  
2.3 How do you recruit participants?  

**Part 3: Methods to Collect Patient and Caregiver Input**  

3.1 How do you collect input using surveys?  
3.2 How do you collect input using interviews?  

**Part 4: Summarizing and Reporting Experiences**  

4.1 How do you summarize the quantitative information?  
4.2 How do you summarize the qualitative information?  
4.3 Examples of how to report findings  

**Appendices**  

Appendix 1: pCODR Deliberative Framework  
Appendix 2: Sample survey for patients  
Appendix 3: Sample survey for caregivers  
Appendix 4: Tips for writing survey questions  
Appendix 5: Sample interview guide  
Appendix 6: Labeling checklist for Interviews and Surveys  

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What is the purpose of this guide?

This guide is designed to help patient advocacy groups like yours complete the pan-Canadian Oncology Drug Review (pCODR) Patient Advocacy Group Input on a Drug Review template. You will find guidance on what information we are looking for within the submission, and how to collect and present that input.

What is the value of patient input?

Understanding the experiences of patients and their caregivers is a key element in making recommendations for drugs under review, and pCODR needs your help to collect that input. The time and effort you put into completing a submission is greatly appreciated by pCODR. Your work gives us important information about what it is like for patients to live with cancer and receive specific cancer therapies. Patient and caregiver input is essential, as pCODR needs to consider the opinions and experiences of those who will be most directly affected by any recommendations we make.

How to use this guide

Please use the sections that are most relevant to you.

This guide includes four sections:

- **Part 1**: The pCODR Process and Input Template gives an overview of the pCODR process and how your submission will be used to make our recommendations. You will find this section very helpful if this is your first submission.

- **Part 2**: Planning for Your Submission helps you think through the steps involved in completing a submission.

- **Part 3**: Methods to Collect Patient and Caregiver Input explains ways to collect patient and caregiver input; including using surveys and interviews.

- **Part 4**: Summarizing and Reporting Responses describes how to write up the input you have received from patients and caregivers, and enter it into the submission template.

Acknowledgements

pCODR, with the help of the Canadian Cancer Action Network (CCAN), would like to thank you for taking the time to be part of the pCODR review process. Your contribution will help us reach our shared goal of improving the lives of those affected by cancer.

Comments and Questions

If you have any comments or questions about the guide, please contact info@pcodr.ca.
1.1 How do patient and caregiver experiences add value to the review process?

Your efforts in collecting patient and caregiver experiences will provide valuable information that directly affects drug reviews. Patient input is an important part of the process, and impacts pCODR’s final recommendations on the drug being reviewed. It is important for us to understand what matters most to patients when they think about the treatments they may be taking or need to take in the future, in addition to how their caregivers’ lives are affected on a daily basis. The best source of this information is patients and caregivers themselves. We want to ensure that patient and caregiver concerns, opinions, and experiences with cancer and cancer treatments are included in this process.

1.2 What is involved in contributing to the pCODR review process?

To be part of the review process, please register on the pCODR website. The information you collect will be used by the pCODR Expert Review Committee (pERC) to develop its recommendations. The review process is a concise evaluation of clinical and economic evidence, and is designed to include input from: clinical groups, pharmaceutical manufacturers, and patient advocacy groups. As a patient advocacy group, your role is to provide patient and caregiver experiences by completing the pCODR Patient Advocacy Group Input on a Drug Review template. The input you provide is summarized into a Clinical Guidance Report, which incorporates the scientific evidence and the patient/caregiver perspective. There are additional groups, such as the Economic Guidance Panel and the Provincial Advisory Group, who provide input during the drug review process as well. Once input from all groups is received, a drug funding recommendation is made and this report is posted on the pCODR website. Final recommendations are submitted to provincial and territorial Ministries of Health. The entire review process takes approximately 5-8 months for a single drug review. To see all of the groups that participate in the process, see Appendix 1 or the pCODR website.

1.3 What information should you include in your submission?

pCODR wants to understand the experiences of those living with and caring for people with cancer. To help you provide the most useful information, Table 1 offers suggestions on what to include in your submission and things to consider when presenting your information. It is helpful to look at the pCODR input template while reviewing this section. For examples of helpful submission responses, please see Section 4.3.
Table 1: What to include in your submission.

<table>
<thead>
<tr>
<th>Section of the Input Template</th>
<th>Considerations</th>
</tr>
</thead>
</table>
| **Information gathering**     | • Mention how information was obtained (e.g., online surveys, interviews, etc.).  
• Include the number of participants.  
• Keep in mind, pCODR is looking for patient and caregiver experiences and not references to literature or printed sources (e.g., statistics), since this type of information is already reviewed in other parts of the drug review process. |
| **Experiences patients have with this type of cancer** | • Report on the experiences of the majority of individuals living with this cancer, rather than exceptional cases. |
| **Patients’ experience with their current therapy** | • Report on current therapies (e.g., drug therapies, surgery, radiation) to understand whether all aspects of the patient’s cancer are being managed. |
| **Impact on Caregivers**      | • Report on how the patient’s cancer and treatment have affected the caregiver and their daily routines. |
| **What are the expectations for the new drug?** | • Keep in mind that this section is designed to be answered by patients who have never used the drug under review.  
• Comment on the anticipated impact of the drug under review, and the desired outcomes of using the drug under review as compared to their current therapy.  
• Explore whether patients are willing to live with some side effects in return for some benefits of the new drug, and if so, which side effects.  
• Comment on the unmet needs of patients’ current therapies, and what major areas of change they would like addressed. |
| **What experiences have patients had to date with the new drug?** | • This section is ONLY to be completed by patients who have been treated with the drug under review in the past or are currently taking the drug.  
• Some patients may currently be on the drug under review. If this is the case, please describe their experiences in this section (not in “What are the expectations for the new drug?” of the input template).  
• The purpose of this section is to get a better understanding of the advantages and disadvantages of the specific drug, and to learn how it has affected patients’ quality of life. |
1.4 What information is not necessary?

