



## **Making Fair and Sustainable Decisions about Funding for Cancer Drugs in Canada**

### **Final Report**

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## Final Report

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In 2016 a series of six public deliberation events were held across Canada on the topic of rising cancer drug costs and the sustainability of Canada's public healthcare system. The events, titled *Making Fair and Sustainable Decisions about Funding for Cancer Drugs in Canada*, were conducted in the provinces of Saskatchewan, Ontario, Quebec (one in English and one in French) and Nova Scotia; there was also a final pan-Canadian event. The objective of this series of events was to seek direction from Canadians on what values should underpin policy decisions related to cancer drug funding when budgets are limited, and how these decisions may be made in a trustworthy manner.

This report describes the genesis of this project, the approach to public deliberation taken for the events, participant recruitment, and an analysis of key recommendations that emerged from each of the six events. It has been prepared for the Canadian Partnership Against Cancer (CPAC), which sponsored the project. As stewards of the Canadian Strategy for Cancer Control, CPAC was motivated to show the range of advice from Canadians on how to address funding issues in cancer control and the implications of this advice for health policy in Canada. CPAC is not involved in making any cancer drug funding decisions.

## Executive Summary

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Provincial and territorial governments across Canada face considerable challenges in making fair and sustainable drug funding decisions. These challenges are particularly evident in the area of cancer, where expenditure on drugs has risen dramatically in recent years compared to other areas of healthcare and is due, in part, to the high price tags for new cancer drugs (Bach 2009; Cressman, Browman, Hoch, Kovacic, & Peacock, 2015; Schrag 2004). Several additional factors also mean that challenges will persist in the longer term: the burden of cancer is high and continues to grow as the population ages; the way some cancer drugs are paid for puts strain on patients and their families, as well as the health system; and decisions about cancer drug funding affect some patient groups more than others. Taken together, these factors put a significant strain on the sustainability of the publicly-financed provincial and territorial cancer systems in Canada.

Addressing this situation requires making fair but difficult decisions about which, and how, drugs should be funded. These decisions involve making trade-offs between the benefits, harms and costs of drugs, and result in large investments of public resources. Since these investments are often made at the expense of other priorities, it is important for policy makers to have input from a wide range of people affected by the issue, including citizens. Public input can assist policy makers in allocating resources and generating policies that are regarded as fair, reflect citizens' values, and are socially acceptable to the community. In particular, forms of deliberative public engagement can be useful sources of public input as they involve citizens in a process of learning and exchanging views directed towards collective problem solving in an effort to identify the acceptable trade-offs for different policy initiatives.

The objective of this project was to engage Canadians through a series of deliberative public engagement events or “citizen panels” in shaping how society addresses complex cancer drug funding decisions, and to generate a series of recommendations that could inform such decisions within different provincial jurisdictions and at a pan-Canadian level. Between April and October 2016, a total of six citizen panels—five provincial panels and one pan-Canadian panel—were held across Canada. Provincial panels were convened in Saskatchewan, Ontario, Quebec (one in English and one in French) and Nova Scotia. The pan-Canadian panel, which was held in October 2016, was comprised of participants from each of the five provincial panels, as well as from an earlier deliberative public engagement event held in British Columbia in 2014. This report contains the findings from the six 2016 panels only.

Across the five provincial panels held in 2016, 115 citizens participated in the deliberative events, with 20 – 25 citizens per panel. Participant recruitment was guided by the goal of identifying a group of citizens who reflected a diversity of life experiences and social perspectives, based on the demographics of the jurisdiction in which each panel was held. Over the course of each two-day panel, participants deliberated in large and small group sessions on a range of topics and questions. Deliberation topics were informed by consultations with provincial cancer decision makers and other key stakeholders from across the country. Deliberations were supported by a number of information sources, including a pre-circulated citizen brief, a video, and an oncologist and a cancer patient representative as expert speakers. Together, these information sources exposed participants to a range of perspectives on cancer drug funding.

Participants developed a total of 86 recommendations over the six panels on a range of themes. Some focused on the types of evidence and principles that should guide policy decisions about whether to fund new cancer drugs, or stop paying for them, and the need to review existing funding decisions on an ongoing basis. Others emphasized the importance of trustworthy governance and identified key elements comprising this. Participants' pervasive and deeply held concerns about inequities in access to cancer drugs between and within provinces, and for different population groups, also motivated a number of recommendations. A number of these focused on working towards a more coordinated, pan-Canadian approach to cancer drug decision making.

The key messages from our deliberations (listed below) affirm many aspects of current decision-making practices in Canada related to the funding of cancer drugs. However, they also point to areas where improvements are needed with respect to achieving value for money with current oncology drugs and where greater attention is warranted to ensure that the processes for making these decisions are trustworthy. In terms of achieving greater value for money, participants accepted the need to make tough funding decisions, including the potential to cease or scale back funding for some currently funded drugs. They also endorsed the review of approved drugs on a regular basis to assess real-world effectiveness and cost-effectiveness, and recommended that priority should be given to treatments that restore patients' independence, mental health, and general well-being.

With respect to trustworthy governance, again, a number of the key messages from our deliberations align with current approaches being taken by bodies such as the Canadian Agency for Drugs and Technologies in Health and the pan-Canadian Oncology Drug Review (CADTH-pCODR) related to ensuring a range of relevant expertise on advisory and decision-making committees, and processes for ensuring transparency of decision-making processes, decisions and their rationales. Some challenges to trustworthy governance remain, however, and were highlighted by participants, such as avoiding conflicts of interest and balancing the stability of membership on decision-making committees, while bringing new perspectives to bear on funding decisions through membership renewal.

A final key message from our deliberations that has been, as yet, inadequately addressed by current decision-making structures and processes for cancer drug funding in Canada is the call for people with similar needs to receive the same care regardless of where in Canada they live.

## **Key messages**

The following paragraphs (one through six) represent a synthesis of the key messages from participants that emerged from the six citizen panel deliberations. They summarize what was most important to the participants. The final key message (seven) presents the perspective of the research team based on their observations and analyses of the deliberations as a whole.

### **1. Cancer drug funding decision processes should be adequately supported through a range of inputs and evidence**

Participants supported including evidentiary inputs like drug costs, clinical benefit of quality and quantity of life, potential side effects, and incidence rates into current decision processes for funding cancer drugs. Participants wanted funding decisions to be based on strong evidence from rigorous clinical trials and real-world drug performance, with funding decisions, their rationales, and grounds for granting compassionate access made transparent and publicly disclosed. They felt that consideration should be given to the effect of a funding decision on other parts of the health system. There was also strong but qualified support to include patients and members of the public in these decision processes.

### **2. Increases in cancer drug spending must be justified using clear and consistent principles**

Participants accepted the principle of resource scarcity, and decisions to fund new cancer drugs should be based on whether a drug can be shown to be good value for money. In response to the decision scenarios presented to them (see Appendix E), participants recommended that significant increases in spending on a drug should result in a significant benefit in return. Participants did not support drugs offering a modest extension of life if a patient's quality of life is poor. Further, they recommended that priority should be given to treatments that restore patients' independence, mental health, and well-being. Priority should also be given to improve access to treatment for those living in rural and remote areas.

### **3. Processes for re-reviewing data and making disinvestments should be developed, and should be based on clear and consistent principles**

All groups accepted the need to make tough funding decisions, and that included the potential to stop or scale back funding for some currently funded drugs. There was strong support across all panels for comparing the cost-effectiveness of currently funded cancer drugs with new cancer drugs, and for the principle that the health system should be funding drugs that are more cost-effective and more clinically effective relative to other cancer drugs. Participants supported making decisions to fund and replace drugs based on cost savings where drugs have the same safety and effectiveness. They endorsed reviewing approved drugs on a regular basis to assess real-world effectiveness and cost-effectiveness to obtain better value for money.

### **4. Ensuring fairness and equity are important principles when considering the funding of cancer drugs**

Fairness and equity of access to cancer treatment were important principles across all panels. Several recommendations focused on improving access in rural and remote locales, and there was strong support for public funding for oral treatments over intravenous drugs as a means of reducing barriers to treatment access. Participants considered it inequitable for patients to bear the burden of travel-related costs and personal responsibility for oral medications taken in ambulatory care. Care must be taken to ensure that marginalized populations are not disadvantaged by funding decisions. As a

matter of fairness, participants specified that delisting practices must include a grandfather clause so that patients currently on the delisted drug can complete their course of treatment.

