

RECOMMENDATIONS TO GUIDE IMPLEMENTATION PLANNING FOR CANCER HEALTH SERVICES AND POLICY RESEARCH IN CANADA



Canadian Cancer
Research Alliance

Alliance canadienne
pour la recherche sur le cancer

JUNE 2021

Discovery Together



Canada's Vision for Cancer Research



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AND POLICY RESEARCH
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Suggested Citation:

Canadian Cancer Research Alliance. (2021). *Recommendations to Guide Implementation Planning for Cancer Health Services and Policy Research in Canada*. Toronto: CCRA.

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ISBN 978-1-927650-58-5 (PDF)

Aussi offert en français.

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EXECUTIVE SUMMARY

This report provides the groundwork to developing an implementation plan that will facilitate rigorous, timely, and relevant health services and policy research to support transformative progress in cancer control. It was sponsored by members of the Canadian Cancer Research Alliance (CCRA) on behalf of the broader cancer research funding community in collaboration with the Canadian Partnership Against Cancer (the Partnership), and the Canadian Association of Provincial Cancer Agencies (CAPCA) and informed by consultations involving over 400 people (researchers, persons affected by cancer, and other experts) in addition to relevant research and other literature.

The 13 recommendations fall under five linked themes—ensure equity, build back better, bridge the research-policy-practice divide, enable learning health systems, and invest in next gen capacity—they build on current and planned work (Figure 1). In this report, several considerations are also identified for each recommendation to more fully capture the ideas shared during the consultations.

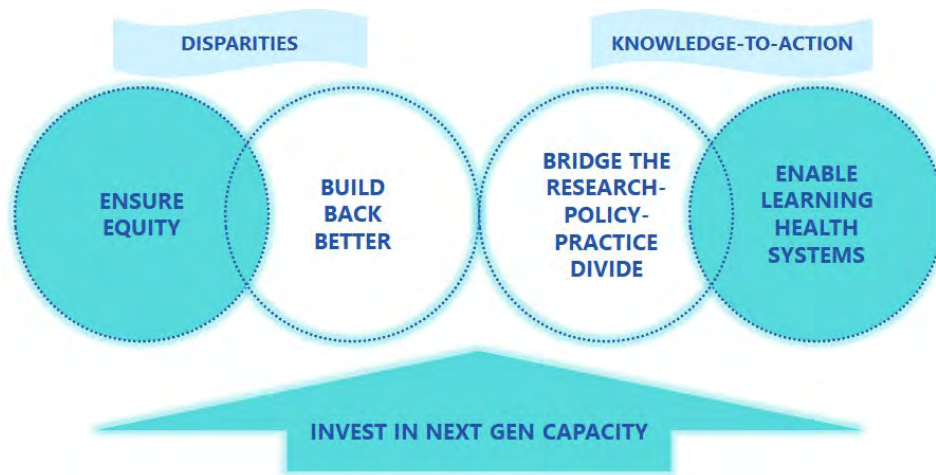


FIGURE 1. INTERRELATEDNESS OF THE FIVE THEMES



Ensure Equity

Prioritize cancer research that addresses historical and systemic inequities and racism, and reform the cancer research funding system to support that research.

1. Support a cancer health services and policy research agenda that will advance equity to those who are underserved and/or disadvantaged by existing structures and systems.
2. Promote the engagement of persons affected by cancer across the health services and policy research lifecycle, with tailored strategies to include the voices of the underserved and/or marginalized.
3. Ensure that cancer health services and policy researchers reflect the diversity of people living in Canada.



Build Back Better

Address disruptions to the cancer system and services delivery created by the pandemic through solutions-based research that will improve resilience.

4. Mitigate the detrimental effects of COVID-19 on cancer patients, survivors, and the larger system via priority investments in health services and policy research methods, approaches, and strategies.
5. Support the development of a pan-Canadian plan for the cancer system in tandem with tailored jurisdictional approaches to improve the resilience of the system going forward.
6. Monitor and redress the impacts of COVID-19 on the career trajectories of those groups of cancer health services and policy researchers who have been most adversely affected.



Bridge the Research-Policy-Practice Divide

Facilitate a needs-based cancer research agenda founded on mutual understanding and cooperation to help reduce the gap between knowledge production and use.

7. Create and sustain a forum to engage decision-makers, cancer system leaders and providers, health services and policy researchers, and patients/caregivers and establish trust, mutual understanding, and a mechanism to identify and address important cancer research priorities and facilitate the translation of evidence into policy and practice.
8. Implement formalized mechanisms for fulsome cross-jurisdictional evidence-sharing across cancer programs.



Enable Learning Health Systems

Invest in infrastructure, platforms, and research that will facilitate learning cancer services and systems with person-centredness at its core.

9. Support the mobilization of resources and partnerships to expedite an accessible, pan-Canadian health information infrastructure and federated platforms that link data cross-jurisdictionally, including existing and new cancer data sets.
10. Boost the investment in cancer health services and policy research, specifically, implementation research (focused on spread and scale) that will fully utilize existing data holdings and promote learning health systems.
11. Embed health services and policy researchers within the cancer systems in each jurisdiction.



Invest in Next Gen Capacity

Continue to fortify and expand the cancer health services and policy research capacity in all jurisdictions in Canada.

12. Build on and enhance a pan-Canadian cancer health services and policy researcher network to facilitate knowledge exchange and methodological innovation and foster interdisciplinary and multi-institutional research collaborations.
13. Expand capacity building efforts to cultivate a passion for person-centred, sustainable cancer control across disciplines and prepare the next cohort of health services and policy researchers to undertake the challenges of the future.

While these recommendations are intended to support the priorities and actions of the Canadian Strategy for Cancer Control (CSCC) and help advance Canada's Vision for Cancer Research, they go beyond the remit of cancer research funders and the Partnership and will require multi-sectoral partnered approaches and sustained commitment to be achieved.

These recommendations will be supported by a five-year implementation plan (2022-2027) for cancer health services and policy research that will be developed with CCRA member organizations, CAPCA, and other allied stakeholders. It will elaborate on the infrastructure needed to facilitate research that is responsive to the cancer control priorities and actions of the CSCC and as needed by the delivery system and decision-makers. This plan is intended to facilitate a culture shift such that the integration of research into cancer control is perceived as needed and essential to driving the quality agenda and furthering the evolution of learning health systems within cancer programs and services.

INTRODUCTION

1.1 BACKGROUND

Health services and policy research includes “research with the goal of improving the efficiency and effectiveness of health professionals and the healthcare system, through changes to practice and policy. Health services research is a multidisciplinary field of scientific investigation that studies how social factors, financing systems, organizational structures and processes, health technologies, and personal behaviours affect access to health care, the quality and cost of health care, and, ultimately, Canadians' health and well-being.”¹

Members of the Canadian Cancer Research Alliance (CCRA) identified a need for a set of actionable recommendations for cancer health services and policy research that would help guide an implementation plan to accelerate the adoption of evidence-based innovation needed to achieve the strategic priorities identified in the *Canadian Strategy for Cancer Control, 2019-2029*² (CSCC) and advance Canada's Vision for Cancer Research.³ Members of the Canadian Association of Provincial Cancer Agencies (CAPCA) were embedded in the consultation process to ensure alignment with the Association's strategic priorities. Although the cancer system can and should learn from and adopt lessons learned from health services and policy research conducted in the broader healthcare system, there are still issues that are specific to the cancer system.

The priorities and actions of the CSCC are intended to ensure equitable, person-centred cancer control across the care trajectory, with the long-range goals being that fewer Canadians develop cancer, more people survive cancer, and those with cancer have a better quality of life. Research, innovation, and data are recognized as critical enablers of evidence-based cancer control and the means to inform decision-making on how best to deliver high-quality care and ensure efficient and sustainable cancer services. Canada's Vision for Cancer Research is an aspirational vision that identifies the key components needed to support a cancer control system that is inclusive, responsive, and fully embeds and benefits from research.

It is recognized that many stakeholders are required to truly advance evidence-based health services and policy that will mitigate cancer risks and improve sustainable person-centred care across the care trajectory for all cancer patients and their families. Figure 2 below shows the key groups of stakeholders and broad areas of health services research involved in cancer-related health services and policy research. Each of these stakeholder groups has an important role in advancing the proposed recommendations.