pCODR is aware that your time is valuable and there is limited space in the template; therefore, we want to help you focus on what is most useful to the drug review process. Since the following information is collected from other sources, you do not need to provide this input in your submission:

<table>
<thead>
<tr>
<th>Not necessary</th>
<th>Reason</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scientific evidence</td>
<td>• The Clinical Guidance Panel completes a thorough analysis of the literature, and provides recommendations on the specific cancer and overall clinical benefit of the drug under review - including: effectiveness, safety, burden of illness, and need of effective alternatives to current drug therapies.</td>
</tr>
<tr>
<td>Summarized or reworded information from sources other than patients or caregivers (i.e., physicians or other health care providers)</td>
<td>• The goal of the pCODR input template is to receive feedback from both patients and their caregivers. Physician input is recognized as important, however, is not the aim of the template. Feedback from physicians is received from the Clinical Guidance Panel, who provides the scientific evidence and physician perspective.</td>
</tr>
<tr>
<td>The same messages repeated under different template headings</td>
<td>• Sometimes it may be difficult to assign information to only one section of the pCODR input template. Please ensure that you are answering the specific question under each section and not repeating information to ‘fill up space’. pCODR wants to ensure that only the most relevant feedback is obtained in order to guarantee the best recommendations possible for the drug under review.</td>
</tr>
</tbody>
</table>
**PART 2**

**Planning for Your Submission**

Completing a submission takes some time and effort, but it is an opportunity for you to provide valuable input regarding patient and caregiver experiences. Putting in time to plan for your submission can help you be more efficient in collecting input and completing the template.

### 2.1 Steps to complete the input template

Start as early as possible.

Creating a plan is a great first step to completing the input template. The list below will help you think through each of the steps:

1. **Identify what information** you will collect (**Section 2.2**)
2. **Decide who** you want information from. For example, you may want to know who is eligible to use the drug in order to narrow your recruitment to the appropriate participants
3. **Select a method to recruit** participants (**Section 2.3**)
4. **Decide on a data collection method(s)** and collect the data (**Part 3**)
5. **Summarize and report** the input you have collected (**Part 4**)

### 2.2 What types of information should you collect?

The type of information you collect will depend on what input you are looking to address; i.e., do you want to measure how much improvement a drug provides (e.g., ranking)?, or do you want to know what it is like to live with cancer (e.g., personal quotes). This information can be grouped into two categories: quantitative and qualitative information.

When collecting input that is either counted or measured - such as: **how much** time do you spend getting to their cancer therapies?; **how long** is drug X effective for?; and **how many** types of cancer therapies have you been on? - you are gathering **quantitative information**. One common way to collect this type of information is by using **closed questions** within surveys, where answers are selected from a pre-determined set of responses (e.g., using ratings on a numbered scale or multiple choice). You can then report the average response or how many times a particular response is chosen. **More information and example regarding surveys** can be found in **Section 3.1** and **Appendix 2-4**.

* Upon using a hyperlink, press ‘ALT + left arrow key’ to return to your last viewed section
It is also important to collect the thoughts, opinions, stories, and feelings of patients and caregivers. This input is called **qualitative information** and answers questions such as:

- **What** challenges have you encountered while managing the side effects of the person you are caring for?;
- **Why** is it difficult to access your current therapy?; and
- Can you **describe** how drug X has or has not improved your quality of life?

Great ways to collect qualitative information include using interviews or **open-ended questions** in surveys. These allow participants to explain their experiences in their own voice. **More information and examples regarding open-ended questions in surveys and interviews can be found in Section 3.1 and Section 3.2.**

**TIP: Conserve your time**

Many of the sections in the input template ask general questions about patient and caregiver experiences with a specific cancer. Therefore, you only need to collect this information once and can use it in multiple submissions. One helpful strategy is to collect this information in advance, then you only need to focus on the questions related to the specific drug.
2.3 How do you recruit participants?

Recruitment takes time, so plan ahead and start early!

Recruiting participants to share their experiences dealing with cancer and specific therapies can be challenging. Patient advocacy groups sometimes struggle to connect with patients who have a particular type of cancer or who have taken a specific drug. Because the goal is to get feedback from these individuals, you may need to use several approaches to recruit participants.

Ways to recruit participants

Feel free to use any combination of the following strategies to recruit participants.

1. Your patient advocacy group’s database
   
   Send a survey or interview invitation out through your patient advocacy group’s database.

2. Connect with external groups or partner organizations
   
   External groups or your partner organizations in other countries may be in regular contact with patients. Ask if they can help you connect with patients and caregivers who have specific cancers.

   Examples of groups to contact:
   - Alberta Health Services
   - Cancer Care Manitoba
   - Young Adult Cancer Canada
   - Cancer Care Nova Scotia
   - Wellwood (Hamilton)
   - Cancer Fight Club

3. Use existing events, meetings, or conferences
   
   You may find a large pool of potential participants at already existing events, meetings, or conferences (e.g., a patient cancer forum or education session). See if you can collect names for future recruitment or conduct interviews at the event.

4. Ask oncologists running clinical trials
   
   Oncologists running clinical trials may be willing to provide patients with a printed postcard containing your group’s contact information and an invitation to provide their experiences living and dealing with cancer.

5. Ask the participants
   
   Once you have recruited some participants, ask them to suggest names and contact information of others who may be willing to participate. The principle behind this approach is that ‘people know people like themselves’.

* Upon using a hyperlink, press ‘ALT + left arrow key’ to return to your last viewed section
PART 3 Methods to Collect Patient and Caregiver Input

Collecting patient and caregiver experiences involves a series of steps that vary depending on whether you will use surveys, interviews, or both.

BOX 1 All information must be kept confidential

The input you collect may contain very sensitive and private information. Because of this, it may be hard for some participants to discuss their personal experiences. It is important for you to reassure individuals of the importance of their feedback to the pCODR process and discuss how it will be kept confidential and anonymous. You should store all information in a secure spot, whether it is in a password protected computer file or a hardcopy document locked in a cabinet. Make sure that all names or other information that could be used to identify a participant is removed before it is included in the pCODR template.