**5. Decision-making processes, decisions, and their rationales should be transparent and made available to the public**

The transparency of decision-making processes and their outputs was a key requirement for participants across all panels, and was regarded as foundational to ensuring trustworthy decision making. Participants called for all decisions, decision-making processes, and the rationales for these to be made available to the public through a range of publicly accessible vehicles.

**6. There should be a pan-Canadian approach to cancer drug funding decisions**

Participants across all panels strongly endorsed the principle that people with similar needs should receive the same care regardless of where in Canada they live. The principle of fairness was regarded as foundational to a pan-Canadian approach to cancer drug funding. While there were expressions of skepticism about the ability of provinces and territories to collaborate on the goal of a common formulary, for example, many participants felt that a pan-Canadian approach was still an important goal to pursue.

**7. Citizens can provide informed, relevant guidance on funding decisions for cancer drugs**

Participants across all panels deliberated thoughtfully and respectfully with one another on a range of complex issues related to the fairness and sustainability of cancer drug funding in Canada. Through a process of learning and exchanging views, they grasped the core issues under consideration, were able to identify acceptable cost-benefit and equity trade-offs, and provided relevant guidance on making cancer drug funding decisions in Canada.

## Introduction

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Provincial and territorial governments across Canada face considerable challenges in making drug funding decisions, especially in the area of cancer drugs where spending has risen dramatically in recent years compared to other areas of healthcare and is due, in part, to the high price tags for new cancer drugs (Bach 2009; Cressman et al., 2015; Schrag 2004). Several factors contribute to the challenge of making fair and sustainable decisions about funding for cancer drugs in this context: the burden of cancer is high and continues to grow; the way some cancer drugs are paid for puts strain on patients and their families, as well as the health system; and decisions about cancer drug funding affect some patient groups more than others. Together, these factors put considerable strain on the sustainability of the publicly financed provincial and territorial health systems in Canada.

In Canada, the pan-Canadian Oncology Drug Review (pCODR) utilizes a national review process for new cancer drugs. pCODR reviews the clinical and economic evidence (among other inputs) about a drug and makes funding recommendations to the provincial and territorial health systems, which are responsible for healthcare funding decisions (Hoch & Sabharwal, 2013). Despite pCODR's guidance on the potential value of new oncology drugs, its recommendations cannot answer the extent to which provincial and territorial decision makers should pay for expensive cancer drugs given their limited budgets and competing health priorities. Addressing this situation requires making fair but difficult decisions about which cancer drugs to fund – decisions that involve making trade-offs between the benefits, harms and costs of drugs, which result in large investments of public resources in health systems. Since these investments are often made at the expense of other priorities, it is important for policy makers to have input from a wide range of people affected by the issue, including citizens.

Involving the public in health policy decisions has gained traction among policy makers over the past two decades (Abelson, Blacksher, Li, Boesveld, & Goold, 2013). By incorporating public input into their decision processes, policy makers aim to allocate resources and generate policies that are regarded as fair, that reflect citizens' values, and inspire social acceptance. Deliberative forms of public engagement, in particular, involve citizens in a process of learning and exchanging views directed towards collective problem solving (Abelson et al., 2013; O'Doherty, 2013) in an effort to identify what are the acceptable trade-offs of a given policy initiative. In Canada, deliberative public engagement methods have taken place to address a variety of healthcare concerns (Julia Abelson et al., 2003; Boivin, Lehoux, Burgers, & Grol, 2014; Bombard, Abelson, Simeonov, & Gauvin, 2011; O'Doherty & Burgess, 2009), including a deliberation in 2014 on the topic of priority setting and cancer drug funding (Peacock, Bentley, Regier, & Burgess, 2015). As yet, however, there has been no coordinated pan-Canadian effort to explore the concerns, perspectives, and values of citizens on this topic, and to bring their recommendations to the attention of policy makers who must confront issues of sustainability and fairness in their healthcare jurisdictions.

The objective of this project was to generate guidance and recommendations from a series of deliberative public engagement events that could inform cancer drug funding decisions provincially and at a pan-Canadian level. The unique features of the deliberative approach used allowed us to identify areas of convergence in public values, as well as areas of tension and disagreement.



## Methods

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Between April and June 2016, five two-day citizen panels were convened in Saskatchewan, Ontario, Quebec (one in English and one in French) and Nova Scotia, which are provinces that represent a variety of geographic regions, drug budgets, and cancer delivery programs across Canada. A sixth “pan-Canadian” panel was convened on October 29-30, 2016 in Burlington, Ontario. It is described as “pan-Canadian” in the sense that it brought together three to five participants from each of the five provincial panels held in 2016, plus five participants from an earlier public engagement event held in British Columbia (BC) in 2014. It was not feasible to recruit participants from all provinces and territories for this project.

The citizen panels convened for this project used a “hybrid” design of deliberative public engagement developed specifically for this project. The hybrid design combined the strengths of two complementary and well-established models: the McMaster Health Forum’s citizen panels ([www.mcmasterhealthforum.org/citizens/citizen-briefs-and-panels](http://www.mcmasterhealthforum.org/citizens/citizen-briefs-and-panels)) and the deliberative public engagement approach developed by Burgess and O’Doherty (Burgess, O’Doherty, & Secko, 2008; O’Doherty & Burgess, 2009). The Burgess-O’Doherty model was used for a deliberative public engagement event that preceded the panels convened for this project and held in BC in 2014. The common feature of each model is that public deliberation designed to support citizens from a variety of backgrounds and perspectives enables participants to engage meaningfully and respectfully with one another and direct their deliberations towards collective problem solving.

### Participant recruitment

Across the five provincial panels, 115 citizens participated in the deliberative events, with 20 – 25 citizens per panel (see Appendix A). The goal of recruitment was to identify a group of citizens who reflected a diversity of life experiences and social perspectives based on the demographics of the province in which each panel was held. An online research company, AskingCanadians™, was engaged to conduct recruitment. Email invitations were sent to a randomly selected group of AskingCanadians™ panel members; those who were interested in participating completed an eligibility survey where information was collected to seek a balance across panels on the following criteria: age, income, education, ethno-cultural background, chronic disease experience, and geographic location within their home province. Individuals were not eligible to participate if they were: employees of healthcare organizations or healthcare professionals; employees or those with a direct financial relationship with a tobacco or pharmaceutical company; health policy makers; individuals who had lobbied for health advocacy groups; elected officials; people who had worked for market research, advertising, public media or public relations firms; or individuals who had previously participated in a citizen panel convened by the McMaster Health Forum.

The pan-Canadian event included 24 participants from each of the five provincial panels. Recruitment for this event involved the identification of three to five participants randomly selected from among participants at each of the provincial panels who, at the end of their provincial event, expressed their interest in being invited back to the pan-Canadian event. AskingCanadians™ was engaged to oversee the initial contact with prospective participants from Saskatchewan, Ontario, Quebec and Nova Scotia. To expand the pan-Canadian scope of this event, participants from the 2014 BC engagement event were re-contacted to identify interested individuals. Personnel at the McMaster Health Forum followed up with invitations to participate, using the same stratified approach as was used for the provincial events.

Participants received an honorarium of \$125 per 8-hour day for the deliberation and their expenses were covered.

Deliberation topics, questions, and information supports

The deliberation topics and questions for both the provincial and pan-Canadian panels were informed by consultations with provincial cancer policy makers in each of the provinces where the provincial panels were held, in addition to members of the project’s steering and advisory committees. Each panel was structured around three broad deliberation topics and related questions, which were designed to address the challenges related to making fair and sustainable decisions about funding for cancer drugs (see Box 1, below). The pan-Canadian panel was further oriented to encourage reflection on the opportunities and challenges that a pan-Canadian approach to cancer drug funding might present, while promoting the explicit consideration of trade-offs inherent in moving in such a direction.