¹ <https://cihr-irsc.gc.ca/e/48809.html>

² <https://www.partnershipagainstcancer.ca/cancer-strategy/>

³ <https://www.ccra-acrc.ca/research-vision/>

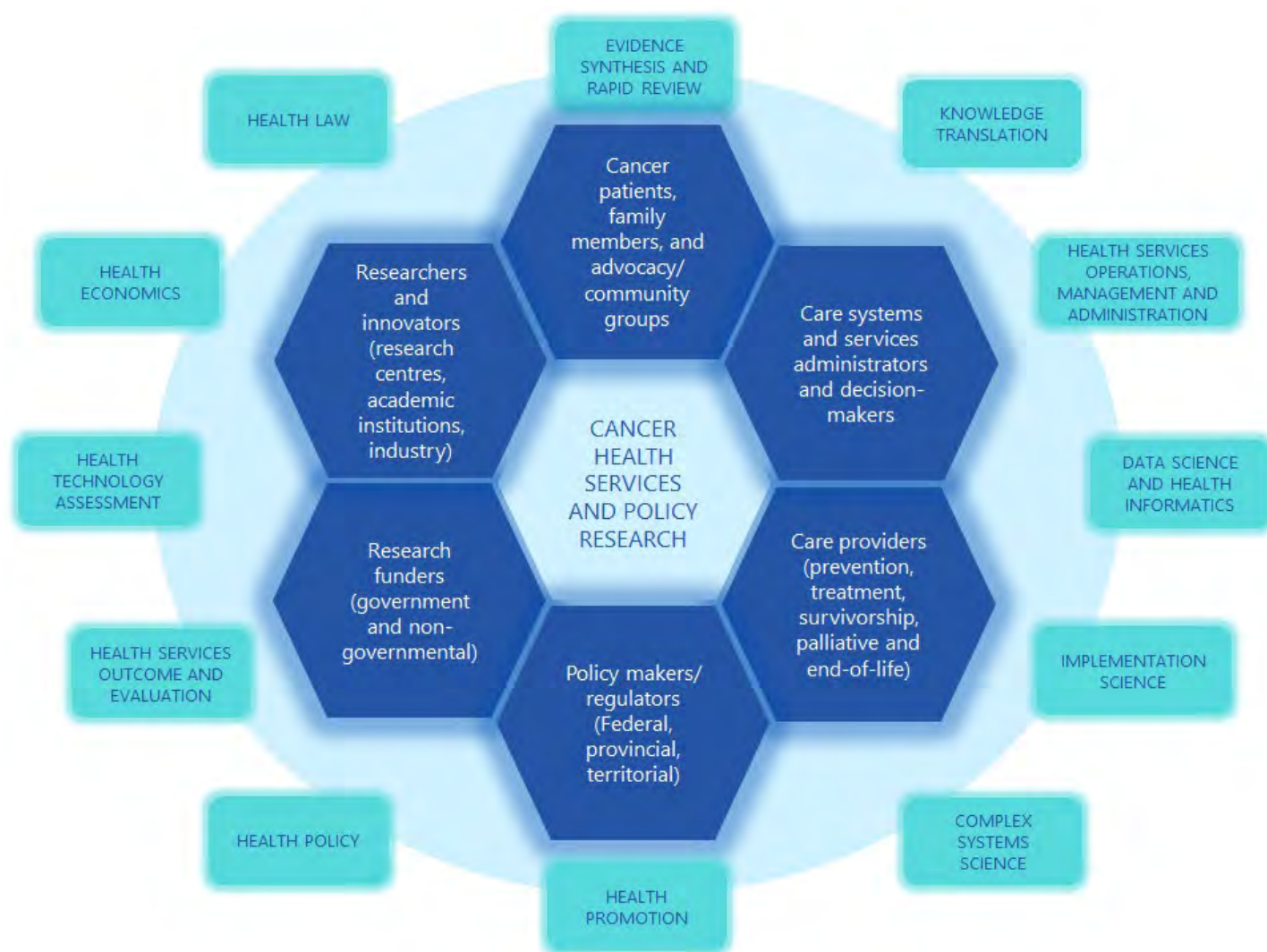


FIGURE 2. STAKEHOLDERS AND DISCIPLINES INVOLVED IN CANCER HEALTH SERVICES AND POLICY RESEARCH

1.2 CURRENT CONTEXT

A challenging environment exists. The federated model of health care poses challenges to delivering a unified approach and equitable access to evidence-based cancer control for all people in Canada. There is a need to level-up and address jurisdictional resource differentials. Cancer patients prioritize the need for a barrierless and truly pan-Canadian approach to cancer control – how can this be facilitated?

Evidence generation is impeded by the lack of an integrated data infrastructure – data are needed to generate evidence and evidence is needed for informed decision-making. Health systems operate for the most part as fragmented data islands and provincial/territorial data assets are highly variable. Is there political will to change this scenario?

The “evidence-to-action” cycle is often not fully realized. There is much research waste and a passive approach to dissemination. Many pilot studies are not sustained and there is a dearth of implementation efforts and knowledge on how best to spread and scale and share cross-jurisdictional learnings, and more research is needed to identify and evaluate planned strategies to support the sustainability of evidence-based interventions in real-

world settings (Shelton, Cooper & Stirman, 2018). What is needed to boost capacity and application of implementation science across the Canada?

And then came COVID-19...the pandemic has brought to the forefront and amplified the existing fault lines in the healthcare system and society at large. Systemic racism and glaring inequities require redress and the solutions needed will require profound changes and sustained commitment at all levels in society. Can we meet this challenge?

Out of necessity, technological innovation (including digital health, virtual care, and artificial intelligence (AI) solutions) has been accelerated by the pandemic in an unprecedented way and this momentum needs to be harnessed. Technology holds great promise for addressing issues of inequitable healthcare access but may also exacerbate inequities. Should equity be a pivotal consideration in health technology assessment (HTA)? What are the opportunity costs to new and expensive cancer treatments and technologies? In the quest for “the new,” are there rudimentary activities or low-hanging fruit that are not actioned or even identified? Primary prevention remains an untapped area for technological innovation. Could boosted investment in primary prevention help mitigate the pending cancer burden created by COVID?

The next decade will be marked by fiscal challenges. Now more than ever there is a need for health services and policy research to inform and improve the coming challenges in cancer control. Prior to the pandemic, 5 cents of every \$1 invested in cancer research went to cancer-related health services and policy research.⁴ With a marked re-direct to COVID research, what does the future hold? Changes in research investments will likely also have an impact on the infrastructure needed for impactful health services and policy research. In addition, for more than a decade, the Canadian Centre for Applied Research in Cancer Control (ARCC) has provided critical infrastructure to support cancer-related health services and policy research. Going forward, how can this ongoing need for capacity building and networking opportunities for cancer health services and policy researchers be supported?

While there has been much focus and investment on patient-oriented research in Canada over the past decade, the lack of patient engagement during COVID suggests that the commitment to embedding patients in the research and healthcare delivery systems is still a work in progress. Person-centred cancer control requires a fulsome commitment to integrating patients and family/caregivers in each step of research and care delivery. How does patient engagement in cancer research become the de facto standard?

1.3 DATA GATHERING

This project was supported by an oversight group of CCRA members and benefited from the guidance and feedback provided by members of an Expert Group (see Acknowledgements). The recommendations were derived from consultations (group and one-on-one) with research leaders and people with lived experience (Appendix A), relevant peer-reviewed literature and reports, the results of an online survey (Appendix B), and virtual touchpoints with members of the Canadian Association of Provincial Cancer Agencies and the CCRA (Table 1). Geographic representation of the key informants is provided in Table 2.

⁴ https://www.ccra-acrc.ca/wp-content/uploads/2020/09/Annual_2018_EN.pdf

TABLE 1. INPUTS INFORMING RECOMMENDATIONS

RESEARCHER OUTREACH	PATIENT OUTREACH	ONLINE SURVEY	LITERATURE REVIEW	TOUCHPOINTS
Five 90-minute online sessions, engaging 34 researchers (online sessions were promoted to 115 researchers) and 16 interviews with leaders from Canada and abroad.	Five 90-minute online sessions in five regions, engaging 44 persons affected by cancer.	382 respondents (promoted to 1000+ prospective respondents). Survey was open from November 6-21, 2020.	Over 60 peer-reviewed articles and documents identified by the Expert Group and through PubMed, and Google Scholar were reviewed.	Three discussions with CAPCA membership. One discussion with CCRA membership.

TABLE 2. KEY INFORMANTS BY LOCATION

	RESEARCHER OUTREACH	PATIENT OUTREACH	ONLINE SURVEY	
Pan-Canadian	3	0	0	3
B.C.	6	4	44	54
Alta.	3	3	61	67
Sask.	0	6	13	19
Man.	2	4	25	31
Ont.	22	13	114	149
Que.	7	10	101	118
N.B.	1	1	2	4
N.S.	1	1	14	16
P.E.I.	0	0	1	1
N.L.	0	2	7	9
Outside Canada	5	0	0	5
TOTAL	50	44	382	476

2. THEMES AND RECOMMENDATIONS



2.1 ENSURE EQUITY

Truly improving cancer outcomes can only be achieved by prioritizing research that will address historical and systemic inequities and racism. Doing so will require changes in the way that research is funded, evaluated, conducted, and implemented (Baumann & Cabassa, 2020). Engagement of the very people this research is intended to serve is a pivotal requirement.

In what will be the post-COVID-19 era of financial challenges, the cancer community must work proactively to protect cancer disparity research funding and support cancer advocacy organizations that provide community engagement activities addressing disparities (Newman, Winn & Carethers, 2021). Ensuring diversity must also extend to the health services and policy researcher community itself. Equity is a major cornerstone of the CSCC and the strategic plans recently released by the Canadian Institutes of Health Research (CIHR)⁵ and CIHR's Institute of Health Services and Policy Research (IHSPR).⁶

WHAT WE HEARD

"There are stark inequities in access and outcome for preventable and treatable cancers in Indigenous populations. If we are committed to the social determinants of health and the provisions of the Truth and Reconciliation Commission's report, you would right that wrong first and then look at other racialized and disadvantaged populations."