3.1 How do you collect input using surveys?

Use simple language. It is easier to answer questions that use simple and clear language.

Surveys are a great way to capture responses from a large group of individuals. Given the pCODR timeline for receiving patient input, web-based surveys (such as Survey Monkey, or Fluid Survey) are the easiest to create and send out. To help you develop your survey, sample surveys for patients and caregivers are provided in Appendix 2 and Appendix 3, respectively.

Types of question and response options

Survey responses are only as good as the questions asked, so spend some time thinking about the structure of the questions.

Survey questions are typically structured in two types of formats: closed or open-ended.

- **Closed questions** allow you to receive input that participants select from a set of pre-determined answers. This type of information is usually collected if you wish to measure or count specific input; such as ‘how many times a year do you travel to receive your current therapy?’ Closed questions allow you to collect quantitative information (see Section 2.2).

If you choose to use **closed questions**, you will need to select which response options you want for each question. Several possible response examples are provided in Table 2.
Table 2: Considerations for choosing response options for closed questions.

<table>
<thead>
<tr>
<th>Type of Response Options</th>
<th>Considerations</th>
<th>Examples</th>
</tr>
</thead>
</table>
| Named categories (e.g., gender, medical diagnosis) | - Do not overlap categories (i.e., do not state age categories as 20-30, 30-40; instead include 21-30, 31-40)  
- Include a “check all that apply” option where applicable  
- Cover all possible categories or include an “other” category | Male; Female  
Under 21; 21-30; 31-40; 41-50; 51-60; 61-70; 71-80; 81-90; over 90 |
| Scaled categories (e.g., frequency or intensity of side effects) | - Balance response sets (i.e., the middle option should be neutral)  
- It is advisable to include an “I don’t know” or “not applicable” response option | 1-Strongly disagree; 2-disagree; 3-neither disagree nor agree; 4-agree; 5-strongly agree  
Completely dissatisfied; very dissatisfied; somewhat dissatisfied; somewhat satisfied; very satisfied; completely satisfied |

- **Open-ended questions** ask participants to provide a response in their own words; such as ‘please describe which side effects you would be willing to tolerate and why’. Open-ended questions allow you to collect qualitative information (see Section 2.2).

Some points you may want to consider when deciding whether to use open-ended questions are:

- Do you wish to collect quotes?  
- How will you analyze responses? (Section 4.2 will describe analysis methods in more detail).

- Is the answer to any of your questions currently unknown? (Open-ended information allows you to collect information that you did not expect.)

**TIP: Use simple language**

It is easy to answer questions that use simple and clear language. Strategies to simplify your language are shown in Appendix 4.
**Survey layout**

Not only is it important to pay attention to the types of questions you ask, the answer options and wording, but the order of the questions affects how people respond as well. Consider the following:

- Begin with simple and relevant questions;
- Group questions of a similar type together (i.e. based on answer options or content);
- Provide instructions at the beginning of the survey and at any point where the survey format changes (e.g., from closed to open-ended questions);
- Provide broader questions first, followed by detailed questions;
- Do not make the survey too long as participants may not complete the full survey;
- Participants should be able to complete the survey in a reasonable time limit (15-20 minutes);
- If you are including questions such as participants’ age or gender, these should be asked at the end of the survey; and
- Thank the participants for their time.

### 3.2 How do you collect input using interviews?

#### How many interviews to conduct

Interviews allow you to get more detail from a small number of participants. There is no rule on the ideal number of interviews to conduct. Generally, you will find that after a certain number of interviews, similar information is being obtained from participants (i.e., participants are not providing new information); typically this happens after about 6 to 8 people have been interviewed. Your aim in interviewing is to explore issues in as much depth as possible. **pCODR recognizes that recruiting patients is difficult**, but try to recruit as many patients and caregivers as you can. For information on recruitment, see **Section 2.3**.

#### How to develop an interview guide

An interview guide is a great way for you to prepare broad, open-ended questions relating to topics or issues of interest for an interview (For information on open-ended questions, see **Section 3.1**). You can use this guide to capture each participant’s unique experiences dealing with cancer and therapies. **Box 3** highlights some of the key considerations for developing an interview guide. You will also find a sample interview guide in **Appendix 5**.
CONSIDERATIONS FOR DEVELOPING AN INTERVIEW GUIDE

• Avoid making the interview guide too long: Do not plan to collect in-depth information on more than 12-15 issues in a single interview.

• Sequence your questions in a logical order: The order in which questions are asked will affect responses. Begin with broad questions and move to more specific questions.

• Approach sensitive topics later rather than sooner: If sensitive topics are addressed, they should be asked later in the interview when participants usually become more comfortable (note that some participants will never feel comfortable).

• Include prompts: Prompts are used to clarify a point or to obtain more information. If there is something you need more clarification on, don’t hesitate to ask a participant to expand on their thought.

• Develop open-ended questions: Questions are intended to reveal what participants are thinking and should encourage a detailed response.

• Ask participants to think about specific experiences: This approach encourages concrete, specific responses about participants’ feelings, attitudes, and beliefs rather than popular opinion.

• Avoid simply asking “why?”: This approach often puts participants on the defensive. Consider alternatives such as “What are the reasons you feel that way?”

• Avoid giving examples: These may limit responses, as participants may focus on the examples provided rather than their own ideas.

CONDUCTING THE INTERVIEW

When conducting an interview, it is important to gather as much information as possible from the participant. Essentially, you can view an interview as a conversation in which you, the interviewer, help to steer the direction of the discussion while giving the participant room to share their experiences in detail. To make gathering information easier, you can use the sample Labeling Checklist (Appendix 6) to keep track of what the participant shares with you. It is also helpful to audio record your interviews, in addition to having a note-taker present. This allows you to go back and recall what participants have discussed.

Depending on where you are in the interview (beginning, middle or end), certain types of questions can help you obtain better quality responses. Table 3 outlines the different types of questions and offers examples of each.

TIP: Take notes during an interview

It is helpful for the interviewer to jot down notes as the participant speaks. Recording points that require clarification or possible probes will help the interviewer gather meaningful information and to capture direct quotes.
Table 3: Types of questions to incorporate into your interview guide.

