Making Fair and Sustainable Decisions about Funding for Cancer Drugs in Canada
Engaging the Public in Meaningful Deliberation

Despite progress in cancer prevention, the number of Canadians affected by cancer continues to rise as a result of a growing and aging population. By 2030 the number of new cancer cases in Canada is expected to increase by 40 per cent.1

Increased demand for diagnostic and treatment services, long-term patient monitoring and palliative care, as well as ongoing increases in costs are already having a significant impact on our limited public resources. In recent years, cancer drug budgets have increased between 43 and 82 per cent in British Columbia, Alberta and Ontario. In Ontario alone that translates to $50 million more per year.2 The stress to the system will be further compounded by proportionally fewer Canadians of working age contributing to the tax base for funding health and social programs.

The Canadian Partnership Against Cancer (the Partnership), is an independent organization funded by the federal government to implement the Canadian Strategy for Cancer Control and to accelerate action on cancer control for all Canadians. In 2016, the Partnership funded a series of public deliberation events in communities across Canada to engage Canadians about their priorities for making cancer drug funding fair and sustainable.

Prior to this work there had not been a pan-Canadian approach to engage with Canadians to understand their concerns and perspectives on how health system resources should be allocated for cancer drug funding, and how to approach making difficult decisions when using public health care funds in a way that is fair to all Canadians and sustainable over time.

The focus of this deliberative engagement program was on cancer drug funding because cancer treatment costs have increased at a faster rate than in other areas of healthcare, and a major driver is cancer drugs.3,4,5 Cancer delivery system leaders rank increasing health system spending and drug costs, in particular, as a leading concern for the sustainability of the cancer system.

2 Canadian Association of Provincial Cancer Agencies: www.capca.ca/current-issues/the-pan-canadian-cancer-drug-funding-sustainability-initiative
Deliberative Public Engagement

To ensure strong and relevant public policies are developed and implemented, policy makers rely on different types of input, which range from data to informed public opinion. 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.

The Partnership funded the Canadian Centre for Applied Research in Cancer Control (ARCC) and the McMaster Health Forum to engage Canadians about their priorities for making cancer drug funding fair and sustainable.

A key objective of this work was to help shape how complex cancer drug funding decisions are made by seeking direction on what shared citizen values should underpin policy decisions related to cancer drug funding, and how these decisions may be made in a trustworthy manner.

Building on a deliberative public engagement event held by ARCC in British Columbia in 2014, the Partnership funded ARCC and the McMaster Health Forum to conduct six deliberative public engagement events in communities across Canada in 2016. The selected communities represented a variety of geographical regions, drug budgets and cancer delivery programs. The events engaged 115 participants, some having lived experience with cancer as a survivor or caregiver or with other acute or chronic diseases. Diversity among participants also included characteristics like gender, an urban versus rural home, ethnocultural background and socioeconomic status.

All participants were concerned about inequities in accessing cancer drugs, both between and within provinces and for different population groups. Participants also focused on the need for a more coordinated, pan-Canadian approach to how cancer drug funding decisions are made.

The 86 recommendations have been grouped into six main themes:

- cancer drug funding decision-making processes should be adequately supported through a range of inputs and evidence;
- cancer drug spending must be justified using clear and consistent principles;
- processes for re-reviewing data and making disinvestments should be developed, and should be based on clear and consistent principles;
- ensuring fairness and equity are important principles when considering the funding of cancer drugs;
- decision-making processes, decisions and their rationales should be transparent and made available to the public; and
- there should be a pan-Canadian approach to cancer drug funding decisions.

Key Themes

Participants from the six deliberative public engagement events identified 86 recommendations on a range of themes. Participants at some events focused on types of evidence and principles that should guide policy decisions relating to funding new cancer drugs, and the importance of regularly reviewing existing funding decisions. Others emphasized the importance of trustworthy governance.

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

- Participants’ recommendation

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

- Participants’ recommendation
A more general conclusion of the ARCC and the McMaster Health Forum researchers is that participants’ collective recommendations reinforce the importance and ability of citizen representatives to provide informed and relevant guidance and input into policy decisions relating to cancer drugs.

More details can be found on page 4.