– Discussant

"Consider the definition of 'evidence' more broadly instead of just doing the same thing over and over with the same assumptions about what is gold standard and what is not—reinforcing power structures that perpetuate ageism, sexism, racism, etc. and structural inequities. We can do better."

– Survey respondent

"Given Canada's geography and demography, we have an opportunity to be world leaders in rural/remote and Indigenous health." – Discussant

RECOMMENDATION	CONSIDERATIONS
1. Support a cancer health services and policy research agenda that will advance equity to those who are underserved and/or disadvantaged by existing structures and systems.	<ul style="list-style-type: none"> Continue to support and prioritize self-determined and governed, First Nations, Inuit, and Métis community-led cancer health services and policy research, including alignment with The First Nations Principles of OCAP™ (ownership, control, access, and possession) as well as Métis and Inuit research principles and protocols. Ensure research applications propose inclusive methodologies appropriate to addressing health equity and utilize intersectionality-informed approaches (Heard et al., 2020) and implementation outcomes that examine the unique contextual factors (social, political, and environmental) of the community or population being engaged.

⁵ <https://cihr-irsc.gc.ca/e/documents/cihr-strategic-plan-2021-2031-en.pdf>

⁶ <https://cihr-irsc.gc.ca/e/52481.html>

RECOMMENDATION	CONSIDERATIONS
	<ul style="list-style-type: none"> • Prioritize strategic research funding designed to identify and reduce the structural determinants of stigma within cancer care and delivery, and identify strategies to reduce inequities. Implementation strategies at the research and care provider levels may include building community trust, enhancing cultural competence, raising critical consciousness, supporting advocacy, and reducing language barriers (Wasserman et al., 2019). • Support research related to inequities in risk factor exposure, which may require testing, adaption, and implementation of policy interventions (Alcaraz et al., 2020).
<p>2. Promote the engagement of persons affected by cancer across the health services and policy research lifecycle, with tailored strategies to include the voices of the underserved and/or marginalized.</p>	<ul style="list-style-type: none"> • Support research that is built on the cornerstones of the person-centredness and care quality and incorporates a patient engagement framework (i.e., participatory action research, community-based participatory research, experience-based co-design, equity by design). • Adapt research adjudication processes so that community-engagement research is valued. • Implement systems-level strategies to address the barriers to ethical clinical trial recruitment—a lack of diversity of cancer patients enrolled in clinical trials hinders the broad applicability of the results and limits access to leading-edge interventions (Bell, Kelly, Gelmon et al., 2020). • Reformulate notions of merit (beyond the “traditional” status quo) – better and more inclusive understandings of excellence are required (Razack, Risør, Hodges & Steinert 2020). • Restructure research funding requirements to include time, resources, and infrastructure to enable the development of partnerships between researchers and underserved communities, including support for training to enable communities to engage as full partners and undertake any needed field research or community-based data collection.
<p>3. Ensure that cancer health services and policy researchers reflect the diversity of people living in Canada.</p>	<ul style="list-style-type: none"> • Continue to address barriers through capacity-building efforts to creating a diversified researcher workforce, with additional effort and resources for recruitment and retention, and funding to support EDI (Equity, Diversity & Inclusion) staff (Universities Canada, 2019). • Press for diversity among senior leadership in academia and healthcare institutions, especially cancer programs.



2.2 BUILD BACK BETTER

No one has been untouched by the pandemic. While affluent groups have always been better able to self-navigate to quicker cancer diagnosis and receive timely treatment compared to deprived groups (Hanna et al., 2020), the pandemic has fully exposed these fault lines, exacerbating existing inequities and creating more and unevenly distributed challenges (McMahon, Nadigel, Thompson & Glazier, 2020). Moreover, McCabe et al. (2020) point out that the pandemic has also demonstrated differential access to “tools of resilience,” including existing income supports and public goods and services.

COVID-19 has fundamentally disrupted the practice of oncology and, in some cases, redefined what treatments patients with cancer should and can receive (Broom et al., 2020). Delays and postponements of cancer screening, surgeries, and clinical trials will erode gains made over the decades in terms of improved outcomes, and reduced mortality (Hanna et al., 2020, Maringe et al., 2020, Sud et al., 2020). Simulation modelling reported by Statistics Canada (2021) revealed that a six-month suspension of primary screening for colorectal cancer could increase cancer incidence by 2200 cases, with 960 more cancer deaths over the lifetime. It has been estimated that clearing the backlog in surgeries for cancers and other diseases in Ontario will take 1.5 years (Wang et al., 2020), an insurmountable feat, and prioritization decisions will need to be formulated to address the who and when. The need for health services and policy research has never been more pressing. Even with these significant setbacks in cancer care, the pandemic has revealed some silver linings. For example, the accelerated uptake of virtual care and virtual assessment of patients in clinical trials have eased the travel burden for persons living in remote locations. Innovations like remote home monitoring of cancer patients and “hospital at home”⁷ may be promising ways to reduce patient burden and improve access to care.

The research enterprise writ large has made a major pivot to address the urgencies of COVID-19 and, for some cancer researchers, this has meant repurposing their cancer research programs to the pandemic. While COVID-19-related funds have been flowing out, there are no agencies keeping track of which health systems and services research teams and centres have pivoted to this research and away from other valuable research (Sutherland, 2021). Lab closures, disruptions in professional interactions, and reductions in fund raising by the charitable sector have adversely impacted the cancer research ecosystem (Colbert et al., 2020).

Furthermore, there has been an uneven impact on certain segments of researchers. Women, who largely continue to assume a prominent role in child and elder care, racialized and minority researchers, and those in the early phases of their careers have all been identified as adversely affected by the disruptions created by COVID (Krukowski, Jagsi & Cardel, 2021; Levine & Rathmell, 2020).

⁷ <https://www.islandhealth.ca/our-services/hospital-home-services/hospital-home>

RECOMMENDATION	CONSIDERATIONS
<p>4. Mitigate the detrimental effects of COVID-19 on cancer patients, survivors, and the larger system via priority investments in health services and policy research methods, approaches, and strategies.</p>	<ul style="list-style-type: none"> • Prioritize support for health services and policy research on: <ul style="list-style-type: none"> ○ effective ways for addressing barriers to cancer screening post-COVID-19, particularly among groups and populations already underserved. <i>The Lancet Oncology</i> (2020) has suggested a re-doubling of efforts on cancer prevention and screening. ○ assessments of the use of telehealth in oncology (Levine, McGillion & Levine, 2020), including appropriate patient selection for telehealth and virtual oncologic care and the unintended consequences/risks of widespread adoption of technology in terms of compounding health disparities (utilize opportunities for natural experiments existing across the country) ○ effective models of care that integrate survivorship within the cancer control system or the broader health system. This is particularly important for cancer survivors at both ends of the age spectrum – pediatric patients (Ryan, Chafe & Moorehead. 2021) and patients in the older age brackets (Puts et al., 2021). These groups require specific considerations for their engagement and involvement in intervention studies and this research should not be de-prioritized in the post-COVID era. ○ appropriate policy approaches to reduce the increased financial burden (cancer <u>and</u> COVID-19) on patients and their families and caregivers ○ ways to enhance and innovate the efficiencies of workflows and operations within cancer centres (address backlogs, resource strains, etc.) ○ inter-sectoral collaborative and evidence-based policy approaches that address social determinants, and more specifically, support implementation of cancer (chronic disease) prevention interventions to mitigate the forthcoming increased cancer burden (Newman, Winn & Carethers, 2021). (The strong correlation between COVID disease severity and obesity underscores this point.) Research to identify effective strategies that improve coordination within and across jurisdictions is vital.

RECOMMENDATION	CONSIDERATIONS
	<ul style="list-style-type: none"> • Leverage existing data/information platforms and simulation tools that may help in research and system priority setting (e.g., OncoSim⁸).
<p>5. Support the development of a pan-Canadian plan for the cancer system in tandem with tailored jurisdictional approaches to improve the resilience of the system going forward.</p>	<ul style="list-style-type: none"> • Identify jurisdictional “lessons learned”—what worked and what did not and how these learnings could inform the improvement process. • Propose solutions to mitigate delays and reduce interruptions to cancer screening, diagnosis, treatment, and survivorship and end-of-life care that are informed by health services and policy research. • Ensure sustained funding/resourcing to support the resulting plan.
<p>6. Monitor and redress the impacts of COVID-19 on the career trajectories of those groups of cancer health services and policy researchers who have been most adversely affected.</p>	<ul style="list-style-type: none"> • Collect and report on metrics to determine which researcher populations have been disproportionately affected and provide strategic funding opportunities for researchers most adversely affected. • Assess the extent to which virtual conferences and collaborations have helped/hindered networking opportunities, multi-institutional grant applications, and publications (Bakouny et al., 2020).