<table>
<thead>
<tr>
<th>When to use the question</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>At the beginning of an interview introduce the topic.</td>
<td>“Have you ever heard of drug X?”</td>
</tr>
<tr>
<td></td>
<td>“What sorts of comments have you heard about the drug - either positive or negative?”</td>
</tr>
<tr>
<td>In the middle of an interview dive more deeply into the topic.</td>
<td>“In what ways do you feel the drug under review has improved your quality of life?”</td>
</tr>
<tr>
<td></td>
<td>“Has the drug lived up to your expectations?”</td>
</tr>
<tr>
<td>At the end of an interview see if anything was missed.</td>
<td>“Is there anything else you would like to say about your experience with drug X?”</td>
</tr>
</tbody>
</table>

A sample agenda is shown in Box 4.

**BOX 4  Sample interview agenda**

- **Introduction**: Begin by introducing yourself and assure the participant that all comments will be confidential.
- **Purpose of the interview**: Review the purpose of the interview and why you are interviewing the participant (“We are looking for a better understanding of …”).
- **Findings**: Provide a brief overview of how the findings will be used (i.e., to inform the content of the input template).
- **Overview of the interview**: Indicate how long the interview will last and the order in which questions will be presented (e.g., first we will ask about your experience with their current therapy and then about drug X).
- **Interview questions**: Ask the questions in the interview guide.
- **Conclusion of the interview**: Thank the participant for their time.
PART 4 Summarizing and Reporting Experiences

Now that you have collected patient and caregiver experiences, the next step is to summarize and report these responses in the input template. The way you present this information will depend on the types of questions you asked. Remember that pCODR is looking for an overview of experiences or themes that are presented across the entire discussion.

4.1 How do you summarize the quantitative information (i.e. closed ended questions in surveys)?

Quantitative information you collect will mostly come from closed questions used in your survey. The open-ended questions should be summarized using the methods presented in Section 4.2 below, since they provide qualitative information. To summarize data, it is helpful to combine responses as averages, frequencies /counts (i.e., number of people), or proportions (i.e., percentages). pCODR is looking for simple statistics. Quantitative information can be presented in sentences or as a table. Depending on how much data you have, it may be easier to use a table which allows you to present a large amount of content in a small amount of space. These examples illustrate both methods.

EXAMPLE Summarizing quantitative information in text

Those who completed the survey ranked ‘infections’ as the most important, with 71.8% (total participants=22) rating it as 10, a “very important” aspect of controlling xxx cancer. ‘Infections’ were followed by ‘kidney problems’, ‘pain’, ‘mobility’, ‘neuropathy’, ‘shortness of breath’ and ‘fatigue’. In all cases, more than 50% of respondents rated these aspects as a 10 “very important” to control. In all cases the rating average was greater than 8, which meant that all listed symptoms were considered important.

EXAMPLE Using tables to report quantitative information

<table>
<thead>
<tr>
<th>Symptom or Problem Related to xxx Cancer</th>
<th>% of Respondents who Rated a “10”</th>
<th># of Respondents</th>
<th>Rating Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infections</td>
<td>71.8%</td>
<td>22</td>
<td>9.17</td>
</tr>
<tr>
<td>Kidney problems</td>
<td>68.2%</td>
<td>21</td>
<td>9.06</td>
</tr>
<tr>
<td>Pain</td>
<td>64.3%</td>
<td>22</td>
<td>9.03</td>
</tr>
<tr>
<td>Mobility</td>
<td>59.7%</td>
<td>22</td>
<td>8.95</td>
</tr>
<tr>
<td>Neuropathy</td>
<td>56.7%</td>
<td>22</td>
<td>8.75</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>51.0%</td>
<td>20</td>
<td>8.42</td>
</tr>
<tr>
<td>Fatigue</td>
<td>50.9%</td>
<td>22</td>
<td>8.69</td>
</tr>
</tbody>
</table>
4.2 How do you summarize the qualitative information (i.e., opened-ended questions in surveys, and interviews)?

Regardless of how you collected input, patient and caregiver experiences need to be summarized. **A great way to present qualitative information is to include quotes from participants.** Before you choose quotes, it is important to analyze all of your qualitative information as a whole. If you begin by selecting random quotes you may not realize that there are specific themes that a majority of participants collectively discussed. Qualitative information can come either from:

- Responses collected through interviews; or
- Open-ended questions asked in your surveys.

Box 6 provides an overview of how to analyze qualitative data. A **sample labeling checklist has been provided in Appendix 6 to help you identify common themes discussed interviews or can be used as a guide when labeling surveys.**

**TIP: Use the voice of the participant**

Remember that findings should be in the voice of the participant e.g., what participants expressed, reported, said, described, etc. It should be made apparent that this result was taken directly from the participant’s experiences, rather than the opinions of the interviewer.

**BOX 6 Summary of the qualitative analysis process**

- Do an initial read through of all documents (e.g., notes) to become familiar with the information.
- During the second reading, highlight sections of text with a label that you think is relevant and representative of what is being said.
- Once you have labelled your documents, look for common themes that can link your labels together, and group them under these broader themes.
- Review your themes. If some themes do not seem to fit on a second review, consider either reassigning the response or creating a new theme. Alternatively, it may become clear that several themes can be combined into a single idea (i.e., if they ultimately are getting to the same topic/point).
EXAMPLE  Using quotes to support themes

For an overall theme called “accessibility” - with codes distance to drug and financial burden - a response may look like this:

Patients reported difficulties with respect to access to drugs. The most widely discussed factor that affected access to medications was financial burden - given that the drug is not covered by some private drug benefit plans. Some patients reported that the particular drug was difficult to access because it was only available at a centre far from their home, which made distance an important factor that limited accessibility. As described by one patient,

“It’s frustrating that my therapy isn’t easier to access because I find that it is working well. I just get so tired having to drive so far to be able to receive my IV drugs at the hospital. This is costing me a lot of time and money, especially since we have to pay for some of my medications out-of-pocket.”
4.3 Examples of how to report findings

To increase the amount of space you have to report responses, remove the instructions and examples provided in the input template.