**Applying the learnings**

The findings will be shared with organizations involved and interested in cancer drug funding, including the Canadian Agency for Drugs and Technologies in Health / pan-Canadian Oncology Drug Review, patient groups, ministries of health, cancer programs and the Canadian Association of Provincial Cancer Agencies. The Partnership is also exploring opportunities to use these findings to support partner organizations responsible for cancer drug funding decisions.

The Partnership and the cancer control community are working together to reduce the burden of cancer on our health care system and on all Canadians.

As steward of the Canadian Strategy for Cancer Control, a key focus for the Partnership is ensuring a sustainable cancer control system. As the number of Canadians with cancer continues to grow and the costs of cancer treatment continue to rise, it is critical that we work together to ensure our shared resources are used most effectively and sustainably.

**Priority should be given to cancer drugs that improve access to treatments where access is poor.**
- Participants’ recommendation

Making Fair and Sustainable Decisions about Funding for Cancer Drugs in Canada – Final Report can be found here on CanEngage.ca.
Snapshot of key findings

ARCC and the McMaster Health Forum synthesized what was most important to participants in Making Fair and Sustainable Decisions about Funding for Cancer Drugs in Canada – Final Report. The following is a snapshot of the findings. The last finding is a general conclusion of the researchers.

1. Cancer drug funding decision-making processes should be adequately supported through a range of inputs and evidence. Drug costs, clinical benefit, side effects and incidence rates should be included in cancer drug funding decision-making processes. Funding decisions should be based on rigorous clinical trials and real-world drug performance with consideration to the impact on other parts of the health system. Patients and the public should be involved in decision processes.

2. Increases in cancer drug spending must be justified using clear and consistent principles. If increase in cost is significant, so too should be the benefit. New cancer drugs should be funded if they are shown to be good value for money but not if the drug offers only a modest life extension with poor quality of life. The priority should be for treatments that restore patients’ independence, mental health and well-being, and improve access to treatment 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. Tough funding decisions are needed, including stopping or scaling back funding for some drugs. Funded drugs should be the most cost- and clinically effective with regular review of approved drugs to assess real-world and cost-effectiveness. When a new drug is shown to have the same safety and effectiveness as a currently funded drug, the more cost-effective option should be considered.

4. Ensuring fairness and equity are important principles when considering the funding of cancer drugs. Reducing treatment barriers and improving access to treatment included improving access in rural and remote areas, and public funding for oral drugs over intravenous drugs. Marginalized populations should not be disadvantaged by funding decisions. Delisting practices must include a grandfather clause so patients can complete treatment.

5. Decision-making processes, decisions and their rationales should be transparent and made available to the public. Transparency in decision-making processes and outputs is critical and was regarded as foundational to a trustworthy process.

6. There should be a pan-Canadian approach to cancer drug funding decisions. Fairness was regarded as a foundational principle to a pan-Canadian approach to cancer drug funding. People with similar needs should receive the same care regardless of where they live in Canada. While there was skepticism about provinces and territories collaborating on a common drug formulary, a pan-Canadian approach to cancer drug funding coverage was still viewed as an important goal.

7. Citizens can provide informed, relevant guidance on funding decisions for cancer drugs. Researchers noted participants’ capacity to deliberate thoughtfully and respectfully on a range of complex issues relating to the fairness and sustainability of cancer drug funding in Canada. Participants grasped the core issues, identified acceptable cost-benefit and equity trade-offs, and provided relevant guidance for making cancer drug funding decisions.

The full report can be found here on CanEngage.ca.

About the Canadian Partnership Against Cancer

As the steward of the Canadian Strategy for Cancer Control, the Partnership works with partners to reduce the burden of cancer on Canadians. Our partner network – cancer agencies, health system leaders and experts, and people affected by cancer – brings a wide variety of expertise to every aspect of our work. After 10 years of collaboration, we are accelerating work that improves effectiveness and efficiency across the cancer continuum, aligning our shared priorities and mobilizing positive change in the cancer control system. From 2017-2022, our work is organized under five themes: improving the quality of cancer care; improving access to care and reducing variations in outcomes for cancer patients; working towards a more seamless patient experience; improving population and cancer data linkages to maximize the impact of research and data; and driving the spread and uptake of quality improvements making cancer care more sustainable for the health system. The Partnership continues to support the work of the collective cancer community in achieving our shared 30-year goals: a future in which fewer people get cancer, fewer die from cancer and those living with the disease have a better quality of life. The Partnership is funded by Health Canada. Visit www.partnershipagainstcancer.ca.