<b>Box 1. Deliberation topics and questions for citizen panels</b>
<i>Provincial panels</i>
<ol style="list-style-type: none"> <li>1) What should guide policy decisions about whether to fund new cancer drugs, or change the funding provided for existing cancer drugs?</li> <li>2) What would make cancer drug funding decisions trustworthy?</li> <li>3) How can we improve existing approaches to decision making about cancer drug funding?</li> </ol>
<i>Pan-Canadian panel</i>
<ol style="list-style-type: none"> <li>1) What are important features of a pan-Canadian approach to making funding decisions about cancer drugs?</li> <li>2) What are the trade-offs associated with a pan-Canadian approach to making funding decisions about cancer drugs?</li> <li>3) How might these trade-offs be addressed to produce trustworthy decisions?</li> </ol>

Several information sources were used to support participants’ deliberations. Prior to each event, participants received a plain-language citizen brief (see Appendix B for a sample citizen brief), which introduced participants to the topic of making decisions about cancer drug funding in Canada, including a description of how decisions are currently made and a portrait of how cancer drugs are paid for in the province in which the panel was held. The brief included information about the underlying problem the panel sought to address; possible approaches to addressing the problem; and consideration of the potential barriers and facilitators to implementing these options. Relevant research evidence was summarized and incorporated into the brief to support reflection, discussion, and collective problem solving.

In addition to the citizen brief, a 22-minute video with expert speakers exposed participants to a range of expert viewpoints on the topic of cancer drug funding. The video, titled “Cancer Dialogues,” was developed specifically for the deliberations and featured two oncologists, a health economist, and a patient advocate who spoke about cancer drug funding from their own perspectives. Participants were sent a link to the video prior to each provincial event; the video was also screened

at the provincial and pan-Canadian events. “Cancer Dialogues” is available in English at <http://cc-arcc.ca/societal-values-and-public-engagement-2/> and in French at <https://youtu.be/Oq5z8axIU3U>.

While the video and citizen brief served to standardize the information participants received across all events, live speakers provided important local context for participants. At each event, a cancer patient representative and an oncologist from the area attended in person to speak about their healthcare experiences and answer questions from participants.

### Structure of deliberations

Panel discussions were structured and facilitated to encourage active participation from all participants. Participants met in both large and small group sessions over the two days. Each event had three small groups of seven to eight participants. The small group sessions provided a less crowded venue for people to share their various perspectives on the topic, and to develop the norms of respectful listening and inquiry necessary to successful deliberation. The focus of the large group sessions was to ensure that all participants received the same information; it was also the forum for collective deliberation and developing recommendations. Participants discussed each of the three deliberation topics in their small group sessions, followed by deliberation by all in the large group setting. Recommendations were crafted and voted on in the large group sessions only.

At least one, and often all three, principal investigators on this project attended each panel to answer questions of clarification from participants, to observe the deliberations first hand, and to support the consistency of methods across the events.

All panels were led by trained facilitators. A professional moderator led the large group discussions. For the English language events, the moderator worked closely with the research team throughout the project and has led numerous public engagement events in Canada and the US. All small group facilitators received training from the lead moderator. The moderator for the French language event has facilitated similar types of public engagement events, and worked closely with the lead moderator for the other events to become familiar with the topic, materials and structure of the deliberation. One principal investigator, a small group facilitator, and the two expert speakers from the Montreal English panel also attended the French language panel to support consistency across the Quebec events.

### Developing recommendation statements

For each deliberation topic, participants worked collectively in the large group to develop recommendation statements that reflected the conclusions reached through their deliberations, which were informed by the themes covered in the small group sessions. Recommendation statements were generated in two different ways: i) through initial report-backs from the small groups, which contained themes that were identified by the facilitator and the participants. The wording of the recommendation statement was negotiated with the participants with little input from the research team; and ii) later in the deliberation, the principal investigators asked participants to consider statements that they thought decision makers would find helpful. The wording of these statements was also negotiated with the participants but the content and format may have been less thoroughly considered and deliberated by them.

Voting on each recommendation was used to gauge the degree of collective support for each statement, and as a technique to efficiently direct attention to points of disagreement or tension that could be recorded and explored more fully. Participants who abstained or voted against a

recommendation were prompted to explain their views and, in some cases, participants who voted for the recommendation also explained their thinking. Participants may have disagreed with a recommendation statement for a variety of reasons. For instance, they may have had concerns with the wording of a statement or an explanatory phrase, they may have believed that the recommendation was not necessary, or they may have simply rejected the statement outright.

### Data collection and analysis

Each deliberative event was audio recorded and transcribed verbatim to support the preparation of individual event summaries, and an integrative thematic analysis of all six events contained in this report. Analysis began with a detailed review of the recommendations within their provincial or pan-Canadian context and through a comparative lens. This initial review led to the identification of a more thematically organized set of categories aligned with our deliberative topics and questions, and that would provide helpful guidance to policy makers. Within each thematic category, we searched for convergence or high-level agreement within and across the panel recommendations, as well as for diversity of viewpoints. This initial stage of analysis was augmented by a more thorough analysis of the event transcripts to assess the consistency of meaning across events for similar words and concepts, and to identify additional themes that might not have been articulated in the recommendations but were given significant weight by participants in their discussions during single or multiple events.

The pan-Canadian event was distinguished from the provincial events by its orientation around different questions (see Box 1, page 10), its involvement of participants who had already participated in a previous deliberation on cancer drug funding, and its focus on a specific policy initiative under active consideration by decision makers, which was the development of a pan-Canadian approach to cancer drug funding. The provincial panels had also discussed the idea of a pan-Canadian approach to cancer drug funding in their deliberations (though not with the same exclusive focus) and the pan-Canadian panel would provide an opportunity to explore this theme more fully. The integration of the recommendations from the pan-Canadian deliberative event with those of the provincial panels was approached carefully, through constant comparison and consultation with transcripts to ensure appropriate interpretation. The different focus of the pan-Canadian from the provincial deliberations also resulted in certain themes being given less attention by the pan-Canadian panel, such as types of evidence and the principles that should guide new funding and disinvestment decisions, in favour of a broader focus on themes of fair distribution, compassion and governance at a pan-Canadian level.

## **Findings**

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A list of the recommendations generated across all six panels is provided in Appendices C and D. For the provincial panels, the recommendations are organized by the three deliberation topics (see Appendix C). Recommendations from the pan-Canadian panel are listed separately, since this group deliberated on a different set of topics (see Appendix D). Each of these sets of 'raw' recommendations was used to identify a smaller set of thematic categories (listed below). Each of these is discussed in the following sections, as a companion to the recommendations tables, to illustrate qualitatively the areas and strength of convergence, as well as of disagreement, of views both within and across the panels, and to capture important nuances from these discussions.

- Evidence and other inputs to support decision making
- Principles to guide funding decisions

- Disinvestment and re-review of data and past decisions
- Ensuring fairness and access
- Transparency of the decision-making process
- Pan-Canadian approach to cancer drug funding and coverage decisions

All recommendations are quoted below in italics. All direct quotations are from participants' collective discussions or collectively-reached recommendations. The phrase "provinces and territories" is a general statement used by participants throughout the deliberations that reflects a concern for inclusiveness. For this reason, it is used to describe the content of participants' deliberations where relevant.

### **Theme 1. Evidence and other inputs to support decision making**

Participants strongly supported the need for thorough assessment of cancer drugs as a foundation for funding and/or disinvestment decisions. This was often discussed in terms of clearly-articulated criteria to guide decision making, the best available data about a drug's effectiveness, and the effects of a funding decision on other parts of the health system. Other important inputs were also discussed, such as patient experience data, and public and patient input.

#### Evidence and criteria to support decision making

There was strong support for clear criteria for making drug funding decisions. Participants recommended that there be "baseline criteria" (Nova Scotia), a "usable database" (Quebec-French), or a "decision-making tool" (Saskatchewan) containing specific data elements to guide decision processes so that decisions are based on adequate, identifiable, and unbiased information.

The Saskatchewan panel made three recommendations that emphasized a "decision-making tool" and listed its components in one recommendation:

*The criteria used in the decision-making tool should include but are not limited to: cost, quality and quantity of life, side effects, effectiveness, accessibility, incidence and type of cancer, mortality, age, duration of treatment, sustainability of the drug (uninterrupted supply), and ability to compare to other provinces' decisions. (Saskatchewan)*

This recommendation reflects participants' discussions across the provincial panels concerning the types of information they felt should guide drug funding decisions. The one exception was the criterion of "age," which Saskatchewan participants regarded as one of many components of a drug funding decision, whereas "age" was explicitly rejected or included in the category of discriminatory practice at all other provincial panels.