⁸ <https://www.partnershipagainstcancer.ca/tools/oncosim/>



2.3 BRIDGE THE RESEARCH-POLICY-PRACTICE DIVIDE

There are tremendous costs to poorly functioning cancer control systems. The gap between knowledge production (cancer health services, policy, and systems research) and knowledge use (cancer care provision and decision-making) is not a challenge unique to Canada and evidence shows that collaboration among all stakeholders and leveraging each other's experience in pursuit of identified common goals can help reduce this gap (Kilbourne, Jones & Atkins, 2020).

Surmounting the challenges of our federated healthcare system can be facilitated with dialogue, cooperation at the federal, provincial, and territorial (FPT) levels, and the creation and prioritization of a common and jurisdictional-agnostic research agenda. It is recognized that forging these partnerships will require a cultural change (Lamontagne & Guyatt, 2020).

WHAT WE HEARD

"Applied research will be more successful if designed with administrators at the table."
– Survey respondent

"Close integration of researchers and the provincial cancer agencies that are then going to carry out the research is really important. There needs to be matching funds from the provincial agencies, so they have some skin in the game. Real integration with those programs is going to be one of the important ways forward." – Discussant

"Folks in government don't tend to look on research in the same way we would. At best, it's viewed as icing on the cake; a kind of peripheral matter. So when we implement things in the cancer system, we don't implement them with a view to designing the implementation in such a way that we can do a really strong evaluation. I think it's partly the ethos and we have to change that and maybe the CCRA could help us change that ethos." – Discussant

RECOMMENDATION	CONSIDERATIONS
7. Create and sustain a cancer forum to engage decision-makers, cancer system leaders and providers, health services and policy researchers, and patients/caregivers, and establish trust, mutual understanding, and a mechanism to identify and address important cancer research priorities and facilitate the translation of evidence into policy and practice.	<ul style="list-style-type: none"> Align research funding opportunities with the priorities identified through the forum, including the need to move from "one-off" to sustained funding to support longer term research relationships oriented towards problem-solving for the cancer control system. Capitalize and build on what has been learned during the COVID-19 pandemic – i.e., targeted and accelerated research response stimulated by an expansion of federal research funding; unprecedented collaboration and cooperation among researchers of different disciplines, researchers and providers, as well as the public and private sectors; expedited evidence to inform public policy and to catalyse methodological innovations; accelerated action on timely and integrated data systems; demonstrated value of digital and health innovation. Leverage the learnings from: <ul style="list-style-type: none"> "National Strategy for High-Cost Drugs for Rare Diseases" (cited as a good example of FPT cooperation) the inaugural "Science Meets Parliament" event, which brought together Tier II Canada Research Chairs from

RECOMMENDATION	CONSIDERATIONS
	<p>diverse disciplines with members of Canadian Parliament and Senators (Zhao et al., 2020)</p> <ul style="list-style-type: none"> ○ Finland's "open policy practice," a set of methods to engage decision-makers and guide policy processes toward a more collaborative approach (Tuomisto, Pohjola & Rintala, 2020)
<p>8. Implement formalized mechanisms for fulsome cross-jurisdictional evidence-sharing across cancer programs.</p>	<ul style="list-style-type: none"> • Invest in cross-jurisdictional comparative research and identify and build on what has been learned from variations in approaches to common challenges and/or common approaches in different contexts. • Facilitate collaborative national planning on how new technologies are brought forward (e.g., proton therapy, molecular diagnostics). • Provide infrastructure to support living systematic review as another mechanism to close the evidence-practice gap. Living systematic reviews are "dynamic, persistent, online-only evidence summaries, which are updated rapidly and frequently" (Elliot et al, 2014).



2.4 ENABLE LEARNING HEALTH SYSTEMS

Learning health systems are “dynamic health ecosystems where scientific, social, technological, policy, legal and ethical dimensions are synergistically aligned to enable cycles of continuous learning and improvement to be routinised and embedded across the system, thus enhancing value through an optimised balance of impacts on patient and provider experience, population health and health system costs.” (Menear et al, 2019). A learning health system requires a deliberate structure as well as “brave leadership” and operational and clinical champions (Osuji et al., 2020). Applying what we already know requires generating new research questions about how interventions can be scaled up and spread to new settings or patient populations. The focus of the research question changes from “is this intervention effective?” to “how can we successfully implement this intervention with this target population?” (Gagliardi et al., 2014; Reid, 2016). Lavis and colleagues at McMaster University have coined the phrase “rapid learning health systems,” where rapid-improvement cycles enable transformations and impacts that improve patient experience and outcomes.⁹

Cancer care occurs across several different settings – hospital and oncology care, primary care, community services. Implementing learning health systems focused on quality person-centred care will require improvement efforts across the care continuum and research that spans these settings and considers the impact of different organizational contexts (Mitchell & Chambers, 2017). Appropriate infrastructure is needed to support ongoing health system research partnerships and there is a vital role for impact assessment to continually feed into and inform the knowledge base. Research expertise, especially implementation science, must be integrated into all aspects of health system decision-making, including the very fabric of the Partnership and provincial cancer agencies, to support “authentic learning” (Bowen, Botting & Graham, 2021).

Emerging innovations in cancer detection and treatment will require health technology assessments (HTA) of precision care technologies—specifically, support is required to build an evidence base, develop rigorous and validated testing strategies, and train the workforce to mobilize information and deliver these technologies to patients. More generally, it was suggested that when a provincial Minister of Health approves funding for a new

IMPORTANT PRE-REQUISITES TO A LEARNING HEALTH SYSTEM

- commit to supporting a learning health system in strategic plans/priorities and through strategic investments in implementation research (implementation science is the potential catalyst for health system reform)
- effective and accessible data systems, which are real-time and “fit-for-purpose” to support decision-making at the coalface, with an acknowledgement that it takes time (and investment) to be led by the insights generated from the data
- cultivation of receptor and research capacity across the system with a sense of shared accountability and an ability to be nimble and pivot quickly (“fail and fail quickly”)
- allocation of dedicated resources, with embedded researchers at the delivery level who are deliberately partnered with internal teams (e.g., operations, quality improvement, health information, business intelligence, etc.) at different levels and disciplines as well as external partners (e.g., patient groups, community organizations, academic institutions, and other health systems) (O’Brien et al., 2018; Psek et al., 2015)
- recognition of the value of integrated knowledge translation, including the creation of incentives and opportunities as well as dissemination processes and portals for ongoing learning

⁹ <https://www.mcmasterforum.org/find-evidence/products/project/creating-rapid-learning-health-systems-in-canada>

program, device, or drug, that at least 1% of the budget be allocated to fund either in-house scientists or a team across the province to study the outcomes and whether the technology is diffused in an equitable way.

RECOMMENDATION	CONSIDERATIONS
<p>9. Support the mobilization of resources and partnerships to expedite an accessible, pan-Canadian health information infrastructure and federated platforms that link data cross-jurisdictionally, including existing and new cancer data sets.</p>	<ul style="list-style-type: none"> • Prioritize the creation and utilization of data systems and data networks. Norway's digital and science innovation policy was cited as an exemplar framework.¹⁰ • Address the 'unevenness' in the data preparedness across jurisdictions. • Ensure cancer stage data (TNM) is available for all cancer patients in all cancer registries. Address the lack of cancer registry data in Quebec, which was flagged as a critical need. • Improve collection of race-based, Indigenous identity, and socio-demographic data and health reporting to accurately determine and monitor health inequities across health system databases.¹¹ Prospectively capture data on Indigeneity, ethnicity, socio-economic and immigration status as well as other contextual variables within the cancer registry databases. • Test, refine and evaluate AI (specifically, machine learning and deep learning) as a means to expedite extraction, standardization, and analysis of data from health information and hospital data systems and as a mechanism to improve access to needed, timely data for cancer care providers. Naylor (2018) has identified key factors to drive the adoption of AI and deep learning in the healthcare system.
<p>10. Boost the investment in cancer health services and policy research, specifically, implementation research (focused on spread and scale) that will fully utilize existing data holdings and promote learning health systems.</p>	<ul style="list-style-type: none"> • Prioritize funding to projects that have: <ul style="list-style-type: none"> ○ embedded researchers who are closely linked to decision-making/decision-makers ○ broader geographic inclusion ○ links to administrative databases (pragmatic trials) ○ ways to address bias in data collection and analysis and/or machine learning algorithms ○ delineated systematic approaches to target inequities ○ direct links to address system needs ○ a focus on the evolution of cancer care over the life span (aging population, multi-morbidity) and survivorship care ○ a focus on effectiveness/evaluation of interventions aimed at cancer risk factors that engage primary care and other allied health professionals

¹⁰ [http://www.oecd.org/officialdocuments/publicdisplaydocumentpdf/?cote=DSTI/STP\(2019\)13/FINAL&docLanguage=En](http://www.oecd.org/officialdocuments/publicdisplaydocumentpdf/?cote=DSTI/STP(2019)13/FINAL&docLanguage=En)

¹¹ <https://www.cihi.ca/sites/default/files/document/proposed-standard-for-race-based-data-en.pdf>

