



COLORECTAL CANCER CANADA'S

# PATIENT VALUES PROJECT

PROJECT BROCHURE 2022

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Colorectal Cancer Canada (CCC) is the national Canadian not-for-profit corporation dedicated to colorectal cancer (CRC) awareness and education, support for patients and their caregivers, and advocacy on their behalf. CCC is comprised of dedicated volunteers, members, management and is governed by a National Board of Directors. An Expert Medical Advisory Board, made up of top healthcare professionals in the field of colorectal cancer, provides counsel to CCC to ensure members are kept abreast of the latest medical advances in the diagnosis and treatment of the disease.

**Charitable Registration Number 86657 2423 RR0001**

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## BACKGROUND

### Colorectal cancer in Canada

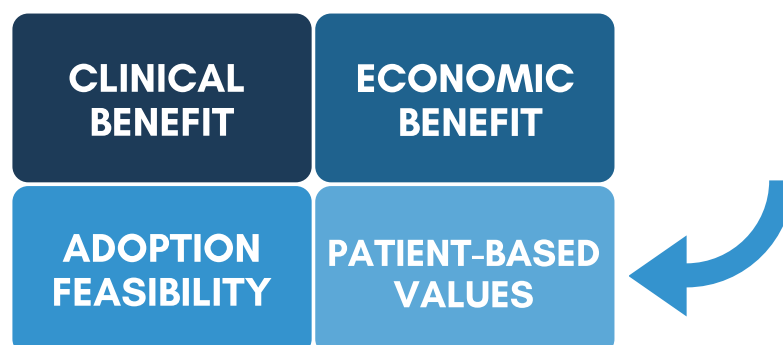
Colorectal cancer (CRC) is the third most commonly diagnosed cancer in Canada, accounting for approximately 26,900 new cases in 2021 alone. In 2021, an average of 68 Canadians were diagnosed with CRC and 26 Canadians died from the disease each day.

Organized screening programs are available in most Canadian provinces and territories, though 1 in 2 people with CRC are diagnosed at a late-stage (stage III or IV). This is significant, as stage at diagnosis is closely linked to survival for colorectal cancers, with the greatest likelihood of survival associated with stage I.<sup>1</sup> Although the incidence of colorectal cancer is declining in older adults thanks to increased screening, incidence rates are increasing among Canadians under 50.

The current landscape in Canadian oncology research involves considerable therapeutic innovation. Unfortunately, the high cost of cancer drugs has resulted in increased pressure on the healthcare system to make difficult decisions regarding the reimbursement or coverage of oncology drugs, as well as other treatment options.<sup>2</sup>

The shift toward value-based medicine has permitted various stakeholders to comment on topics such as pharmacogenomics, therapy management, compliance issues, and a patient's quality of life. However, the perspectives of patients are most central to the definition of value, yet they remain the least understood and the most difficult to measure. Consequently, it has been a challenge to attribute an explicit weight to patient preferences in health technology assessment (HTA) decisions regarding provincial oncology drug reimbursement.<sup>3</sup>

pERC's Deliberative Framework for drug funding recommendations focuses on 4 main criteria:



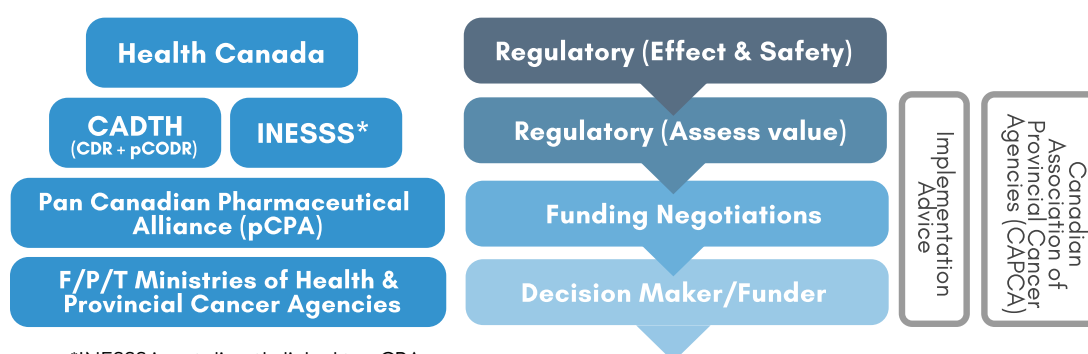
## The Patient Voice in Health Technology Assessment

In Canada, the HTA process has evolved to include the pan-Canadian Oncology Drug Review (pCODR) as part of the Canadian Agency for Drugs and Technologies in Health (CADTH). This enables patient groups to provide experiential input as part of the criteria to be evaluated by expert committees responsible for recommending the reimbursement of new cancer drugs to provincial and territorial health ministries.