#### Other types of inputs

Participants saw the value of including a range of inputs in drug funding decisions processes. Both the Quebec-English and Quebec-French panels recommended incorporating patient input to support drug evaluations, and the Quebec-French panel suggested a "usable database" that specified patient experiences to support drug funding decisions:

*We should implement a usable database – mandatory and confidential, and updated by physicians – accessible to researchers and, within certain limits, decision makers allowing them to have a clear picture of patients’ cancer journey (previous characteristics, cancer types, medications or interventions, short- to long-term clinical effects). (Quebec-French)*

Saskatchewan participants discussed the importance of non-scientific data in making assessments, and the panelists made a recommendation to bring “diverse public input” to bear on funding decisions. Similarly, Nova Scotia recommended that public input in the form of “public values” should “play a role in cancer drug funding decisions.” For further elaboration of participants’ views on public input in decision processes, see the discussion of “Transparency of the decision-making process,” below.

Participants in Ontario made several recommendations related to types of evidence. They fully supported the need to consider drug costs in light of “other parts of the health system” and “opportunity costs.” Their recommendation was:

*Decision makers need access to the best available comprehensive data on how effective the drug is and what are the effects on other parts of the health system when making policy choices (opportunity costs). (Ontario)*

Ontario panelists referenced the value of information about the public’s willingness to pay for minimal survival improvements, reinforcing the point that there may be a threshold beyond which some drugs are not funded:

*When we fund new drugs we should be clearer about what the public is willing to pay for minimal improvements in survival, even though this may mean saying no to some new cancer drugs. (Ontario)*

Another Ontario recommendation stated the importance of clinical trial evidence as a necessary condition of funding a drug; however, participants did not want to disadvantage patients who may have to wait “until the evidence becomes stronger,” which led to an unresolved or persistent disagreement on this recommendation:

*Drugs should not be funded unless we have strong evidence (e.g., a well-designed clinical trial) that they are effective, even though this means some patients may not get the new drug until the evidence becomes stronger. (Ontario)*

Similarly, Ontario participants were divided over the proposition that “drugs that increase the chance for full recovery should be prioritized.” While some participants supported the statement, others disagreed with it because they did not want to discriminate against patients with terminal cancers and were uncertain about what “full recovery” would mean.

A recommendation from Nova Scotia emphasized the importance of the completeness and rigor of the data to be used by decision makers:

*Evidence of effectiveness must be based on full disclosure to the regulator of clinical trial sample characteristics, full data sets, and should be peer reviewed. (Nova Scotia)*

## **Theme 2. Principles to guide funding decisions**

As participants became more immersed in the first deliberation topic they began to move from identifying the types of information that should guide decision making to articulate the principles they felt should underwrite funding decisions, through a process of moral reasoning.

Panel participants reflected deeply in both large and small group settings on the role that cancer drugs should play in extending life versus improving the quality of life and what would be required to justify increases in spending on new cancer drugs. Quality and length of life were often considered interdependently. Modest life extension alone, unless it was sustaining a pre-existing good quality of life, was generally thought to be insufficient justification for approving new or more expensive drugs over alternatives.

Participants at the provincial panels were presented with decision scenarios in which they were asked to play the role of decision makers (see Appendix E). The scenarios invited participants to consider what would be a reasonable expectation for a drug that cost twice as much as the one it replaced.

The Quebec-French panel recommended that drugs that represent a “significant increase in the cost of drugs” must show “a significant improvement in the quality of life.” A review of the transcripts from this panel shows that the participants did not consider improved quality of life in isolation from improved length of life, but sought to articulate the interrelationship between the two, and cost.

Participants at the Saskatchewan and Quebec-English panels recommended that restored independence for patients justified higher costs or priority funding for cancer drugs. The Quebec-English panel’s recommendation was:

*Doubling the cost of a drug is worth it if it means patients can go from being dependent to being independent. Being independent lowers the costs elsewhere in the system and beyond. (Quebec-English)*

A review of the transcripts from the Quebec-French panel shows similar support for expensive drugs if they restore patients’ independence. Further transcript review shows that support for improved mental health is an important benefit of expensive drugs for many participants in Saskatchewan and for both Quebec panels.

When asked in the decision scenarios to trade-off a significant cost (i.e., a doubling of the cost) of a cancer drug for a specified duration of life (i.e., benefit), the majority of participants in Ontario and Saskatchewan thought the expenditure was worthwhile only if life was extended by at least 12 months, with some support for more or less duration of life.

## **Theme 3. Disinvestment and re-review of data and past decisions**

There was strong support across all panels for comparing cost across drug funding alternatives, and for the principle of funding drugs that were more versus less cost-effective. The recommendations broadly supported making decisions to fund and replace drugs based on cost savings for similar effectiveness or safety. This included the expectation that approved drugs are to be reviewed on a regular basis for actual performance and comparative cost-effectiveness with other drugs.

### Disinvestment

Participants in Ontario made two recommendations related to disinvestment. They felt it was appropriate to weigh the costs and benefits of comparable drugs in an effort to identify drugs that are candidates for “delist[ing].” They also suggested that “any amount of money” saved might be justified even if the less expensive drug was slightly less beneficial. The two recommendations are:

*When we consider new drugs, we need to consider the costs and benefits of existing drugs and, if needed, to delist the existing ones (grandfathering allowed). (Ontario)*

*Even if a drug offers slightly less quality of life and quantity of life but is still comparable, if it saves any amount of money it's justified to select it. (Ontario)*

Saskatchewan made the same recommendation as Ontario about accepting savings for slightly less benefit, but disagreed somewhat with the statement over concerns about “any amount” of savings being sufficient justification and about future real-world effectiveness. (Note: Participants made this recommendation in response to a specific decision scenario with which they were presented. See scenario 1c in Appendix E.)

Nova Scotia and both Quebec panels also supported cost comparisons between drugs in an effort to identify cost savings. However, the Quebec panels stipulated that any savings gained through disinvestment be ear-marked for cancer drugs or cancer research envelopes. In response to decision scenario 1c in Appendix E, they recommended that:

*When there isn't a lot of difference between two drugs, we prefer any amount of savings provided the savings are reinvested in the drug funding budget. (Quebec-English)*

*If the saving realized by a change in a drug allows for investment in cancer research, this change is justified. (Quebec-French)*

It should be noted that the Quebec-French panelists also voiced fundamental concerns about disinvestment, which was interpreted as a decrease in the cancer drug budget. This may account for another Quebec-French panel recommendation—namely, that “*The government should not disinvest in cancer drugs*”—that seems to contradict their support for realizing cost savings.

### Re-review data and past decisions

There was strong support for the practice of reviewing and reassessing cancer drugs already listed on a formulary as an important component of decision processes for funding cancer drugs (see Box 2, below). Almost all panels made recommendations specifying the need to review cancer drugs “subsequent to their approval” (Quebec-French) and that are “already in use” (Quebec-English), and transcript review indicates strong support across all panels for reassessing funded drugs on an ongoing basis.



**Box 2. Support for re-evaluating cancer drugs already on a formulary – sample recommendations**

*Drugs should be re-reviewed based on evidence of alternative drugs already in use and also considering patient experiences. (Quebec-English)*

*Approved drugs should be reviewed based on data – clinical and experiential – subsequent to their approval (and those data must be systematically collected). (Quebec-French)*

*Approved drugs should be re-reviewed based on post-approval data. (Nova Scotia)*

*There should be a standard process to re-evaluate drugs already on the formulary to ensure their effectiveness. If they aren't effective, they should be delisted and the funds used elsewhere. (Saskatchewan)*

*A re-evaluation process of the effectiveness of each drug that is funded is an important part of a pan-Canadian approach. (Pan-Canadian)*

*Re-evaluated drugs that are found to be less effective than originally thought, or compared to alternatives, should be considered for delisting or reduced pricing. (Pan-Canadian)*

**Theme 4. Ensuring fairness and access**

How to address the principle of fairness in cancer drug funding decisions was a common theme across all panels. There was concern that individual patients not be disadvantaged by funding decisions—evidence of this was the stipulation of what participants referred to as a “grandfather clause” to allow patients to continue their course of treatment when a drug is delisted—but it was the desire to treat people fairly that largely motivated participants’ deliberations and framed many of their recommendations.

