



Optimizing Diagnosis in Canadian Cancer Care

Prepared by Tina Sahay, Health Promotion Consulting Group
for All.Can Canada

The All.Can Canada initiative is made possible with financial support from Bristol Myers Squibb (main sponsor), Merck, Johnson & Johnson, Novartis and Amgen (sponsors)

About All.Can International

All.Can is an international, multi-stakeholder policy initiative aiming to identify ways to optimize the use of resources in cancer care by focusing on outcomes that matter most to patients – and create greater efficiency in cancer care. This involves examining what system inefficiencies exist, finding examples of how we can improve efficiency in cancer care, and implementing concrete policy actions based on these findings.

All.Can is comprised of leading representatives from patient organizations, policymakers, health care professionals, research and industry. The All.Can Group consists of All.Can International, plus All.Can national initiatives currently established in 18 countries including Canada.

In 2018, All.Can conducted a patient survey conducted in over 10 countries, including Canada, which asked almost 4,000 cancer patients and caregivers where they identified inefficiencies in their care. The survey asked respondents to choose the one area in which they experience the most inefficiency. Nearly one-third (30%) of respondents from Canada chose diagnosis – more than any other area of cancer care.

All.Can International is a not-for-profit organisation (ASBL) registered in Belgium. Its work is made possible with financial support from Bristol Myers Squibb (main sponsor), Roche (major sponsor), MSD and Johnson & Johnson (sponsors), Baxter and Illumina (contributor), with additional non-financial (in kind) support from Helpsy, Intacare and Goings-On.

About All.Can Canada

All.Can Canada was established under the auspices of Save Your Skin Foundation (SYSF), a national, patient-led, not-for-profit group dedicated to leading the fight against non-melanoma skin cancers, melanoma and ocular melanoma. SYSF was established as All.Can Canada's Secretariat to lead the initiative in Canada, bringing the approach and lessons learned by the international group to Canada. To start, SYSF convened a working group to discuss how best to bring All.Can into Canadian health care.

Members of this preliminary working group were:

Kathy Barnard, President, Save Your Skin Foundation

Louise Binder, Health Policy Consultant, Save Your Skin Foundation

William Dempster, CEO, 3Sixty Public Affairs

Amy Rosvold, Director of Marketing and Communications, Save Your Skin Foundation

Suzanne Wait, Managing Director, The Health Policy Partnership

The working group completed a discovery phase that involved a scan of nation-wide and province-specific health care reports to identify the top reported areas of waste and inefficiency in cancer care in Canada. These findings were then prioritized through anonymous surveys with cancer care stakeholder groups, including pharmaceutical industry representatives, patient group representatives, health care professionals, provincial policy makers, and health technology assessment bodies. This information was also reviewed in light of responses from over 300 Canadian cancer patients who took part in the All.Can International Patient Survey.

Following this discovery phase, SYSF hosted an inaugural multi-stakeholder roundtable meeting on November 14, 2019 to share findings on top areas of inefficiency and to assess consensus on priorities and next steps to move All.Can

Canada forward. As a result, an All.Can Canada interim steering committee was assembled with representation from all stakeholder groups to support, guide, and oversee the progress of a multi-year project that was derived from the roundtable. The roundtable participants reached consensus that the priority area of focus for All.Can Canada should be ***ensuring swift, accurate and appropriately delivered diagnosis as the entry point into the cancer care system***. The first step in this project was to conduct an environmental scan on patients' entry into cancer care across Canada – and this is the subject of this report.

Acknowledgements

This research was conducted by an independent third-party consultant with strategic oversight and guidance by All.Can Canada's patient-led, multi-stakeholder **Interim Steering Committee** and project management by the All.Can Canada Secretariat from **Save Your Skin Foundation (SYSF)**. Patients and patient group representatives held the majority of seats on the Interim Steering Committee. The remaining membership included at least one representative from each of the following sectors or people with recent extensive professional experience in one of these sectors: health care providers; researchers; and policy-makers. Pharmaceutical industry representatives participated only as non-voting observers.

Interim Steering Committee members:

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At the Canadian level, the All.Can Canada initiative is made possible with financial support in the form of unrestricted grants from Bristol-Myers Squibb (main sponsor), Merck, Johnson & Johnson, Novartis and Amgen.

Glossary of Terms

Allied health professional

Regulated health professionals who are not nurses or physicians (Care, 2021).

Caregiver

Any person who plays a vital role in supporting individuals living with complex, chronic conditions, older adults with a frailty, and those at end-of-life (Canada C. , 2021).