Specifically, accredited cancer patient groups may provide evidence regarding the patient experience of living with the illness, the needs and preferences of patients in managing symptoms and side effects of treatment, and the limitations that the illness imposes upon patients and their loved ones.

Unfortunately, patient views are often deemed subjective, and the concern is that this evidence may only be used to add qualitative information if cost effectiveness is established by the evaluating expert committee. To avoid tokenism of the patient voice, a novel evaluation process involving a new criterion to permit patient preferences to be held on equal standing with others is required by pERC's (pCODR Expert Review Committee) Deliberative Framework for drug funding recommendations.

It is essential that the patient voice on values be clear and evidence-based, and obtained through transparent and structured research. However, this is both a lengthy and costly process for cancer patient groups entailing a literature review, the development and execution of surveys, the analysis of patient reported outcomes (PROs), and appropriate reporting. It may also involve contacting patients internationally when clinical trials are not carried out in Canada. It also requires lengthy, detailed and comprehensive phone interviews with patients and caregivers which permit the thoughtful capturing of disease and drug-related information that may be incorporated in the patient group submission to HTA authorities.



\*INESSS is not directly linked to pCPA

\*The Institut national d'excellence en sante et services sociaux (INESSS) in Quebec will soon streamline their patient engagement process to allow for better patient group input.

# THE VALUE OF THE PATIENT VOICE

The explicit incorporation of patient preferences in HTA processes in Canada is still a relatively unexplored area despite the growing emphasis on patient reported outcomes and patient engagement. Individual patient perceptions of value may vary with different treatment options. They may also change with age, presence of other co-morbidities, personal finances, individual goals, religious beliefs, and other life circumstances. The unique knowledge and perspectives that patients have impact treatment compliance and adherence, and can provide a broader view of real-world health technology efficiency. Patients' needs, goals, and preferences must be considered in a dynamic framework, yet little research has been done to define, measure, and attach a weight to these values.

Incorporation of the patient voice in HTA offers many benefits:

## Relevance

Patients have knowledge, perspectives, and experiences that are unique and provide essential evidence for HTA

## Fairness

Patients have the same rights to contribute to the HTA process as other stakeholders and have access to processes that enable effective engagement

## Equity

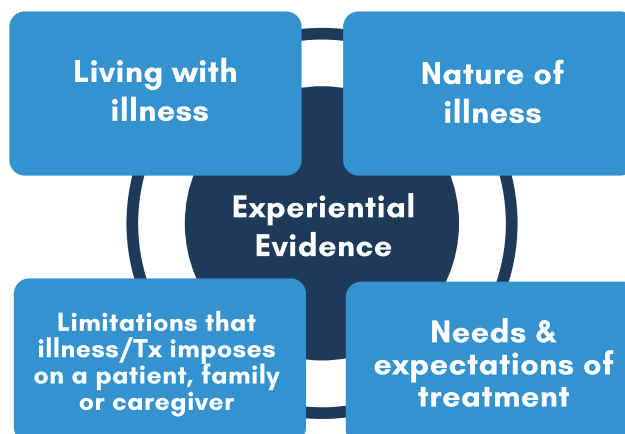
Patient engagement in HTA contributes to equity by seeking to understand their diverse needs with a particular health issue, balanced against the requirements of a health system that seeks to distribute resources fairly among all users

## Legitimacy

Patient involvement facilitates those affected by the HTA recommendations to participate in the process, contributing to the transparency, accountability, and credibility of the decision-making process

## Capacity Building

Patient involvement processes address barriers to involving patients in HTA and build capacity for patients and HTA organizations to work together



## Representing the patient voice in HTA is important for several reasons:

1. Patients have unique knowledge and perspectives that can influence decisions by pointing out what the most important aspects or outcomes are for them in a drug therapy setting
2. Patient preferences directly impact patient compliance or adherence to therapy or treatment and can provide a broader view of real-world health technology efficiency. These outcomes can ultimately influence the cost-effectiveness of treatment
3. Patient preferences may serve as an important and evidence-based source of information and may improve the uptake of current health priorities and policy gaps
4. Including patient engagement in health decision-making processes supports fair and ethical healthcare systems and processes
5. It has been shown that if the drug treatment is consistent with patient preferences, it improves positive outcomes, which can help mitigate the negative effects of illness and can assist clinicians in decision-making

## THE PATIENT VALUES PROJECT

Colorectal Cancer Canada's Patient Values Project (PVP) aims to define, measure, and assign a weight to patient values in cancer drug treatment to ensure Canadian patients are heard in the evaluation of cancer care and the reimbursement of cancer drugs by public agencies.