Several recommendations focused on improving access in remote locales and on public funding for drugs independent of their mode of administration (i.e., oral and intravenous delivery). Travel-related costs and personal responsibility for oral medications taken in ambulatory care were seen as inequities. They recommended that care be taken to be sure that marginalized populations are not disadvantaged by funding decisions.

Participants in Ontario, at both Quebec panels, and in Nova Scotia specified that priority be given to funding oral treatments over treatments delivered intravenously as a means to enhance equity of access to cancer care for patients (see Box 3, below). Nova Scotia made two recommendations related to fair access to cancer treatments, and transcript review indicates this panel’s concerted effort to foreground fairness in their deliberations.

**Box 3. The importance of equity of access – sample recommendations**

*Enhance access in remote communities by investing in portable drugs (i.e., oral instead of IV drugs). (Ontario)*

*Ensure that remote regions have access to the same treatments against cancer. (Quebec-French)*

*We should prioritize cancer drugs that are easier to access in remote locations, as long as the medications are of comparable effectiveness. (Quebec-English)*

*How cancer drugs are administered should not restrict whether funding is provided for them (e.g., whether in the hospital or in the community). (Nova Scotia)*

*Priority should be given to cancer drugs that improve access to treatments where access is poor. (Nova Scotia)*

Equitable access to cancer drugs across Canada inflected the deliberations amongst the pan-Canadian group as well. While their discussions tended to focus on removing provincial barriers to treatment access for all Canadians, they made a specific recommendation to implement “equity audits” so that vulnerable populations are not overlooked. Their specific recommendation was:

*The committee shall undergo regular equity audits to ensure the needs of vulnerable populations are met. (Pan-Canadian)*

A Quebec-English recommendation emphasized the importance of intra-provincial equity:

*Once a drug has been approved by the province, it should be communicated about and made accessible across the province as quickly as possible. (Quebec-English)*

Meeting individual patient needs is also an important aspect of fairness

Discussions that focused on principles such as “compassionate access” and “grandfathering” seemed to reflect the notion that patients on treatment should not be disadvantaged by funding decisions and should have the opportunity to continue their treatment. This sense of equity seemed different from considering the type of information to be included in funding decisions. While it might be tempting to think of it as the need for compassion in how funding decisions are implemented, and exceptions granted, the phrasing and context suggests that participants tended to articulate these aspects as part of fairness or equity rather than compassion to people in unique circumstances. Ontario, Nova Scotia, and Saskatchewan all specified that grandfathering be permitted as a matter of fairness to patients currently on the delisted drug.

This emphasis was important enough to participants in Saskatchewan, for instance, that they made two recommendations on disinvestment, with the second recommendation motivated by an insistence that a grandfathering mechanism be part of delisting practices as a condition of fairness. The second recommendation was:

*If a drug is delisted, patients should be given the option to stay on that drug (grandfathering) while other alternatives are being considered. (Saskatchewan)*

The pan-Canadian deliberation considered compassionate access in situations of “scientific uncertainty” and disinvestment, where there should be “regulated mechanisms” established to provide opportunities to remain on a drug:

*When there is scientific uncertainty there should be a regulated mechanism for compassionate access for funding for drugs outside of approved uses when recommended by the treating oncologist. (Pan-Canadian)*

*Disinvesting should be pursued as much as possible [while] giving patients and their oncologists the opportunity to stay on that drug. (Pan-Canadian)*

### **Theme 5. Transparency of the decision-making process**

The transparency of decision processes was important to participants at all panels, and was regarded as foundational to making decision governance trustworthy. Participants were clear and forceful in their call for all decisions, decision-making processes, and the rationales for these, to be made available to the public. The different aspects of decision processes to be made transparent included: the relevant decision-making criteria, who are the decision makers involved, the process used to make decisions, as well as any decision-making processes and decisions to make medications available on an exceptional basis.

The Saskatchewan and Nova Scotia groups made recommendations emphasizing transparency in the criteria used to make decisions “so the public understands how decisions are made and who is making them” (Nova Scotia) and to “facilitate decision making that is sustainable, defensible, transparent, objective, accountable, and fair” (Saskatchewan).

The Quebec-English panel wanted “more public awareness and transparency around the cancer drug approval process” and the Quebec-French panel highlighted how transparency in decision processes should be achieved through “a wide range of mechanisms ... for informing and communicating (in an accessible language), the various options available during the decision-making process, the choices made, and their effects.”

The pan-Canadian event also supported transparent decision governance:

*The decision-making process and justification for funding a drug or disinvesting or not funding should be made public. (Pan-Canadian)*

**Decision-making bodies need to represent a range of different perspectives and appropriate expertise**  
The composition of decision-making bodies that make funding decisions for cancer drugs generated a great deal of discussion in both the large and small groups. Emphasis was given to seeking membership that would capture both a diversity of perspectives and relevant expertise. The proposed composition often included a mix of patients, the public, healthcare professionals and policy makers (see Box 4, below). The Quebec-English recommendation included the most expansive list, which specified the types of healthcare providers who should be involved. Only Ontario

recommended that industry be included in decision processes so as to make them accountable for their data, while Saskatchewan, both Quebec groups and the pan-Canadian recommendations excluded industry based on conflict of interest concerns.

**Box 4. Composition of decision-making bodies – sample recommendations**

*There should be a panel that includes input from stakeholders (including but not limited to policy makers, long-term care workers, patient advocates, financial analysts, oncologists, healthcare providers, researchers, pharmacists) directly related to the cancer drug that is being considered for funding. (Quebec-English)*

*All bodies that oversee drug funding decisions should have members who represent lots of different perspectives, e.g., industry, patients, public, oncologists, academics, and policy makers. (Ontario)*

*Membership of the pan-Canadian decision-making body should include a health economist, a clinician, and a representative from each province and territory at minimum. (Pan-Canadian)*

A review of the transcripts indicates some hesitation about the direct involvement of patients in drug funding decisions. For instance, some participants in Nova Scotia and Quebec (English and French panels) felt current patients may be too emotionally tied to decisions under consideration, which is why the Quebec panels specified in their recommendations that decisions have input from “patient advocates” (Quebec-English) and “patient associations” (Quebec-French) because these groups would be more at arm’s length. The hesitation over public involvement by some participants generally related to concerns that members of the public are not experts in the fields of cancer research and health policy.

Participants in the Quebec-French panel also made a recommendation on the importance of establishing “a process for regularly replacing members of decision-making committees to ensure the contribution of new perspectives and ideas.”

Members of decision-making bodies should not have conflicts of interest

Assessing and avoiding conflicts of interest among those who make drug funding decisions was a high priority for panel participants. Any commitments that might conflict with the public interest were to be avoided. Industry was often the target, but the net was sometimes cast very wide to include politicians and policy makers. See Box 5, below.

The Saskatchewan and Quebec-French recommendations suggested screening members of decision-making bodies for their ability to act in the public interest, while both Quebec groups made recommendations that specifically excluded pharmaceutical companies from funding decisions.

**Box 5. Avoiding conflict of interest in drug funding decision processes – sample recommendations**

*People involved in making drug funding decisions should be screened so they act in the interest of the public, not of themselves. (Saskatchewan)*

*Pharmaceutical companies should not be involved in decisions to fund cancer drugs. (Quebec-English)*

*Pharmaceuticals must not be part of this process. (Quebec-French)*

*Ensure that members on the decision-making committee are not in conflict of interest. Limiting the duration of mandate could contribute to this objective. (Quebec-French)*

*Any individual with a conflict of interest, be it personal or professional, shall not sit on the committee. (Pan-Canadian)*

Members of the public may have a role on decision-making bodies

There was strong support for involving members of the public in decision processes, but the support was qualified by a desire, on the one hand, to include public values and perspectives and concern, on the other hand, that publics might not be adequately informed or could be influenced.

The Saskatchewan panelists recommended “broad, diverse public input” to inform funding decisions, but they did not explicitly recommend citizen participation on decision-making bodies. Recommendations from the Ontario and both Quebec deliberations included patients and the public in the list of perspectives or stakeholders to be included on the decision-making body.