RECOMMENDATION	CONSIDERATIONS
	<ul style="list-style-type: none"> • Explore mechanisms to partner with CIHR IHSPR on integrated care. • Modernize grant review process to elevate innovative and inclusive methodologies (Sarma et al., 2020) and recognize the contributions of researchers to health system improvements and policy implementation. • Provide longer-term, core funding opportunities for teams (unit-based grants) to provide the timeframes needed to support implementation research. • Leverage learnings from current initiatives like: <ul style="list-style-type: none"> ◦ the upcoming evaluation of PAROLE-Onco, a study that integrates patient advisors as full-fledged members of clinical oncology teams in Quebec (Pomey et al., 2021). ◦ the BC Academic Health Science Network's in-depth environmental scan to identify groups in BC working to operationalize and implement a learning health system model ◦ Choosing Wisely Canada¹² and other partners to identify low-value care and approaches within cancer care ◦ the Canadian Network for Learning Healthcare Systems and Cost-Effective 'Omics Innovation (CLEO), which will generate information on how to design learning healthcare systems in the genomics era¹³ ◦ the strategic clinical network (SCN) model in Alberta as a mechanism to promote implementation research and evaluation through close collaboration between clinical and operational leads¹⁴ • Examine the applicability of approaches used in other jurisdictions – e.g., the UK's comprehensive approach to learning health system development (Scobie & Castle-Clarke, 2020), the US National Cancer Institute's Implementation Science Centers in Cancer Control Program¹⁵ and the US-based Health Care Systems Research Network (Rahm et al., 2019).
11. Embed health services and policy researchers within the cancer systems in each jurisdiction.	<ul style="list-style-type: none"> • Support permanent and senior researcher positions within cancer programs (where they do not exist) and facilitate strong ties with relevant academic faculties.

¹² <https://choosingwiselycanada.org/>

¹³ <https://www.bccrc.ca/dept/ccr/programs/canadian-network-learning-healthcare-systems-and-cost-effective-omics-innovation-cleo>

¹⁴ <https://albertainnovates.ca/programs/partnership-for-research-and-innovation-in-the-health-system-prihs/>

¹⁵ <https://cancercontrol.cancer.gov/is/about>

RECOMMENDATION	CONSIDERATIONS
	<ul style="list-style-type: none"> • Expand CIHR Health System Impact (HSI) Fellowships more broadly within cancer programs. • Examine the viability of a “franchise model,” where health systems adopt practices developed and deployed by another health system's embedded research program, and receive assistance with implementation (Isaacson & Simpson, 2020). • Facilitate the active engagement of community, patients, and operational and clinical staff in research priority setting and the research projects themselves. Create complementarities to bring value to and reinforce each other’s competencies (Côté-Boileau et al., 2019).



2.5 INVEST IN NEXT GEN CAPACITY

Innovation at the level of health services and policy research training is needed to prepare a researcher workforce that can meet the challenges of the cancer system of the future. As previously mentioned, embedded fellowships are an important mechanism for capacity building (Cassidy, Burgess & Graham, 2019). Connecting embedded fellows across provinces and providing opportunities for shared learning is an additional feature of a rich and valuable experience (Sim et al., 2019) and these fellowship programs have legitimized the choice to work within the health system as a credible career pathway (McMahon, Bornstein, Brown, Simpson et al., 2019).

It is important to support a diverse pipeline of researchers and to enhance the attractiveness of a career within cancer health services and policy research. A network of health services and policy researchers from across the career trajectory is needed to facilitate interdisciplinarity, drive new methodologies, and ensure these new approaches are promulgated across the wider community and contribute to a growing evidence base.

WHAT WE HEARD

“As the Director of an interdisciplinary team, it is hugely difficult to bring health services and policy researchers into my projects because there are so few of them. We must build capacity in implementation research, and we need an innovative approach to capture the interest of young people to work in this field.” – Discussant

“We are losing our best people to industry. We need to generate trainees who are passionate about research for patient benefit. The people I’m able to recruit to my program are very passionate about patient-centred, sustainable cancer control and new methods not just applications.”
– Key informant

“We need leadership on theoretical concepts and approaches to guide analyses on big data.”
– Key informant

RECOMMENDATION	CONSIDERATIONS
12. Build on and enhance a pan-Canadian cancer health services and policy researcher network to facilitate knowledge exchange and methodological innovation and foster interdisciplinary and multi-institutional research collaborations.	<ul style="list-style-type: none"> • Capitalize on the depth and strength of the network and community of practice created by ARCC and capitalize on the assets (e.g., impact assessment framework) created by the Canadian Health Services and Policy Research Alliance (CHSPRA).¹⁶ • Ensure that all Canada Research Chairs involved in health services and policy research are connected to the network. • Develop methods to expand and broaden interdisciplinary engagement to both strengthen the network and build capacity. • Explore the viability of a member-funded structure.
13. Expand capacity building efforts to cultivate a passion for person-centred, sustainable cancer control across disciplines and prepare the	<ul style="list-style-type: none"> • Convene health services and policy research leaders to identify training/capacity-building needs. Important areas include: <ul style="list-style-type: none"> ○ implementation science

¹⁶ <https://www.chspra.ca/resources-publications>

RECOMMENDATION	CONSIDERATIONS
<p>next cohort of health services and policy researchers to undertake the challenges of the future.</p>	<ul style="list-style-type: none"> ○ health economics, including pharmaco-economics, value for money analysis, econometrics, and microeconomics ○ HTA ○ user-centred design ○ integration of mixed methods with data collected 'on the hoof' (i.e., utilization of available, real time, and emergent data from smart phones, wearable devices, social media, technological data, personal biographies, visual data) (Rapport & Braithwaite, 2018) ○ applied clinical trials, sequential/SMART trials ○ complexity theory ○ culture competence (implicit bias) • Work with health sciences faculties in academia to develop the next generation of clinicians and other healthcare providers who are adept at managing information, continuous improvement methods, and systems-based approaches to practice (Braithwaite, Glasziou & Westbrook, 2020). • Boost support for cancer health services and policy researchers in the initial stages of their career (see Gibson, Bennett, Gillespie, Güler et al., 2020).

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ABBREVIATIONS

AI	Artificial intelligence
ARCC	Canadian Centre for Applied Research in Cancer Control
CAHSPR	Canadian Association for Health Services and Policy Research
CAPCA	Canadian Association of Provincial Cancer Agencies
CCRA	Canadian Cancer Research Alliance
CCS	Canadian Cancer Society
CCSC	Canadian Strategy for Cancer Control
CHSPRA	Canadian Health Services and Policy Research Alliance
CIHR	Canadian Institutes of Health Research
EDI	Equity, Diversity and Inclusion
HTA	Health technology assessment
IHSPR	Institute of Health Services and Policy Research

ACKNOWLEDGEMENTS

The consultations and initial recommendations for this report were completed by Terrence Sullivan & Associates and guided by input from members of the Oversight and Expert Working Groups. We gratefully acknowledge the thoughtful contributions of these individuals and would like to thank the many research leaders, and patients and caregivers, who gave their time to provide their experiences and insights as part of the online consultative sessions, individual interviews, and online survey. We hope that the synthesized recommendations are an accurate reflection of what was shared.

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**Dr. Bell retired from Genome Canada on March 31, 2021, and was replaced by Dr. Karl Tibelius.*

APPENDIX A. LIST OF EXPERTS CONSULTED

International

- Dr. Gaston Arnolda, Senior Research Fellow, NHMRC Centre for Research Excellence in Implementation Science in Oncology, Macquarie University & Australian Institute of Health Innovation
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Pan-Canadian

- Dr. Rick Glazier, Scientific Director, CIHR Institute for Health Services & Policy Research
- Dr. Meghan McMahon, Associate Director, CIHR Institute for Health Services & Policy Research
- Ms. Cindy Morton, CEO, Canadian Partnership Against Cancer

Alberta

- Ms. Sherianna Duiker, Lived experience - Patient/Survivor
- Ms. Colleen Packer, Lived experience - Patient/Survivor
- Dr. Christopher J. McCabe, Executive Director and CEO, Institute of Health Economics (IHE)

- Dr. Paula J. Robson, Scientific Director, Cancer Research and Analytics & Scientific Director, Cancer Strategic Clinical Network, Cancer Care Alberta, Alberta Health Services
- Dr. Jessica E. Simon, Associate Professor & Head for the Division of Palliative Medicine, Departments of Oncology & Community Health Sciences and Medicine, University of Calgary
- Mr. Donald (Don) R. Wood, Lived experience - Family member/Caregiver