These weights will be adopted by Canadian and international cancer patient groups to empower them to provide objective input regarding patient values and preferences to inform the HTA deliberative process.

### Objectives

- Develop a definition of patient values and determine the appropriate metrics to measure these values
- Determine the relative importance of measured values to form an expert HTA committee decision in drug evaluation
- Provide objective and quantifiable input concerning patient values based on validated research techniques
- Empower patient groups in their effort to provide research-based input to HTA authorities
- Increase timely access to effective treatments
- Allow for a more reasoned and balanced rationale in the assessment of new cancer drugs by the expert committees



# Methods

## Overview

A literature review has been conducted by a research team at the University of Calgary to inform survey development. A Quality of Life (QoL) survey based on internationally accepted and validated assessment tools and a Discrete Choice Experiment (DCE) have been pre-tested in a subset of colorectal cancer (non-metastatic and metastatic; n=6) patients. The pre-test was carried out via an in-person or telephone interview, wherein participants were asked to “talk out loud” and provide feedback while completing the survey.

## Pilot Testing

The survey was revised based on feedback from the pre-testing phase, an online survey was programmed for a pilot phase involving another sample of CRC patients (non-metastatic and metastatic; n=30-50). The pilot testing allowed us to ensure that specifics of each choice in the (DCE) component of the survey reflect trade-offs that are appropriate and aligned with real-world situations. The pilot phase of the survey was administered in 3 centers; BC Cancer Agency (Vancouver, BC), Tom Baker Cancer Centre (Calgary, AB), and Odette Cancer Centre at Sunnybrook Health Sciences Centre (Toronto, ON).

## Recruitment Population

- Patients with non-metastatic CRC
- Patients with mCRC
- Caregivers of patients with mCRC or non-metastatic CRC
- People from the general population (neither patients nor caregivers)

### Groups 1 & 2 (active recruitment)

- Canadian adults (18+) who are patients at one of 6 participating cancer centres
- Able to speak, read, and write English or French
- Clinically diagnosed with metastatic or non-metastatic colorectal cancer
- Currently undergoing treatment for colorectal cancer (any stage; treatment with oncology drugs) or history of undergoing treatment for colorectal cancer

### Group 3 (active recruitment)

- Canadian adults (18+)
- Able to speak, read, and write English or French
- Have experience caring for an adult with colorectal cancer who is/was a patient at one of the participating cancer clinics

### Group 4 (complete)

- Canadian adults (18+)
- Able to speak, read, and write English or French

## **Participants from Groups 1-3 will be recruited in cancer clinics from the following:**

1. BC Cancer Agency (Vancouver, BC)
2. Tom Baker Cancer Centre (Calgary, AB)
3. Cancer Care Manitoba (Winnipeg, MB)
4. Odette Cancer Centre, Sunnybrook Health Sciences Centre (Toronto, ON)
5. Jewish General Hospital (Montreal, QC)
6. QEII, Dalhousie University (Halifax, NS)

## **Qualitative Interviews**

CRC patients and caregivers have been interviewed to help inform the creation of the DCE survey. Dr. Jennifer Bell and Dr. Mary Jane Esplen from the Princess Margaret Cancer Centre in Toronto led this important study to determine how patients value their treatments across the trajectory of CRC disease.

Groups collaborating internationally with Colorectal Cancer Canada will be able to:

- Adopt and adapt the Patient Values Survey to their CRC population
- Adopt and adapt the survey to other cancer sites
- Combine information from various surveys to compare patient values between countries

## **Survey**

### **A. Recruitment Approach #1**

The PVP survey will include questions on the responder's experience, demographics, and quality of life. It will measure the quality of life based on validated assessment tools and use a discrete choice experiment (DCE)\* to measure what patients value most, and what patients are willing to trade-off in terms of harms and benefits. The stage of the disease will be noted in the survey to distinguish variances between early and late-stage patients.

The survey will be administered through the University of Calgary together with CCC and will be piloted with a small cohort of CRC patients prior to being conducted in 6 centres across Canada. The pilot cities will include Vancouver, Calgary, and Toronto. The main field of the survey will be administered in 6 centres as described above: BC Cancer Agency (Vancouver, BC), Tom Baker Cancer Centre (Calgary, AB), Cancer Care Manitoba (Winnipeg, MB), Odette Cancer Centre, Sunnybrook Health Sciences Centre (Toronto, ON), Jewish General Hospital (Montreal, QC) and QEII, Dalhousie University (Halifax, NS).