The involvement of the public and patients on decision-making bodies was more contentious in the Nova Scotia and Quebec-English deliberations. Two recommendations from Nova Scotia reflected participants’ division over whether patient and public input should or “should NOT” be part of decision processes, which led to persistent disagreements on both recommendations. Transcript review of this discussion, however, shows that participants believed governments should already be making trustworthy decisions regardless of whether the public or patients are directly involved; in other words, direct public and patient input “should NOT” be a requirement of accountable and trustworthy governance. A third Saskatchewan recommendation on this topic stated that “the public and public values” should be incorporated in “different ways and at different times” into cancer drug funding decisions, thus reflecting the importance of public values informing allocation decisions for cancer drugs for this group.

**Theme 6. Pan-Canadian approach to cancer drug funding and coverage decisions**

While all groups accepted the need to make decisions that included refusing or ceasing to fund drugs, they also expressed concern that people with similar needs should receive the same care regardless of

where in Canada they live. While there were expressions of deep skepticism about the ability of provinces and territories to collaborate on this goal, many participants were not inhibited by this belief and even the skeptics seemed generally supportive of the ideal.

Nova Scotia and both Quebec panels recommended that the same cancer drugs be available in all the provinces and territories of Canada. Transcript review of the Quebec deliberations indicates that some participants perceived that a common drug formulary would mitigate regional differences in treatment access within the province. This can be seen, for instance, in the Quebec-French recommendation:

*Ensure the harmonization of drug formularies across Canada and between hospitals within the same province. (Quebec-French)*

Participants in Saskatchewan recommended that the provinces “should work” towards greater coordination of access to the same cancer drugs across the country:

*Provinces and regions should work towards a common drug formulary. (Saskatchewan)*

Transcript review suggests that the need for a common drug formulary and review process across Canada was seen by at least some of the Saskatchewan panelists as an opportunity to share information and avoid the duplication of decision effort across provinces, more than an equity-driven opportunity.

Participants in Ontario were divided over whether they would be willing to stop funding any current drugs to achieve a common Canada-wide formulary, and whether a Canada-wide formulary could be sensitive to different regional health needs:

*Canadian provinces and territories should fund exactly the same bundle of cancer drugs (i.e., oral, IV and other cancer drugs), even though this may mean some provinces/territories will have to stop funding some drugs, while other provinces/territories will have to start funding some more drugs. (Ontario)*

Equity of access was strongly visible in key recommendations of the pan-Canadian panel:

*There should be a mandatory pan-Canadian approach to cancer drug funding decisions. (Pan-Canadian)*

*Generally, if a pan-Canadian approach approves a drug for funding, if one can get it, everybody gets it; if one doesn't, nobody does. (Pan-Canadian)*

An emphasis on equity of access arising from the pan-Canadian group may not be surprising, since this event was framed as an opportunity to shape current efforts to develop a pan-Canadian formulary, or at least an approach to one. Further, all participants in the pan-Canadian event had participated in one of the provincial events, all of which produced recommendations in support of inter-provincial collaboration.

All panels viewed a shared drug formulary as having the advantage of decreasing costs through bulk purchasing; however, only the Quebec-French panel made explicit recommendations about achieving

purchasing power through harmonization across Canada. This group went even further to recommend that the production of pharmaceuticals be nationalized:

*Nationalize the production of pharmaceutical products to save money as long as this does not impede access to all medications. We could target those where savings should be better.*  
(Quebec-French)

## Discussion of key findings and policy implications

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The following paragraphs (numbered one through six) represent a synthesis of the key messages from participants that emerged from the six citizen panel deliberations and their resulting recommendations. They summarize what was most important to the participants. The final key message (seven) presents the perspective of the research team based on their observations and analyses of the deliberations as a whole.

Our findings affirm many aspects of current decision-making practices in Canada related to the funding of cancer drugs. However, they also point to areas where improvements are needed with respect to achieving value for money with current oncology drugs and where greater attention is warranted to ensure that the processes for making these decisions are trustworthy. In terms of achieving greater value for money, participants accepted the need to make tough funding decisions, including the potential to cease or scale back funding for some currently funded drugs. They also endorsed the review of approved drugs on a regular basis to assess real-world effectiveness and cost-effectiveness, and recommended that priority should be given to treatments that restore patients' independence, mental health, and general well-being.

With respect to trustworthy governance, again, a number of the key messages from our deliberations align with current approaches being taken by bodies such as the Canadian Agency for Drugs and Technologies in Health and the pan-Canadian Oncology Drug Review (CADTH-pCODR) related to ensuring a range of relevant expertise on advisory and decision-making committees, and processes for ensuring transparency of decision-making processes, decisions and their rationales. Some challenges to trustworthy governance remain, however, and were highlighted by participants, such as avoiding conflicts of interest and balancing the stability of membership on decision-making committees, while bringing new perspectives to bear on funding decisions through membership renewal.

A final key message from our deliberations that has been, as yet, inadequately addressed by current decision-making structures and processes for cancer drug funding in Canada is the call for people with similar needs to receive the same care regardless of where in Canada they live.

### **1. Cancer drug funding decision processes should be adequately supported through a range of inputs and evidence**

Participants supported including evidentiary inputs like drug costs, clinical benefit of quality and quantity of life, potential side effects, and incidence rates into current decision processes for funding cancer drugs. Participants wanted funding decisions to be based on strong evidence from rigorous clinical trials and real-world drug performance, with funding decisions, their rationales, and grounds for granting compassionate access made transparent and publicly disclosed. They felt that consideration should be given to the effect of a funding decision on other parts of the health system.

There was also strong but qualified support to include patients and members of the public in these decision processes.

## **2. Increases in cancer drug spending must be justified using clear and consistent principles**

Participants accepted the principle of resource scarcity and decisions to fund new cancer drugs should be based on whether a drug can be shown to be good value for money. In response to the decision scenarios presented to them (see Appendix E), participants recommended that significant increases in spending on a drug should result in a significant benefit in return. Participants did not support drugs offering a modest extension of life if a patient's quality of life is poor. Further, they recommended that priority should be given to treatments that restore patients' independence, mental health, and well-being. Priority should also be given to improve access to treatment for those living in rural and remote areas.

## **3. Processes for re-reviewing data and making disinvestments should be developed, and should be based on clear and consistent principles**

All groups accepted the need to make tough funding decisions, and that included the potential to stop or scale back funding for some currently funded drugs. There was strong support across all panels for comparing the cost-effectiveness of currently funded cancer drugs with new cancer drugs, and for the principle that the health system should be funding drugs that are more cost-effective and more clinically effective relative to other cancer drugs. Participants supported making decisions to fund and replace drugs based on cost savings where drugs have the same safety and effectiveness. They endorsed reviewing approved drugs on a regular basis to assess real-world effectiveness and cost-effectiveness to obtain better value for money.

## **4. Ensuring fairness and equity are important principles when considering the funding of cancer drugs**

Fairness and equity of access to cancer treatment were important principles across all panels. Several recommendations focused on improving access in rural and remote locales, and there was strong support for public funding for oral treatments over intravenous drugs as a means of reducing barriers to treatment access. Participants considered it inequitable for patients to bear the burden of travel-related costs and personal responsibility for oral medications taken in ambulatory care. Care must be taken to ensure that marginalized populations are not disadvantaged by funding decisions. As a matter of fairness, participants specified that delisting practices must include a grandfather clause so that patients currently on the delisted drug can complete their course of treatment.

## **5. Decision-making processes, decisions, and their rationales should be transparent and made available to the public**

The transparency of decision-making processes and their outputs was a key requirement for participants across all panels, and was regarded as foundational to ensuring trustworthy decision making. Participants called for all decisions, decision-making processes, and the rationales for these to be made available to the public through a range of publicly accessible vehicles.

## **6. There should be a pan-Canadian approach to cancer drug funding decisions**

Participants across all panels strongly endorsed the principle that people with similar needs should receive the same care regardless of where in Canada they live. The principle of fairness was regarded as foundational to a pan-Canadian approach to cancer drug funding. While there were expressions of skepticism about the ability of provinces and territories to collaborate on the goal of a common



formulary, for example, many participants felt that a pan-Canadian approach was still an important goal to pursue.