Care pathway

A complex intervention for the mutual decision-making and organisation of care processes for a well-defined group of patients during a well-defined period. The aim of a care pathway is to enhance the quality of care across the continuum by improving risk-adjusted patient outcomes, promoting patient safety, increasing patient satisfaction, and optimizing the use of resources (Guus Schrijvers, 2012).

Clinical practice guideline

Evidence-based recommendations that help health care professionals make appropriate clinical decisions (Canada H. C. , 2012).

Determinants of Health

The broad range of personal, social, economic and environmental factors that determine individual and population health. The main determinants of health include: income and social status; employment and working conditions; education and literacy; childhood experiences; physical environments; social supports and coping skills; healthy behaviours; access to health services; biology and genetic endowment; gender; culture; race / racism (Canada G. , 2020).

Diagnosis

The time from when an individual first tries to contact or interacts with a health care

provider over a suspicion of cancer to the time a confirmed diagnosis is made (or cancer is ruled out).

Early diagnosis

Accurately identifying cancer without delay at the earliest possible stage and rapidly providing treatment (WHO, 2017).

Health equity

The absence of unfair systems and policies that cause health inequalities. Health equity seeks to reduce inequalities and to increase access to opportunities and conditions conducive to health for all (Canada G. , 2020).

Health inequalities

Refers to a situation in which the benefits of good health are not equally enjoyed by all. Many of these inequalities are the result of social, political, and economic disadvantages, which affect our chances of achieving and maintaining good health (Canada G. , Pan Canadian Health Inequalities Reporting Initiative, 2021).

Inefficiency

The allocation of resources to anything that does not focus on what matters to patients (Suzanne Wait, 2017).

Patient navigator

Described using many terms, including care coordinator, pivot nurse, patient advocate, and health coach, the role refers to someone assigned to the patient who is available and accessible throughout the diagnosis process from beginning to end and who is responsible for effective patient-to-provider communication and information sharing; clinical patient navigation; connecting the patient with other needed supports, including psychosocial supports; and consistent, accurate, and timely provider-to-provider communication

Patient satisfaction

Patient satisfaction refers to a patient's expectations for his or her care encounter.

Patient satisfaction is a subjective healthcare measure. Two patients can receive the exact same care but have different satisfaction levels because they had different subjective expectations (AHRQ, 2020).

PREMs

Patient reported experience measures (PREMs) gather information on patients' views of their experience while receiving care. They are an indicator of the quality of patient care, although do not measure it directly. In contrast to PROMs, PREMs do not look at the outcomes of care but the impact of the process of the care on the patient's experience, e.g., communication and timeliness of assistance. They differ from satisfaction surveys by reporting objective patient experiences, removing the ability to report subjective views. PREMs can be classified as either relational or functional. Relational PREMs identify the patient's experience of their relationships during treatment, e.g., did they feel listened to. Functional PREMs examine more practical issues, such as the facilities available (Kingsley, 2016).

Primary care provider

Regulated health professionals who are nurses or physicians (Care, 2021).

PROMs

PROMs are measurement instruments that patients complete to provide information on aspects of their health status that are relevant to their quality of life, including symptoms, functionality and physical, mental and social health (CIHI, 2021).

Social Determinants of Health (SDH)

Refer to a specific group of social and economic factors within the broader determinants of health. These relate to an individual's place in society, such as income, education or employment. Experiences of discrimination, racism and historical trauma are important social determinants of health for certain groups such as Indigenous Peoples, LGBTQ and Black Canadians (Canada G. , 2020).

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Executive Summary

The prevalence, complexity and costs of cancer are rising. The cost of cancer care in Canada has risen from \$2.9 billion in 2005 to \$7.5 billion in 2012, mostly owing to the increase in costs of hospital-based care (Oliveira, 2018). As the personal, economic and social costs of cancer continue to rise, there is a growing burden on our health care systems and an urgent need to improve efficiencies and reduce waste in cancer care. Most importantly, research suggests that removing wasteful or ineffective interventions could lead to an average gain of approximately two years of life expectancy in industrialized countries (Wait, 2017). Improving efficiency is not only a question of cost-cutting, but of allocating resources more efficiently to ensure the sustainability of our health care systems and, ultimately, to improve health outcomes and quality of life for patients.

Defining inefficiencies requires a look across the entire spectrum of cancer care to try to identify practices, policies or processes that do not provide meaningful benefits for patients with the resources used. This is no small task – inefficiencies may occur at the system, institutional or individual level – and at every step along the cancer care continuum.

Inaccurate and delayed diagnoses were identified as the top area of waste and inefficiency by cancer care stakeholders in Canada – more than any other area of cancer care in both the All.Can International patient survey conducted in Canada and through surveys led by SYSF with different stakeholder groups.