British Columbia

- Dr. Stirling Bryan, President & Professor, BC Academic Health Science Network & School of Population and Public Health, University of British Columbia
- Mr. Vikram Bubber, Lived experience - Patient/Survivor
- Ms. Lin Chen, Lived Experience – Family member/Caregiver
- Ms. Robin Fried, Lived Experience – Patient/Survivor
- Dr. Lindsay Hedden, Assistant Scientific Director, BC Academic Health Science Network
- Dr. Arminée Kazanjian, Professor, School of Population and Public Health, University of British Columbia
- Dr. Kimberlyn M. McGrail, Professor & Scientific Director, Health Data Research Network Canada (and SPOR Canadian Data Platform) & Population Data BC and Director of Research, UBC Health, School of Population and Public Health, University of British Columbia
- Dr. Stuart J. Peacock, Leslie Diamond Chair in Cancer Survivorship, Co-Director, Canadian Centre for Applied Research in Cancer Control (ARCC) & Head, Cancer Control Research, BC Cancer, Health Sciences, Simon Fraser University
- Ms. Adriane Peak, Lived Experience – Family member/Caregiver
- Dr. Dean A. Regier Assistant Professor & Scientist, Cancer Control Research, BC Cancer,

School of Population and Public Health,
University of British Columbia

- Dr. Kelli I. Stajduhar, Professor, School of Nursing and Institute on Aging and Lifelong Health, University of Victoria

Manitoba

- Ms. Linda Abraham, Lived Experience - Family member/Caregiver
- Ms. Alyson Haiart, Lived Experience - Patient/Survivor
- Dr. Alan Katz, Director, Manitoba Centre for Health Policy & Professor, Community Health Sciences and Family Medicine, University of Manitoba
- Mr. David Laird, Lived Experience - Patient/Survivor
- Dr. Marshall W. Pitz, Section Head, Clinical Research, Research Institute, Chief Medical Information Officer & Associate Professor, CancerCare Manitoba & Health Sciences, University of Manitoba
- Dr. Sandra Sukhan, Lived Experience - Family member/Caregiver

Newfoundland & Labrador

- Lois Coombs, Lived Experience - Family member/Caregiver
- Melissa Coombs, Lived Experience - Patient/Survivor

New Brunswick

- Dr. Ted McDonald, Professor & Academic Director, New Brunswick Research Data Centre, Faculty of Law, University of New Brunswick (Fredericton)
- Ms. Lesley McGuire, Lived Experience - Patient/Survivor

Nova Scotia

- Dr. Robin L. Urquhart, Associate Professor, Canadian Cancer Society (Nova Scotia Division) Endowed Chair in Population Cancer Research,

Community Health and Epidemiology, Dalhousie University

- James Archibald (Archie) Stewart, Lived Experience - Patient/Survivor

Ontario

- Dr. Yvonne Bombard, Scientist & Associate Professor, Li Ka Shing Knowledge Institute and Institute of Health Policy Management and Evaluation, University of Toronto
- Dr. Christopher M. Booth, Canada Research Chair in Population Cancer Care, Professor and Clinician-Scientist, Queen's University and Kingston General Hospital Research Institute & Cancer Centre of Southeastern Ontario
- Dr. Ann N. Burchell, Canada Research Chair in Sexually Transmitted Infection Prevention, Associate Professor & Research Director and Scientist, Dalla Lana School of Public Health, University of Toronto & St. Michael's Hospital/Unity Health Toronto
- Dr. Kelvin (Kar-Wing) Chan, Medical Oncologist & Associate Scientist, Odette Cancer Centre, Co-Director, Canadian Centre for Applied Research in Cancer Control (ARCC) & Associate Professor, Sunnybrook Health Sciences Centre and Institute of Health Policy Management and Evaluation, University of Toronto
- Ms. Julie Chessell, Lived Experience - Family member/Caregiver
- Dr. Natalie G. Coburn, Surgical Oncologist and Senior Scientist & Professor, General Surgery, Sunnybrook Health Sciences Centre and University of Toronto
- Dr. Roslyn Doctorow, Lived Experience - Family member/Caregiver
- Dr. Beverley Essue, Associate Professor, Institute of Health Policy Management and Evaluation, University of Toronto (formerly Canadian Partnership Against Cancer)
- Dr. Mary Gospodarowicz, Emeritus Scientist & Professor, Radiation Oncology, Princess

Margaret Cancer Centre and University of Toronto

- Dr. Jeremy Grimshaw, Canada Research Chair in Health Knowledge Transfer and Uptake, Senior Scientist & Professor, Ottawa Hospital Research Institute and Department of Medicine, University of Ottawa
- Dr. Patti A. Groome, Senior Scientist and Professor, Public Health Sciences, Queen's Cancer Research Institute and Queen's University
- Dr. Sumit Gupta, Staff Oncologist and Clinician Investigator and Associate Professor, Pediatrics and Institute of Health Policy Management and Evaluation, The Hospital for Sick Children and University of Toronto
- Ms. Jill Hamer-Wilson, Lived Experience - Patient/Survivor
- Dr. Timothy P. Hanna, Clinician Scientist I, Radiation Oncologist and Assistant Professor, Ontario Institute for Cancer Research, Cancer Centre of Southeastern Ontario and Queen's University
- Ms. Audrey Harvey, Lived Experience - Patient/Survivor
- Mr. Terry A. Hawrysh, Lived Experience - Patient/Survivor
- Dr. Ruth E. Heisey, Chief, Family & Community Medicine, Medical Director and Associate Professor, The Peter Gilgan Centre for Women's Cancers, Women's College Hospital and University of Toronto
- Dr. Jennifer M. Jones, Senior Scientist and Director, Cancer Rehabilitation and Survivorship Program & Associate Professor, Psychiatry and Public Health, Princess Margaret Cancer Centre and University of Toronto
- Ms. Shannon Kadar, Lived Experience - Patient/Survivor
- Dr. Monika K. Krzyzanowska, Medical Oncologist and Academic Physician & Professor, Institute of Health Policy Management and Evaluation, Princess Margaret Cancer Centre and University of Toronto
- Dr. Aisha K. Lofters, Scientist and Women's College Research Institute Chair in Implementation Science & Associate Professor, Family & Community Medicine, The Peter Gilgan Centre for Women's Cancers, Women's College Hospital and University of Toronto
- Dr. Emily McIntosh, Lived Experience - Patient/Survivor
- Ms. Christine McKay, Lived Experience - Patient/Survivor
- Ms. Donna Pepin, Lived Experience - Patient/Survivor
- Dr. Martine T.E. Puts, Associate Professor & Director, Masters of Nursing Program, University of Toronto
- Dr. Linda Rabeneck, Vice-President, Prevention & Cancer Control and Professor, Departments of Medicine, Health Policy, Management and Evaluation, and Public Health, Ontario Health (Cancer Care Ontario) and University of Toronto
- Mr. Denis Raymond, Lived Experience - Patient/Survivor
- Dr. Danielle L. Rodin, Radiation Oncologist, Director of the Global Cancer Program & Assistant Professor, Radiation Oncology, Princess Margaret Cancer Centre and University of Toronto
- Dr. Vera Samarkina, Lived Experience - Patient/Survivor
- Dr. Hsien-Yeang Seow, Canada Research Chair in Palliative Care and Health System Innovation and Associate Professor, Oncology, McMaster University
- Ms. Maureen Smith, Lived Experience - Family member/Caregiver
- Dr. Michael Taccone, Lived Experience - Patient/Survivor
- Dr. Ross Upshur, Assistant Director, Lunenfeld Tanenbaum Research Institute, Professor, Family and Community Medicine & Public Health and Head, Clinical Public Health, Sinai Health System and University of Toronto

- Dr. Toni Zhong, Clinician Investigator and Associate Professor, Princess Margaret Cancer Centre and University of Toronto
- Dr. Camilla C.U. Zimmermann, Rose Family Chair in Palliative Medicine and Supportive Care, Senior Scientist, Professor and Division Director, Palliative Medicine, Princess Margaret Cancer Centre and University of Toronto

Prince Edward Island

- Ms. Sharon MacNeill, Lived Experience - Patient/Survivor

Quebec

- Mr. Kelvin Arroyo, Lived Experience – Family member/Caregiver
- Mr. Rémi Beaulieu, Lived Experience - Patient/Survivor
- Mr. Marc Bond, Lived Experience – Family member/Caregiver
- Dr. Mylaine Breton, Chaire de recherche du Canada sur la gouvernance clinique des services de première ligne et professeure, Médecine et des sciences de la santé, Université de Sherbrooke
- Dr. Alberto Cambrosio, Professor, Social Studies of Medicine, McGill University
- Ms. Claire Côté, Lived Experience - Patient/Survivor
- Mr. Claude Côté, Lived Experience - Patient/Survivor
- Ms. Roxanne Côté, Lived Experience - Patient/Survivor
- Dr. (Elena) Alice Dragomir, Assistant Professor, Surgery (Urology), Scientist, Health Economics and Outcomes Research & Associate Professor, Medicine, McGill University and Pharmacie, Université de Montréal

- Ms. Joy Gandell, Lived Experience – Family member/Caregiver
- Mr. Hugues Langlois, Lived Experience - Patient/Survivor
- Mr. Richard Larocque, Lived Experience - Patient/Survivor
- Dr. Hermann Nabi, Chercheur régulier axe oncologie et professeur adjoint, Médecine sociale et préventive, Université Laval et Centre de recherche du CHU de Québec-Université Laval
- Ms. Isabelle Roy, Lived Experience - Patient/Survivor
- Dr. Jacques R. Simard, Chaire de recherche du Canada en oncogénétique et professeur titulaire de médecine moléculaire, Médecine de l'Université Laval et Centre de recherche du CHU de Québec-Université Laval
- Dr. Erin C. Strumpf, Associate Professor & William Dawson Scholar, Departments of Economics & Epidemiology, Biostatistics and Occupational Health, McGill University
- Dr. Dominique Tremblay, Professeure, Médecine et des sciences de la santé, Université de Sherbrooke

Saskatchewan

- Ms. Nathalie Baudais, Lived Experience - Patient/Survivor
- Ms. Louise Bird, Lived Experience - Patient/Survivor
- Ms. Diana Ermel, Lived Experience - Patient/Survivor
- Ms. Amanda Anne Niebergall, Lived Experience - Patient/Survivor
- Ms. Sandra Strachan, Lived Experience - Family member/Caregiver

APPENDIX B. ONLINE SURVEY – METHODOLOGY AND RESULTS

The survey was developed in QuestionPro in both official languages. 1096 prospective respondents were approached via email to participate. 75% of emailed prospects were researchers identified through the Canadian Cancer Research Survey as a health services researcher. There were 61 stale emails.