### **7. Citizens can provide informed, relevant guidance on funding decisions for cancer drugs**

Participants across all panels deliberated thoughtfully and respectfully with one another on a range of complex issues related to the fairness and sustainability of cancer drug funding in Canada. Through a process of learning and exchanging views, they grasped the core issues under consideration, were able to identify acceptable cost-benefit and equity trade-offs, and provided relevant guidance on making cancer drug funding decisions in Canada.

## **Evaluation**

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The “hybrid” design used for the six citizen panels convened was tailored to the unique context of this project. As such, we sought to assess the effectiveness of this method for seeking citizen guidance to inform decision making for cancer drug funding. To do this, we used a combination of participant surveys and team member observations and reflections, guided by an evaluation framework that focused on the following three components of our deliberations: i) recruitment and representation; ii) deliberative structure and process; and iii) deliberative outputs and impact (J. Abelson et al., 2003).

Key findings from the participant surveys where participants assessed the citizen brief, their knowledge of the deliberative topic, and the panels are in Appendix F.

### Recruitment and representation

Our recruitment approach was generally successful in achieving our goal of bringing a group of 20-25 participants together for each panel that reflected a diversity of life experiences and social perspectives based on the demographics of the province in which each panel was held. Overall, our participant demographics (see Appendix A) demonstrate a good balance of gender and age, education, income and ethnicity, although representation in the 18-24 age range tended to be lower than in the other categories. While the panels reflected the perspectives of urban and rural populations, other deliberative designs take additional measures to ensure or emphasize the inclusion of certain populations (e.g., First Nations) to achieve greater diversity of life experiences that might be related to different approaches to healthcare and funding.

### Deliberative structure and process (including information supports)

Overall, the implementation of the “hybrid” two-day panel design worked well. Participants’ overall assessment of the citizen panel was very high (6.6 out of 7) in terms of it achieving its purpose of a full discussion about a high-priority issue to inform action. The mean ratings for the different features of the panel fell between 6.4 and 6.7.

From a structural standpoint, the real-world scenarios presented on Day 2 of the provincial events were especially helpful in breaking down the complexity of the deliberation topic. Importantly, they also pushed participants to make important cost-benefit trade-offs, such as investing in costly cancer drugs that extend life or improve the quality of life for patients when budgets are limited. An inevitable drawback of the scenarios was that they structured participants’ thinking around specific trade-offs, which had the effect of limiting the range of recommendations produced. For instance, the implications of funding for rare cancers were not explored in relation to issues of fairness and sustainability. Moreover, the scenarios inevitably focused on some decision assumptions and

excluded others (e.g., stage of disease, treatment type, overall budget), which further constrained the trade-offs considered.

The pan-Canadian panel represented the team's first effort at bringing together a sub-set of participants from previous deliberation events to form a new citizen panel. The aim was to shift the focus of the new panel from the broader considerations in making fair and sustainable decisions for cancer drug funding in Canada to consider the potential for a more coordinated approach to cancer drug funding across the country. This shift had two distinct advantages: i) it helped avoid the frustration and defense of previously-formed opinions that participants experience when asked to re-deliberate topics, which the research team has observed on other projects; and ii) it seemed to successfully reconstruct the participants from different (i.e., provincial) groups and identities into a new mini-public. Constituting a new mini-public from previous participants can also help relieve participants of the obligation to be the spokesperson for their provincial panelists.

Despite these strengths, the pan-Canadian panel also presented unique challenges on several fronts. The panel was pan-Canadian in two senses: it drew participants from the five 2016 provincial panels as well as the BC event held in 2014, so participants came from across Canada to deliberate about the possibility of a pan-Canadian approach to cancer drug funding. The emergent nature of the topic, however, meant that there was little available background information that could be shared to support participants' efforts and frame the agenda, despite lengthy consultation with policy makers in advance of the event. In addition, participants' awareness of the historical lack of cooperation between federal and provincial levels of government injected a level of cynicism into their deliberations, which resulted in repeated questioning of the task at hand and, for some, less openness to the idea of a pan-Canadian approach.

Concern about citizens' ability to deal with the volume and complexity of the information on a topic such as decision making about cancer drug funding often undermines support for public involvement as a legitimate input to policy making. For our events, citizen panel participants were supported in their deliberations through a variety of means: by a pre-circulated citizen brief, a video produced specifically for the project, and live expert speakers from the province in which the deliberation was held. Participants' overall assessments of the citizen brief were high (6.2 out of 7) and the ratings related to its design ranged from 5.5 to 6.3. Participants were considerably more knowledgeable after participating in the panel, with a mean rating for the "how knowledgeable are you about the issue" shifting from 4.6 to 6.2 before and after the panel.

Throughout each event, we sought a balance between providing enough relevant information to support quality deliberation and avoiding the provision of too much or certain types of information that would distract from the project mandate and the public policies the deliberations were meant to inform. For instance, contextual information about industry's role in producing drugs, the challenges of federal transfer payments, and the "real world" performance of post-clinical trials drugs was relevant to the deliberations; however, if we provided more information on these topics, the deliberations might have shifted focus. Moreover, the two-day model (versus the four-day model of Burgess-O'Doherty) meant there was limited time to address the broader but relevant context in which cancer drug funding decisions are currently made in Canada.

Although we did not assess this formally, the event speakers appeared to have varying degrees of influence on the participants' deliberations: elements of some presentations were returned to often and others were almost ignored; the degree of influence was strongly linked to the presenters'

effectiveness as communicators; and the clinicians' presentations tended to exert more active engagement from participants.

### Deliberative outputs and impacts

This final report is the primary deliberative output from this project. It contains 86 recommendations—which are the 'raw' deliberative outputs—made by participants as advice to policy makers. Summary reports from the provincial and pan-Canadian panels show the demographics and recommendations for each event and are also deliberative outputs. A key outcome of this project is that it demonstrated that lay citizens can deliberate thoughtfully and respectfully with one another on a range of complex issues related to the fairness and sustainability of cancer drug funding in Canada. Through a process of learning and exchanging views, they grasped the core issues under consideration, were able to identify acceptable cost-benefit and equity trade-offs, and provided relevant guidance on making cancer drug funding decisions in Canada. A second key outcome is the robust and fruitful collaboration between researchers and leading knowledge users in cancer control to identify and address vital policy dilemmas, and engage the public in finding acceptable solutions to them.

This report identifies key aspects of the deliberations that may have implications for cancer drug funding policy in Canada. Assessing whether the project and its outputs have effects on policy and practice cannot yet be done, although key decision makers in Canadian and provincial cancer organizations have been consulted throughout the project, with some attending the deliberations as speakers or observers to see first-hand how participants' discussions and recommendations can be useful to policies in their jurisdiction. Feedback from decision makers suggests that the project may have an influence on how they and their agencies consider involving the public in the future.

Some caution should be taken in attributing the differences between provinces to geographical differences in values. The differences in the mix of participants and the provincial healthcare delivery and funding arrangements likely influenced what was considered important and how it was articulated. Similarly, the five provincial events should not be viewed as replications of the deliberation in five locations. While the provincial events had a common focus and background information, each deliberative event was a unique collaboration with participants and informants to produce recommendations and advice that reflected the deliberation of that specific group of participants. As discussed earlier, the pan-Canadian event differed from the regional events in its orientation around different questions, the involvement of participants who had already participated in a deliberation on cancer drug funding, and in its focus on the potential for a pan-Canadian approach to funding decisions about cancer drugs. Given these differences, the recommendations from the pan-Canadian event cannot simply be integrated with the regional recommendations, although it is notable how many of the pan-Canadian recommendations seem to align with the provincial recommendations.

### **Lessons learned**

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The following paragraphs represent the research team's observations and reflections on the project overall. They follow from and in some cases extend the evaluation of the project outlined above.

### **1. The challenges and strengths of drawing participants from provincial panels to form a pan-Canadian panel.**

Bringing together a sub-set of participants from previous panels to deliberate on a new set of questions for cancer drug funding in Canada presented unique challenges and as well as advantages. The shift from general questions about making fair and sustainable decisions for funding cancer drugs in Canada to a consideration of a more coordinated approach to cancer drug funding across Canada had two distinct advantages: i) it helped avoid the frustration and defense of previously-formed opinions that participants experience when asked to re-deliberate topics, which the research team has observed on other projects; and ii) it seemed to successfully reconstruct the participants from different (i.e., provincial) groups and identities into a new mini-public. Constituting a new mini-public from previous participants can also help relieve participants of the obligation to be spokespersons for their provincial panelists.