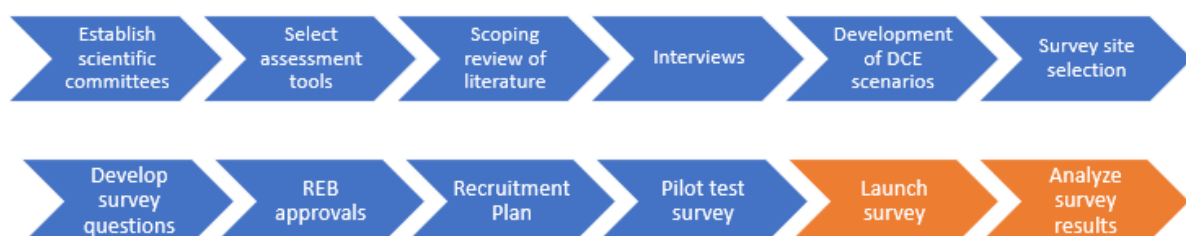


## B. Recruitment Approach #2

In parallel to the recruitment at the six cancer centers, Colorectal Cancer Canada (CCC) is also assisting with recruitment by disseminating survey recruitment materials to pertinent colorectal cancer communities via numerous outlets. First, social media platforms, including Facebook, Twitter, Instagram as well as LinkedIn, will be utilized to reach and attain a larger outreach sample size of eligible participants. Second, CCC is circulating the survey recruitment materials to fellow Canadian cancer societies, NGOs, patient advocacy groups, among others. Each entity will invite its colorectal cancer members (patients, survivors and/or caregivers) to participate in our survey. Third, CCC's monthly newsletter, a printed and electronic bulletin issued periodically to the members of the organization and contains colorectal cancer-related news, resources, activities, among others, will also be used as a method of dissemination of survey recruitment materials. This newsletter has a distribution list of 16,000 individuals (patients, survivors, caregivers, experts in colorectal cancer, public, among others). Finally, a mailing list (~ 2000) of individuals impacted by colorectal cancer (maintained by CCC), including patients, survivors, and caregivers, will be leveraged to recruit from various colorectal cancer communities across the Canadian provinces. As our study recruitment materials are being posted publicly using multiple platforms, it is possible that they will be shared beyond these approaches by other organizations or individuals.

Results of the survey will only be presented in aggregate form across all survey respondents. An informed electronic consent (e-consent) will be obtained. The survey will open with a brief introduction of the purpose of the survey, its contents, benefits from participating in the survey, and confidentiality assurance.

Once the main field of the pilot survey is completed and tested with the appropriate metrics, it will be adapted to different cohorts of patients in other cancer disease sites, both in Canada and internationally. \*DCEs are used to elicit patient preferences and their utility for characteristics or healthcare processes or services. Such approaches to measuring preferences are required to estimate the full value of treatment, as some important health and non-health outcomes of treatment are not captured by traditional measures.



# Research Phases & Questions

	<b>PHASE I</b>	<b>PHASE II</b>	<b>PHASE III</b>
<b>PHASE AIM</b>	Design and administer a survey based on the following questions using validated Quality of Life (QoL) assessment tools and a discrete choice experiment (DCE)	Development of key metrics/indicators to measure values captured in survey data	Generate/assign a weight to Patient Values to become part of the patient submission to pERC (pCODR Expert Review Committee)
<b>RESEARCH QUESTIONS</b>	<p>How do colorectal cancer patients (early and metastatic) value different aspects of drug treatments when weighing the associated benefits and risks?</p> <p>How do values differ based on patients' demographics, quality of life, stage of cancer and experiences?</p> <p>What are the relative quantitative weights for the benefits and risks of treatment decisions?</p>	<p>What combination of attributes in treatment decisions provide colorectal cancer patients with the greatest personal utility?</p> <p>How can we apply the attributes to inform a framework for drug reimbursement decisions?</p>	<p>How could these patient values be explicitly incorporated into the current HTA cancer patient group submission process for new drug treatment evaluation?</p> <p>What proportion of the expert committee's decision on reimbursement for oncology drugs should be allocated for patient values?</p> <p>How does including patient values as developed in the study impact drug reimbursement decisions?</p>
<b>APPROACH</b>	Survey	Consultation with experts to develop Patient Values Framework	Consultation with experts to develop framework, focus groups and interviews.

## Sections included in Patient Group forms:

- Information about the advocacy group
- Patients' experience with a particular type of cancer
- Patients' experience with current therapy
- Impact on caregivers
- Expectations for the new drug
- Patient experiences with the new drug
- Conflict of interest declaration

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