The survey was promoted by the Canadian Association of Provincial Cancer Agencies (CAPCA), CCRA members, and Canadian Centre for Applied Research in Cancer Control (ARCC) as well as via Twitter by the CCRA and CIHR Institute of Health Services and Policy Research (IHSPR). In addition, community organizations in Quebec broadly promoted the survey. The survey was open for completion from November 6 to November 21, 2020.

382 respondents who completed all or almost all questions in the survey were included in the analysis. This included 77 respondents who completed the French version of the survey.

- 68% of respondents indicated that they were in the 35-64 years age group.
- 67% reported that they were female.
- 78% identified as white.
- 47% of researchers indicated that they had more than 15 years of experience.
- 54% of respondents who identified as a person affected by cancer resided in Quebec.
- 38% of researcher respondents resided in Ontario.

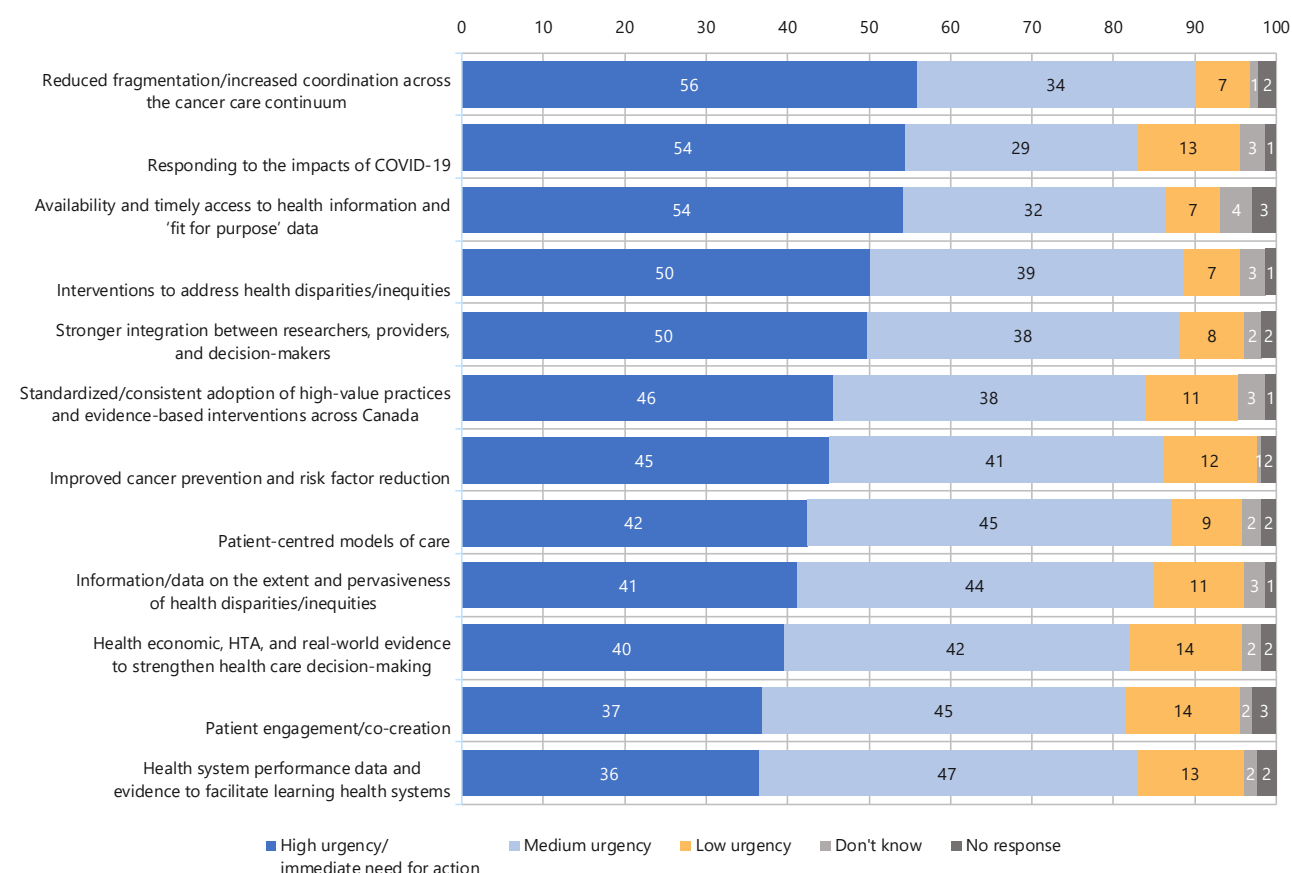
Key Findings

Priorities for Funding

Respondents were asked to indicate the urgency for action among a dozen supplied areas/themes. Responses for all respondents are provided in Figure 1. Five areas were rated as “highly urgent/immediate need for action” by half or more of all respondents. In rank order, these were:

- Reduced fragmentation/increased coordination across the cancer care continuum
- Responding to the impacts of COVID-19
- Availability and timely access to health information and ‘fit for purpose’ data
- Interventions to address health disparities/inequities
- Stronger integration between researchers, providers, and decision-makers

FIGURE 1

AREAS FOR ACTION BY URGENCY, N=382 (%)

Significant differences emerged, however, when responses were analyzed by respondent perspective. Figure 2 shows the top five rankings (numbered) by area for the four largest respondent groups. Similar areas across columns are coloured coded. One area, "Reduced fragmentation/increased coordination across the cancer care continuum," (light blue) was in the top five rankings for each group.

FIGURE 2

TOP FIVE AREAS IDENTIFIED FOR URGENT ACTION BY RESPONDENT GROUPS

Researcher/ clinician researcher (N=162)	Health care provider (N=40)	Health care DM/administrator (N=21)	Person with lived experience (N=123)
1. Interventions to address health disparities/inequities	1. Availability and timely access to health information and 'fit for purpose' data	1. Reduced fragmentation/increased coordination across the cancer care continuum	1. Responding to the impacts of COVID-19
2. Availability and timely access to health information and 'fit for purpose' data	2. Reduced fragmentation/increased coordination across the cancer care continuum	2. Availability and timely access to health information and 'fit for purpose' data	2. Reduced fragmentation/increased coordination across the cancer care continuum
3. Stronger integration between researchers, providers, and decision-makers	3. Standardized/consistent adoption of high-value practices and evidence-based interventions across Canada	3. Responding to the impacts of COVID-19	3. Patient-centred models of care
4. Reduced fragmentation/increased coordination across the cancer care continuum	4. Improved cancer prevention and risk factor reduction	4. Information/data on the extent and pervasiveness of health disparities/inequities	4. Patient engagement/co-creation
5. Responding to the impacts of COVID-19	5. Interventions to address health disparities/inequities	5. Interventions to address health disparities/inequities	5. Improved cancer prevention and risk factor reduction

In terms of additional areas, 36% (137/382) of respondents provided a response to the open-ended question, “In your opinion, are there other highly urgent cancer health services and policy research priorities not captured in the above list that require immediate attention?” Most responses were under the theme of survivorship care and psychosocial supports for cancer patients or related to underserved populations and inequities. In this context, Indigenous peoples, pediatric and adolescent and young adult cancer patients were identified.

Respondents were also asked to identify needs unique to your region/jurisdiction that they felt required priority attention. 19% (72/382) of respondents answered this question and respondents were from all provinces. The number of responses by province is too small to comment on similarities or differences. Overall, remote/rural access, disparities/inequities in care/services, with specific mention of Indigenous peoples, and provider access were the most frequently identified research priorities.