The pan-Canadian panel also presented challenges related to the emergent nature of the topic of a pan-Canadian approach to funding for cancer drugs. Although the research team consulted broadly with policy makers who put forward this topic, its emergent nature meant that there was little available background information to share with participants to support their deliberations and shape the agenda. In addition, participants' awareness of the historical lack of cooperation between federal and provincial levels of government injected a level of cynicism into their deliberations, which resulted in repeated questioning of the task at hand and, for some, less openness to the idea of a pan-Canadian approach.

### **2. Citizens can provide informed, relevant guidance on funding decisions for cancer drugs**

Participants across all panels deliberated thoughtfully and respectfully with one another on a range of complex issues related to the fairness and sustainability of cancer drug funding in Canada. Through a process of learning and exchanging views, they grasped the core issues under consideration, were able to identify acceptable cost-benefit and equity trade-offs, and provided relevant guidance on making cancer drug funding decisions in Canada.

### **3. The appropriate amount of information to support deliberation can be difficult to gauge**

The complex nature of the topic of deliberation across the events presented some challenges to striking a balance between providing enough relevant information to support quality deliberation and avoiding the provision of too much or certain types of information that would distract from the project mandate and the public policies the deliberations were meant to inform. For instance, contextual information about industry's role in producing drugs, the challenges of federal transfer payments, and the "real world" performance of post-clinical trials drugs was relevant to the deliberations; however, if we provided more information on these topics, the deliberation might have shifted focus. Moreover, the two-day model (versus the four-day model of Burgess-O'Doherty) meant there was limited time to address the broader but relevant context in which cancer drug funding decisions are currently made in Canada.

Although we did not assess this formally, the event speakers appeared to have varying degrees of influence on the participants' deliberations. For instance, elements of some presentations were returned to often and others were almost ignored; the degree of influence was strongly linked to the presenters' effectiveness as communicators; and the clinicians' presentations tended to exert more active engagement from participants.

#### **4. Recruitment was generally successful**

The recruitment goal for a public deliberation event is to bring together a group of 20-25 participants who together reflect a diversity of life experiences and social perspectives based on the demographics of the local population. This recruitment goal was met for all six panels. Overall, our participant demographics (see Appendix A) demonstrate a good balance of gender and age, education, income and ethnicity, although representation in the 18-24 age range tended to be lower than in the other categories. While the panels reflected the perspectives of urban and rural populations, other deliberative designs take additional measures to ensure or emphasize the inclusion of certain populations (e.g., First Nations or rural populations) to achieve greater diversity of life experiences that might be related to different approaches to healthcare and funding.

#### **5. Real-world decision scenarios encouraged participants to make cost-benefit trade-offs**

The real-world scenarios presented to participants on Day 2 of the provincial events were especially helpful in breaking down the complexity of the deliberation topic. Importantly, they also pushed participants to make cost-benefit trade-offs, such as investing in costly cancer drugs that extend life or improve the quality of life for patients when budgets are limited. An inevitable drawback of the scenarios was that they structured participants' thinking around specific trade-offs, which had the effect of limiting the range of recommendations produced. For instance, the implications of funding for rare cancers were not explored in relation to issues of fairness and sustainability. Moreover, the scenarios inevitably focused on some decision assumptions and excluded others (e.g., stage of disease, treatment type, overall budget), which further constrained the trade-offs considered.

### **Limitations to the findings**

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There are some limitations to the findings from this project. Two limitations relate to the nature of public deliberation and of qualitative research in general: i) the representativeness of the participants; and ii) the generalizability of the findings. While overall the participant sample reflected a good balance of key demographic criteria across all six panels—with the exception of under-representation in the 18-24 age range—we did not intend to produce a statistically representative sample population of each province in which the event was held in order to emphasize certain populations and perspectives (e.g., First Nations or rural populations) that might be diluted by statistical representation. In addition, we did not recruit participants from every province and none were recruited from the territories. Other provinces and the territories will have different healthcare issues and systems, as well as varying drug budgets and cancer delivery programs.

The findings from this project are also limited because they cannot be generalized to other populations and locations. As is the case with all qualitative research, the events and participants were socially situated, meaning each event constituted a specific collection of people deliberating under specific conditions at a specific time. Consequently, the five provincial events should not be viewed as replications of the deliberation in five locations. The differences in the mix of participants and the provincial healthcare delivery and funding arrangements likely influenced what was considered important and how it was articulated.

Given the differences between the provincial and pan-Canadian events—namely, their orientation around different questions and the involvement of participants in the pan-Canadian event who had already participated in a provincial event—the recommendations from the pan-Canadian panel

cannot simply be integrated with the regional recommendations, although it is notable how many of the pan-Canadian recommendations seem to align with the provincial recommendations.

Participants were recruited from AskingCanadians™ panels, which could result in a bias toward people who are oriented toward participating in a wide range of data collections. Any recruitment would have some self-selection bias of this sort, and the AskingCanadians™ panel may reflect this bias more strongly. There are alternative approaches to recruitment, including mail outs to postal codes lists as a way to develop the initial pool of participants, followed by screening based on demographics and other questions. It is unknown what, if any, impact these different approaches to recruitment have on the quality and outputs of deliberation.

The need to focus deliberations on the project mandate and the shorter timeframe for deliberation under the hybrid model limited the range of topics explored in relation to issues of fairness and sustainability. For instance, healthcare prevention was important to participants at the outset of the deliberations but was subsequently downplayed by the research team in the need to refocus discussion on the topic of cancer drug funding. For panelists in Nova Scotia, prevention was important enough to make it their first recommendation. The example of the real-world decision scenarios showed that participants were able to make specific cost-benefit trade-offs; however, the scenarios' structure limited the range of recommendations participants produced. For instance, the implications of funding for rare cancers were not explored in relation to issues of fairness and sustainability. Moreover, the scenarios inevitably focused on some decision assumptions and excluded others (e.g., stage of disease, treatment type, overall budget), which further constrained the trade-offs considered.

A final limitation relates to gauging whether the project and its outputs have effects on policy and practice. It is too soon to assess the impact of the event on cancer policy in Canada, although key decision makers in Canadian and provincial cancer organizations have been consulted throughout the project, with some attending the deliberations as speakers or observers to see first-hand how participants' discussions and recommendations can be useful to policies in their jurisdiction. Feedback from decision makers suggests that the project may have an influence on how they and their agencies consider involving the public in the future.

## Conclusion

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This project engaged five provincial groups (one in French and one in English in Quebec) and a pan-Canadian group to produce advice from an informed public based on their basic understanding of the complex process of making funding decisions for cancer drugs in Canada. The approach has the strength of producing advice that is informed about some of the technical information, considers different social perspectives, and reflects group perspectives and priorities rather than aggregating individual preferences. The strength of being informed and civic-minded comes at the cost of not being statistically or politically representative. As such, decisions makers using this advice must consider it together with other important inputs, including the expertise of clinicians, policy analysts and decision makers, patients and families. Nevertheless, this report and the events that were held across the country provide a set of baseline perspectives on what these participants collectively thought made for good, trustworthy decisions about funding for cancer drugs in a fair and sustainable way. This is advice that should be considered in at least two areas that are beyond the scope of this report to develop in detail.

First, CPAC and others might want to consider how to develop a more sustained approach to an informed and deliberative engagement with the public. These events and this report establish that members of the public can understand the relevant information and help to assess what is in the public interest in drug decisions. A very strong next step would be to move from event-based public engagement to a more sustained model, which might be a public panel or the incorporation of multiple members of the public into existing committees. Care must be taken, however, to ensure that the members of public who are engaged are adequately informed and supported to understand the diversity of views that need to be considered.

Second, this report is an important input for those considering whether to develop a pan-Canadian approach to funding decisions for cancer drugs. The development of a pan-Canadian approach was not only supported, but elements of fairness that should inform such an approach were also considered. As before, this report of these events is one among many inputs, but it is an important one.

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