You are now ready to present patient and caregiver experiences in the input template! Don’t be intimidated by this step; there is no right or wrong way to report your responses. Just remember to highlight important experiences from a group of participants, rather than exceptional cases. A great way to do this is to describe general trends and then present a quote to support the finding. This section provides sample responses from previous submissions organized in the order of the questions in the template:

- **Information gathering**
- **Experiences patients have with this type of cancer**
- **Patients’ experience with current therapy**
- **Impact on caregivers**
- **What are the expectations for the new drug?**
- **What experiences have patients had to date with the new drug?**

**Information gathering**

**EXAMPLE**

**Helpful response**

[Patient advocacy group] conducted an anonymous online survey, which was sent via e-mail to xxx patients and caregivers across Canada who were registered on the [patient advocacy group] database. Respondents of the survey were from across Canada with each province represented. There were no respondents from the territories and xxx respondents were from outside of Canada. There were a total of xxx respondents; of this total xxx were individuals living with [cancer], and xxx were caregivers. A total of xxx respondents indicated that either they, or the person they provide care for, used [drug under review] for their [cancer].

This section can be short and concise! The most important information to get across is:

- The method used to collect patient and caregiver experiences; and
- The number of participants (divided by patients and caregivers) who were recruited (e.g., who were sent the survey), who participated, and who are on the drug under review.

* Upon using a hyperlink, press ‘ALT + left arrow key’ to return to your last viewed section
Experiences patients have with this type of cancer

**EXAMPLE**  Helpful response

According to the survey, xxx% of patients are negatively impacted by their [cancer] in their day-to-day life. Only xxx% indicated no major change. The respondents indicated that the biggest impact has been on their ability to work or volunteer (xxx%). In many cases, individuals retired early or went on extended leave due to the increased fatigue and pain of living with the disease.

“Symptoms and problems at this time impact my day-to-day life and quality of life to a great extent. In the past xxx months I have found that I needed to build up stamina to cook and many times I overexert myself with any day-to-day housekeeping activities. I still need to rest for a minimum of 1-2 hours each afternoon and go to bed between 8-9 each evening. The limitations of this disease are frustrating and can bring about fits of depression.”

As a patient advocacy group, you know how important it is understand how patients are dealing with their cancer on a daily basis. Your goal is to highlight how the diagnosis of cancer impacts patients’ lives by emphasizing general trends and providing quotes, like in the example above. The focus is not to present information you would find in a textbook or scientific article. Members of the pCODR drug review team collect scientific evidence separately, but do not have the expertise to report on experiences unique to patients and their caregivers. You are being asked to provide patient and caregiver experiences on a personal level. The following is an example of what pCODR is not looking for.

**EXAMPLE**  Unhelpful response

[cancer] is the most common [cancer] diagnosed in xxx. The most recent statistics for [cancer] are from xxx, where almost xxx people were diagnosed and nearly xxx passed away. Patients are generally diagnosed in their xxx’s and xxx’s - it is usually a disease of an older population though [cancer] has been diagnosed in people much younger. Children do not get this disease. This is a chronic, slow-progressing cancer for many who are diagnosed, though there are cases where the disease does progress quickly. People may live with the disease for years before requiring chemotherapy or other drug therapy. While there are treatment options available that are life-extending for the patient, they do not cure the disease and relapse will happen. If survival is looked at over a longer time-span, median survival decreases significantly. There are many genetic variables that help doctors predict how the disease will progress and how patients will respond to treatment.
This section should focus on experiences from patients that have never been on the drug under review.

**EXAMPLE** **Helpful response**

xxx% (xxx respondents) of individuals living with [cancer] and their caregivers indicated that they did experience some hardship in accessing treatment for [cancer]. Hardships included:

- the need to pay out-of-pocket for treatments;
- the need to travel great distances to receive treatment;
- the need to meet significant criteria to qualify for treatment;
- discontinuance of the treatment when the funding ran out; and
- lack of access through the hospital or drug plan to necessary treatment.

Patients may be on one of many therapies, yet they may describe similar experiences across therapies. The sample labeling checklist - found in Appendix 6 - can help you group similar thoughts together. It is also helpful to discuss both the positive and negative effects of a cancer therapy.

**Impact on caregivers**

**EXAMPLE** **Unhelpful response**

Based on responses from xxx patients, the biggest impact on their caregivers lives was daily routine or lifestyle (xxx%). Often patients expressed that their caregivers put their life and needs on hold to be able to provide care for them. In many cases, this limited the amount of time caregivers could spend with their children or other family members and friends. Patients expressed disruption to their caregivers’ daily routine as their sole focus had been on them and helping to manage their appointments, treatments, meals and other personal care matters.

Caregivers’ experiences are an essential component to understanding the impact of cancer therapies on the daily routines, quality of life, relationship with family/friends, and stress/mental health of those dealing with cancer. Being able to discuss these challenges is the central goal of this section. Usually caregivers put on a strong face in front of patients, in order to ensure they are a stable form of support, so patients may not have an accurate description of their true feelings. It is best to ask these questions directly to caregivers rather than through the patient survey.
What are the expectations for the new drug?

**EXAMPLE**  
**Helpful response**

- In considering new treatments, xxx% of the respondents (n=xxx) indicated that it is ‘extremely important’ to see an improvement in their cancer (tumour shrinkage, tumour stability, pain reduction, improved breathing).

- xxx% of the respondents (n=xxx) indicated that it was ‘extremely important’ to realize an improved Quality of Life when considering a new therapy.

- When asked about whether it was important to evaluate the average period of the expected benefit, again, the respondents (xxx%) (n=xxx) indicated an extremely high degree of importance to this decision.

- In considering a new therapy, xxx% of the respondents (n=xxx) indicated that they were willing to tolerate a moderate to high degree of side effects (xxx respondents in the range of 5 to 10, where 10 = ‘significant side effects’).