Types of Support

Respondents were asked to rank 11 types of support to enable the areas for urgent action that they identified in the first portion of the survey. If they rated a support option as “very important” or “somewhat important,” they were also asked to indicate the organization(s) best suited to support that option. Overall respondent results are presented in Figure 3. The mechanisms with the highest percentage of respondents rating them as “very important” were:

- Long-term funding programs to provide sustained support for pragmatic trials, implementation studies, evaluation of innovations, etc.
- Creation of a Pan-Canadian data infrastructure that enables health services, health economics, and policy research and supports decision-making in cancer control
- Implementation science teams (provincial/territorial or regionally-based) to support the implementation and adoption of evidence-based, implementation-ready cancer control interventions
- Research function embedded in cancer care delivery and responsive to system needs (e.g., direct decision support for provincial cancer agencies through targeted research contracts; formalized process for connecting academic institutions with cancer systems to address priority cancer system challenges)
- Continued capacity building/training in areas such as implementation science, health technology assessment, digital and virtual care, health economics/value for money, mixed methods, sequential trial design

Although proportionally very few respondents indicated that the presented options were “not at all important,” there were large percentages of respondents who did not respond to the question or indicated that they had no opinion and did not feel that they knew enough to comment. This varied per item (from 11 to 35% for all respondents) and was higher for respondents who were persons with lived experience (range 15 to 43%). Alternative metrics was the item with the highest non-response rate.

Although not to the same degree as the priorities, some differences emerged in terms of the proportion of respondents rating a mechanism as “very important” when the data were examined by respondent perspective. See Figure 4 below.

Respondents who marked a mechanism with a “very important” or “somewhat important” rating were asked to indicate which from a range of supplied organizations/organization types would be best positioned to support

this mechanism. Results are provided in Figure 5. Across all 11 mechanisms, the organizations best positioned to support the mechanisms were:

- Canadian Institutes of Health Research
- Provincial/territorial cancer agencies/services
- Canadian Partnership Against Cancer (abbreviated as CPAC in this Figure only)

In response to the question, “Are there other mechanisms/supports that would best address the urgent areas for action that you identified?”, the Canadian Centre for Applied Research in Cancer Control (ARCC) was identified, specifically in connection with health economics infrastructure, capacity building, and convening diverse stakeholders. Universities/academic hospitals and research centres were also frequently identified in relation to capacity building and the implementation science laboratories/meta-laboratories.

FIGURE 3

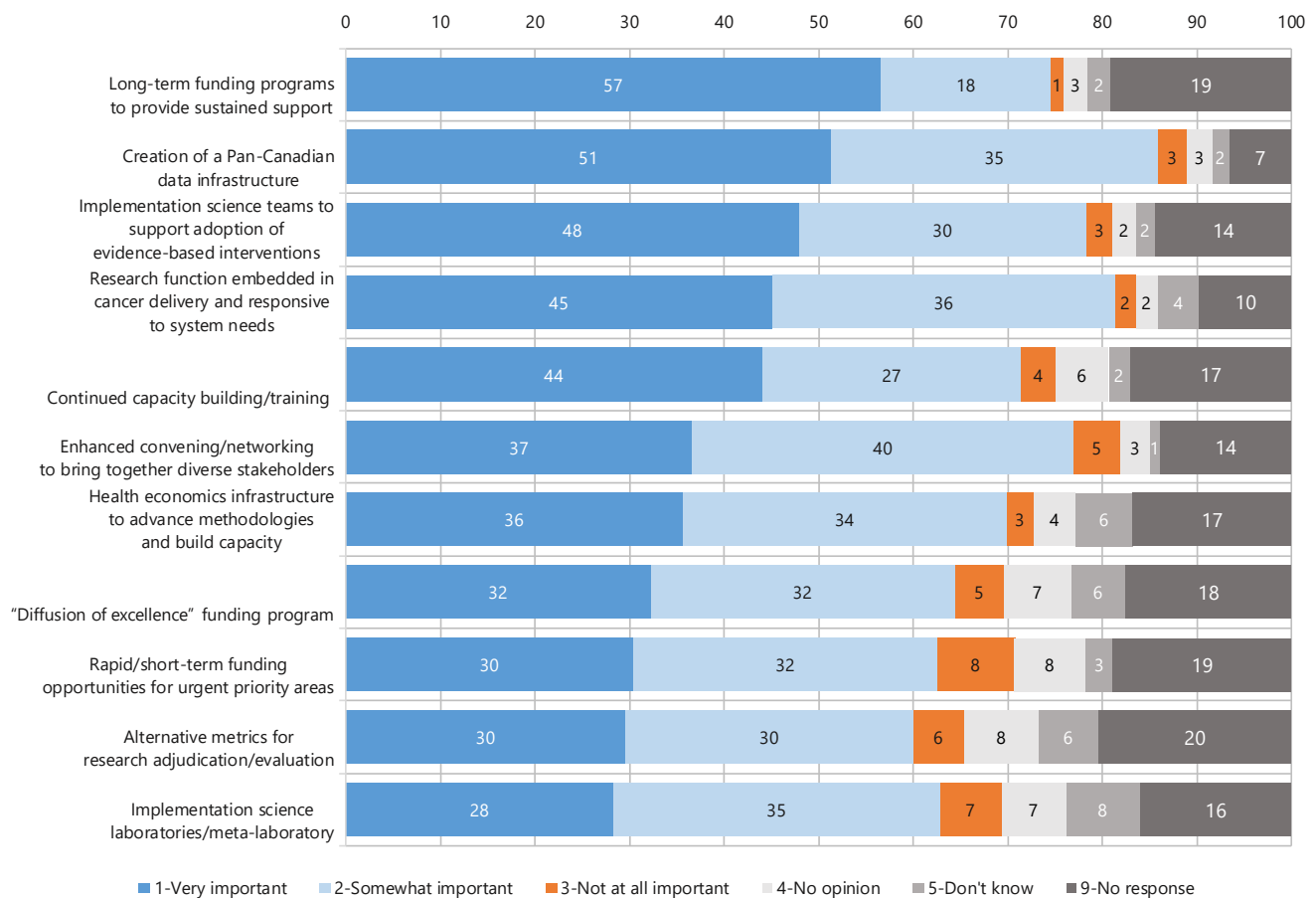
SUPPORT MECHANISMS BY IMPORTANCE, N=382 (%)

FIGURE 4

TOP THREE MECHANISMS IDENTIFIED AS VERY IMPORTANT BY RESPONDENT GROUPS

Researcher/ clinician researcher (N=162)	Health care provider (N=40)	Health care DM/administrator (N=21)	Person with lived experience (N=123)
1. Long-term funding programs to provide sustained support	1. Creation of a Pan-Canadian data infrastructure	1. Long-term funding programs to provide sustained support	1. Implementation science teams to support adoption of evidence-based interventions
2. Creation of a Pan-Canadian data infrastructure	2. Research function embedded in cancer delivery and responsive to system needs	2. Health economics infrastructure to advance methodologies and build capacity	2. Creation of a Pan-Canadian data infrastructure
3. Continued capacity building/training	3. Long-term funding programs to provide sustained support	3. Continued capacity building/training	3. Enhanced convening/networking to bring together diverse stakeholders

FIGURE 5

TOP ORGANIZATIONS IDENTIFIED AS PROSPECTIVE SUPPORTERS BY MECHANISM

	Most frequent	Second most frequent	Third most frequent
Creation of a Pan-Canadian data infrastructure	CIHR	P/T cancer agencies	CPAC
Research function embedded in cancer delivery and responsive to system needs	P/T cancer agencies	CIHR	CPAC
Enhanced convening/networking to bring together diverse stakeholders	CPAC	P/T cancer agencies	CIHR
Implementation science teams to support adoption of evidence-based interventions	P/T cancer agencies	CIHR	CPAC
Implementation science laboratories/meta-laboratory	CIHR	P/T cancer agencies	CPAC
Health economics infrastructure to advance methodologies and build capacity	P/T cancer agencies	P/T governments	Health Canada
Continued capacity building/training	CIHR	P/T cancer agencies	CPAC
"Diffusion of excellence" funding program	CPAC	P/T cancer agencies	CIHR
Rapid/short-term funding opportunities for urgent priority areas	CIHR		
Long-term funding programs to provide sustained support	CIHR	P/T cancer agencies	CPAC
Alternative metrics for research adjudication/evaluation	CIHR	P/T cancer agencies	

Respondents were asked: "What are the most important considerations (facilitators, policy levers, financial, etc.) to successfully advance cancer health services and policy research in Canada in the coming decade?" 33% (127/382) of respondents provided a response to this question. The most frequent themes were: the importance of funding, especially sustained funding; the value of all forms of collaboration and coordination, between researchers (multi-disciplinary and international) as well as between providers, decision-makers, and researchers; and the need for accessible data with specific mention of issues of data privacy/security inherent in inter-jurisdictional data sharing.

APPENDIX C. PROJECT SUPPORTERS



**Canadian
Cancer
Society**



CIHR IRSC
Canadian Institutes of Health Research Instituts de recherche
en santé du Canada



**CANADIAN PARTNERSHIP
AGAINST CANCER**
**PARTENARIAT CANADIEN
CONTRE LE CANCER**



GenomeCanada



OUR MEMBERS



Affiliate Member:





Canadian Cancer
Research Alliance

Alliance canadienne
pour la recherche sur le cancer

Canadian Cancer Research Alliance (CCRA)
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Toronto, Ontario M5H 1J8 CANADA

<https://www.ccra-acrc.ca>

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