Bullet points are a quick and easy way to discuss a number of topics in a small amount of space. In the example, the patient advocacy group was able to describe the key expectations of the drug under review, in combination with quantitative information (e.g., percentages). It is helpful to include rating scales when reporting quantitative information to help the reader understand the level or severity of the response.

**EXAMPLE**  
**Unhelpful response**

Input from patients without direct experience with [drug under review] indicated that patients are seeking treatments which can extend their life expectancy, even if only for a short period of time. In addition, treatments with manageable side effect profiles that would not affect a patient’s daily life would also be considered favorable to patients.

Patient input highlighted that the currently available therapies provide time-limited relief (some patients note improvement in symptoms from weeks to years until disease progression and/or symptom worsening) or that therapies are inconsistent at maintaining relief. Patients note that currently available therapies prolong life at best, however, provide very little or no increase in quality of life. Moreover, patients expressed concerns of secondary infections, risk of death, and other complications that may arise from invasive interventions such as splenectomy or transplants.

At first, this example may seem appropriate, but it does not present information on the patients who responded (e.g., the number of patients) or how strongly they felt about the topics discussed. Without this information, it is difficult to understand the impact of the statement.
What experiences have patients had to date with the new drug?

It is important to always provide the specified response under the correct section. Many patient advocacy groups tend to combine the expectations of the drug under review with the experiences of those currently on the drug therapy.

**EXAMPLE**

**Helpful response**

A total of xxx respondents had direct experience with [drug under review], in which xxx% were accessing it in either the third, fourth or fifth-line of therapy. xxx respondents were receiving it in the second-line and one person was receiving [drug under review] in the first-line. When asked about the side effects experienced with [drug under review], respondents mentioned fatigue, nausea, diarrhea and hypertension. In rating the side effects of [drug under review], xxx% of xxx respondents assigned a score of low to moderate (respondents in the range of 1 ‘no side effects at all’ to 4) and xxx% indicated that the side effects were debilitating (respondents in the range of 8 to 10, with one of these respondents (xxx%) rating the side effects at 10 or ‘debilitating side effects that impact daily living’). Of the side effects experienced, respondents indicated xxx% were willing to accept them, xxx% felt that some were acceptable and others were not, one person (xxx%) had an adverse event/discontinued usage and xxx respondents did not answer directly.

The above example incorporates a number of points into a small paragraph. This response highlights:

- The number of respondents who had direct experience with the drug under review;
- The key side effects experienced by patients; and
- The percentage of respondents who fell into each section of the rating scale.

**EXAMPLE**

**Unhelpful response**

Positive and negative effects are described above. The drug manages to control tumour growth better than existing therapy thereby preventing potential blockages in the body. The drug can cause reactions to develop in some patients. Hand and foot disease is acceptable, and grey hair is acceptable and a certain level of fatigue is acceptable, and pain up to 5 or 6 out of 10 is acceptable. The drug is easier to use than some other drugs, and the patient can remain at home. The drug can extend life for each patient, and for some, quite significantly.

The above example discusses experiences that were highlighted in previous sections, which is not useful for the current question. In addition, it is not clear how many participants felt a specific way since scales are not defined. As always, it is helpful to present rating scale definitions alongside scale values to ensure readers understand which extreme of the scale respondents are on (i.e., 1: no side effects vs. 10: debilitating side effects).
Patient advocacy groups are a central part of the overall drug review process. Within the timeframe to produce recommendations for a specific drug under review, patient advocacy groups provide feedback:

1. Early in the process for use in preparation of the initial recommendations; and
2. Later in the review after the pCODR Expert Review Committee has made its initial recommendations.

This guide will help you with providing input on point 1 above, for which patient advocacy groups have approximately 10 days to complete upon receiving notification that a drug is going under review.

### pCODR Deliberative Framework

<table>
<thead>
<tr>
<th>Group Name</th>
<th>Responsibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical Guidance Panel</td>
<td>• Report on the potential health benefit of the drug under review, safety, burden of illness, and need of effective alternatives to current drug therapies.</td>
</tr>
<tr>
<td>Patient Advocacy Groups</td>
<td>• Provide patient values regarding the appropriate use and impact of the drug under review; taking into consideration both patient and care giver perspectives.</td>
</tr>
<tr>
<td>Economic Guidance Panel</td>
<td>• Report on the efficiency of the drug under review, and companion technology, compared to other drug and non-drug alternatives; looking at economic evaluation and feasibility.</td>
</tr>
<tr>
<td>Provincial Advisory Group</td>
<td>• Assess the ease with which the drug under review can be adopted into the overall health care and cancer care systems; looking at economic and organizational level feasibility.</td>
</tr>
</tbody>
</table>
**APPENDIX 2**

**Sample Survey for Patients**

The following survey is aimed to help you in framing your questions in order to receive the appropriate responses, which will inform your submission. These questions are aligned with the [pCODR Patient Advocacy Group Input on a Drug Review](#) template, which makes it easy to use the survey data to complete your submission. **You are not required to use this survey. You can create your own from scratch or adapt any of the questions in the sample survey.** Placeholders (i.e., _____; and [text]) have been left for your patient advocacy group to insert information. Please note that this survey is specifically targeted for patients. If you are seeking caregiver experiences, please use the sample survey for caregivers.

**Introduction**

We at [Name of your patient advocacy group] would like to learn about your experiences dealing with cancer and how certain therapies have affected your daily life. The input you provide will be used by the pan-Canadian Oncology Drug Review (pCODR) as part of their drug review process, to inform their recommendations for new cancer drugs, including [drug name]. As a patient with [specific cancer], we invite you to complete this survey to help pCODR better understand what it is to live with [specific cancer], and your experience with current therapies and/or [drug name].

This survey will take approximately _____ minutes to complete. **The information you provide will remain anonymous.**

We thank you in advance for your contribution and greatly appreciate your participation in this survey. If you have any questions, concerns, or technical difficulties while completing this survey, please contact _____ [email address and/or phone number].

The deadline to complete the survey is _____ by _____ (AST/EST/CST/MST/PST).
**Part 1: Condition and Current Therapy**

The following questions will ask you about your experience with [specific cancer], and your current therapy (ies).

**Question 1:** In your own words, please describe how your life has been impacted by [specific cancer] (e.g., daily routines, physical functioning, etc.). Please include anything relevant to your cancer experience.

<table>
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<tr>
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<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>(No impact)</th>
<th>(Extremely large impact)</th>
</tr>
</thead>
<tbody>
<tr>
<td>[symptom]</td>
<td>○</td>
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</tbody>
</table>
**Question 2b:** Are there any cancer symptoms that affect your quality of life but have not been listed above? If yes, please list them below.


**Question 3:** What therapy (ies) are you currently using to treat your [specific cancer]? (i.e., specific drug therapies, surgery, radiation). If you are using multiple therapies, please list them all.


**Question 4:** Please describe your overall experience with your current therapy (ies) including positive and negative experiences you have had?


**Question 5a:** Please rate how much you agree or disagree with the following statement: “My current therapy (ies) are able to manage my [specific cancer] symptoms?”


<table>
<thead>
<tr>
<th></th>
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<th>2</th>
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<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(Strongly disagree)</td>
<td>(Neutral)</td>
<td>(Strongly agree)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
</tbody>
</table>
Question 5b: Please describe why you provided the above rating.


Question 6: Please list and describe any side effects from your current therapy (ies) that affect your quality of life.


Question 7a: On a scale of 1 (not at all difficult) to 7 (extremely difficult), how difficult is it to access your current therapy (ies)?

1 2 3 4 5 6 7
(Not difficult at all)

○ ○ ○ ○ ○ ○ ○ ○ ○

(Extremely difficult)

Question 7b: If you answered the above question with a 5 or higher, please describe why it is difficult to access your current therapy (ies).


Part 2: Expectations for the new drug being reviewed

Only answer the following questions if you are **not currently** on the drug under review and have had **no previous experience** using the drug.

**Question 8:** How much do you know about [drug name]?

<table>
<thead>
<tr>
<th>1</th>
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<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Nothing)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(Extremely knowledgeable)</td>
</tr>
</tbody>
</table>

**Question 9:** On a scale of 1 (extremely unimportant) to 7 (extremely important), which of the following symptoms are the most important for [drug name] to manage.

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Extremely unimportant)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(Extremely important)</td>
</tr>
</tbody>
</table>

[symptom] [symptom] [symptom] [symptom] [symptom] [symptom] [symptom]

Other: ________

**Question 10a:** Which of the following side effects would you be willing to tolerate if [drug name] were to improve your overall daily functioning.

[side effect] [side effect] [side effect] [side effect] [side effect] [side effect] Other

□ □ □ □ □ □ □
**Question 10b:** Please describe why you would be willing to tolerate these side effects.

---

**Part 3: Experiences with the new drug being reviewed**

Only answer the following question if you are currently or were previously on [drug name]. If you have had no previous experience with the drug, please do not fill out this section.

**Question 11:** Please describe your overall experience with [drug name].

---

**Question 12:** Please select the symptoms of [specific cancer] that [drug name] manages or managed better than previous therapies you have used.

- [ ] [symptom]
- [ ] [symptom]
- [ ] [symptom]
- [ ] [symptom]
- [ ] [symptom]
- [ ] [symptom]
- [ ] Other

**Question 13:** Which of the following side effects have you experienced as a result of using [drug name]?

- [ ] [side effect]
- [ ] [side effect]
- [ ] [side effect]
- [ ] [side effect]
- [ ] [side effect]
- [ ] [side effect]
- [ ] Other
**Question 14:** Please rate how much you agree or disagree with the following statement: “[Drug name] has improved my quality of life compared to previous therapies I used.”

1 2 3 4 5 6 7
(Strongly disagree) (Neutral) (Strongly agree)
○ ○ ○ ○ ○ ○ ○ ○

**Question 15:** Please describe how [drug name] has or has not improved your quality of life.


*Note: Your patient advocacy group may choose to ask questions such as the patients’ age or gender at the end of the survey. Feel free to include those and any additional pieces of information that you feel are necessary to adequately capture patient experiences regarding their cancer, current therapy, and drug under review.*
Introduction

We at [Name of your patient advocacy group] would like to learn about your experiences caring for someone with [specific cancer] and how certain therapies have affected your daily life. The input you provide will be used by the pan-Canadian Oncology Drug Review (pCODR) as part of their drug review process, to inform their recommendation for new cancer drugs, including [drug name]. As a caregiver, we invite you to complete this survey to help pCODR better understand what it is like to care for someone with [specific cancer], and your experience with their current therapies and/or [drug name].

This survey will take approximately _______ minutes to complete. The information you provide will remain anonymous.

We thank you in advance for your contribution and greatly appreciate your participation in this survey. If you have any questions, concerns, or technical difficulties while completing this survey, please contact _______ [email address and/or phone number].

The deadline to complete the survey is _______ by _______ (AST/EST/CST/MST/PST).

**Question 1:** Which category best describes your relationship with the person you are caring for?

- Spouse/Partner
- Child
- Immediate family relative (i.e., aunt, uncle, cousin, niece, nephew, etc.)
- Friend
- Other: _______

**Question 2:** In your own words, please describe how your life has been impacted by [specific cancer] (e.g., daily routines, physical functioning, emotionally, etc.). Please include anything relevant to your cancer experience.

[Blank space for text input]
Question 3: Are there any cancer symptoms that affect your quality of life as a caregiver? If yes, please list them below.

Question 4: What therapy (ies) does the individual you are caring for currently using to treat their [specific cancer]? (i.e., drug therapies, surgery, radiation). If they are using multiple therapies, please list them all.

Question 5: What challenges have you encountered while managing the side effects of the person you are caring for? Please describe these challenges related to their current therapy (ies).

Question 6: Please describe which side effects you would be willing to tolerate and why.

Note: Your patient advocacy group may choose to ask demographic questions at the end of the survey. Feel free to include those and any additional pieces of information that you feel are necessary to adequately capture caregiver experiences in dealing with individuals’ cancer, current therapy(ies), and drug under review.
The following table provides suggestions and examples to help you simplify the language of your survey questions.

<table>
<thead>
<tr>
<th>Suggestion</th>
<th>Example - Less Ideal</th>
<th>Example - More ideal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoid using technical jargon (i.e., those words or phrases for which you must provide a definition)</td>
<td>“List any adverse drug reactions as a result of abnormal pharmacokinetics or synergistic effects”</td>
<td>“List the side effects of your cancer therapy”</td>
</tr>
<tr>
<td>Use “spoken” rather than “written” language</td>
<td>“Over the past month, what proportion of your time has been spent disabled by cancer symptoms?”</td>
<td>“In the past month, how often have you felt you couldn’t carry out your normal activities?”</td>
</tr>
<tr>
<td>Use complete sentences</td>
<td>“Therapy?”</td>
<td>“What is the name of the current therapy you use?”</td>
</tr>
<tr>
<td>Avoid acronyms, abbreviations, and slang terms</td>
<td>“Are you on several cancer meds?”</td>
<td>“Are you currently taking more than one prescription medication for your cancer?”</td>
</tr>
<tr>
<td>Do not include two questions in one</td>
<td>“Do you think the benefits offered by chemotherapy and radiation outweigh the side effects?”</td>
<td>“Do you believe the side effects from chemotherapy outweigh the benefits?” (Ask the same question about radiation separately)</td>
</tr>
<tr>
<td>Make the survey items match the response scale</td>
<td>“Are you unhappy with your current treatment?” (response scale: strongly disagree to strongly agree)</td>
<td>“Please rate how much you agree with the following statement: I am unhappy with my current treatment?” (response scale: strongly disagree to strongly agree)</td>
</tr>
<tr>
<td>Word open-ended questions to prevent one word answers (e.g., yes/no)</td>
<td>“As a result of cancer, have you suffered financially?”</td>
<td>“Describe whether your cancer had any impact on your ability to regularly attend work?”</td>
</tr>
</tbody>
</table>
1. Please describe your overall experience with [specific cancer]?
   Probes
   a. Can you describe the main challenges?
   b. What aspects of your life have been impacted the most?
   c. How would you describe your overall physical functioning since you were diagnosed with [specific cancer]?

2. What therapy are you currently undergoing for [specific cancer]? Please describe specific drugs if you remember the names of them and what they are for, as well as any surgery, radiation or other treatments that make up your cancer therapy.

3. What do you think has been successful about your therapy so far?
   Probe
   a. What has improved about your condition as a result of your therapy?

4. What do you think have been the main challenges of your therapy?
   Probes
   a. What aspects of your condition have not improved?
   b. What side effects have you had? Of these, which have been the most challenging and why?

5. Can you describe your overall level of satisfaction with your current therapy?

6. Can you describe how your therapy impacts your overall cancer experience?
   Probe
   a. How do you feel your current therapy has impacted your quality of life? Your outlook on life?

If the patient has not used the drug under review then ask the following questions:

The drug that pCODR is reviewing is called [drug]. [Drug] is designed to [elaborate on its purpose and indication]. Given this information...

7. Would you consider taking [drug] if it were made available to you? Why or why not?

8. Can you describe the value of making [drug] a part of your cancer therapy?
   Probe
   a. How do you think your cancer experience would be different if you were using [drug] compared to your current cancer experience?

9. Would you be willing to tolerate the side effects of [drug]? Why or why not?
If the patient has used the drug under review, then ask the following questions:

The drug that pCODR is reviewing is called [drug]. [Drug] is designed to [elaborate on its purpose and indication]. You have used [drug] previously. I would like to ask you a few questions about your experience with using [drug].

10. Can you describe your overall experience using [drug]?
11. What changes in your cancer experience did you see after you began to use [drug] (if any)?
12. Were there any challenges associated with using this drug?
13. Would you recommend that the drug be made available to all patients who qualify with [specific cancer]? Why/why not?
## Labeling Checklist for Interviews and Surveys

While conducting interviews, it is helpful to identify topics that patients describe regarding their experiences. This checklist can help label and group patients’ responses. Each of the below labels aligns with common answers from patients that parallel questions within the input template. **Note that this is not an exhaustive list. Please make sure to take notes during all interviews to capture responses from patients that do not fall within the checkboxes.**

### 1.1: Patients’ experiences with this type of cancer

| □ Symptom management | □ Financial burden |
| □ Daily functioning | □ Relationship with family/friends |
| □ Quality of life | □ Stress/mental health |
| □ Outlook on life | □ Other: |
| □ Disease progression or severity |   ○ □ X |

### 1.2: Patients’ experience with current therapy

| □ Types of drugs used: | □ Flexibility of therapy (i.e., choice) |
|   ○ □ X | □ Daily functioning |
| □ Side effects: | □ Quality of life |
|   ○ □ X | □ Financial burden |
| □ Drug tolerance | □ Relationships with family/friends |
| □ Disease progression or severity | □ Stress/mental health |
| □ Remission | □ Other: |
| □ Accessibility of drugs |   ○ □ X |

### 1.3: Impact on caregivers

| □ Daily routine | □ Stress/mental health |
| □ Quality of life | □ Other: |
| □ Relationship with family/friends |   ○ □ X |

### 2.1: What are the expectations for the new drug?

| □ Symptom management | □ Daily functioning |
| □ Side effects | □ Quality of life |
| □ Disease progression | □ Financial burden |
| □ Remission | □ Relationships with family/friends |
| □ Accessibility of drugs | □ Stress/mental health |
| □ Flexibility of therapy (i.e., choice) | □ Other: |
| □ Drug toleration |   ○ □ X |

### 2.2: What experiences have patients had to date with the new drug?

| □ Symptom management | □ Drug toleration |
| □ Side effects | □ Quality of life |
| □ Disease progression | □ Financial burden |
| □ Remission | □ Relationships with family/friends |
| □ Accessibility of drugs | □ Stress/mental health |
| □ Flexibility of therapy (i.e., choice) | □ Daily functioning |