To address the challenges and leverage new opportunities in obtaining a swift, accurate and appropriately communicated cancer diagnosis, **All.Can Canada embarked on a comprehensive assessment of how well Canada is doing in terms of ensuring people have optimized entry into cancer care.** The purpose was to obtain an up-to-date picture of the current state of cancer diagnosis in Canada in order to

identify priority areas and concrete actions to inform the work of policy makers and other stakeholders working or studying in cancer control.

This research was conducted from June 2020 to March 2021 by an independent third-party consultant with strategic oversight and guidance by All.Can Canada's multi-stakeholder Interim Steering Committee. It comprised of a review of literature to identify current Canadian practices underway which aim to reduce inefficiencies in the diagnosis phase; qualitative interviews with cancer survivors across Canada to understand the diagnosis experience from patient's perspectives and what matters most to them as they traverse the diagnosis process; and, a survey of providers across Canada to understand what they perceive to be the main inefficiencies in the diagnosis system and the factors that are essential for a quality diagnosis process.

From the research we learned that across all phases of the diagnosis journey, from the earliest point at which an individual first tries to contact or interacts with a health care provider with a symptom or a suspicion of cancer to the time a confirmed diagnosis is made, **seven outcomes were voiced by people as being critical to the quality of their diagnosis experience:**

1. **Swiftness** of the diagnosis process
2. **Validation** of concerns by primary care providers
3. Excellent **patient-provider communication**
4. Effective **provider-provider communication**
5. Better **information**
6. Integrated **psychosocial support**
7. **Coordinated and managed care**

Attainment of these outcomes resulted in a more satisfactory diagnosis experience, while failing to attain any one of these outcomes had a negative, and oftentimes detrimental, impact. For the majority of people in our study, the diagnosis experience was bleak and was described by many as the most challenging period in their entire cancer experience. What mattered most to people throughout their diagnosis journey was oftentimes the opposite of what actually happened.

While the degree to which desired outcomes are currently being achieved varies considerably by phase of the diagnosis process, and to some extent by type of cancer, age and geographic location of the patient, it is clear that we have a lot of work to do to achieve all seven outcomes which people identified as being the most important for a quality diagnosis process. This research not only showed us the labyrinth most patients currently experience when trying to diagnose a suspicion of cancer, but also provided a **clear picture of the improved, future state for cancer diagnosis in Canada.** It also begins to build the foundations of a quality framework for cancer diagnosis in Canada.

It is important to note that this research aimed to understand equity issues and heard from patients from rural, remote, suburban, and urban areas across Canada and from a range of income levels, including people living on low incomes. This research is intended to **set the foundation for future work in cancer diagnosis** with next steps including the identification of areas to address the specific needs of Indigenous and underserved populations.

Achieving a future, more desirable state of cancer diagnosis does not mean starting from scratch. There exist numerous opportunities and good practices that, if adapted, spread and scaled for jurisdictional and regional needs, can be an excellent place to begin the realization of a future, more desirable state of cancer diagnosis in which desired outcomes are achieved for everyone. Innovating to fill gaps that cannot be addressed by existing practices and policies is another important means to move towards a better future in cancer diagnosis. Towards this end, recommendations for achieving a swift, accurate and appropriately communicated cancer diagnosis for all Canadians are presented below.

Recommendation #1:

National convening and coordination of the efforts of various stakeholders in implementing these recommendations are required, with patients and patient representatives providing meaningful leadership in any ongoing multi-stakeholder implementation efforts.

Recommendation #2:

Create opportunities to enhance primary care provider knowledge of cancer types, associated symptoms, and established diagnosis pathways.

- A. **Catalogue currently available cancer training/education in order to then improve upon and better integrate knowledge into relevant post-secondary medical and continuing education programs** for practicing providers including knowledge of cancer types, symptoms, and diagnostic pathways.
- B. Work with professional colleges to **offer knowledge mobilization and awareness raising opportunities** for practicing providers.
- C. Work with provincial cancer systems to **ensure awareness and utilization of established standardized diagnostic pathways and guidelines** by all providers working in cancer control, including primary care providers and allied health professionals, through a common repository of diagnostic pathways.
- D. Work with provincial cancer systems, researchers, cancer patients, and other stakeholders to **develop new standardized diagnostic pathways and guidelines** for more types of cancers.

- E. **Develop electronic decision supports** for primary care providers to enable them to assess risk for various types of cancers (e.g., standardized clinical decision support/risk assessment algorithms). Work with key national organizations in Canada to ensure the work is done, standardized, and knowledge is translated and adapted from one province/territory to another (e.g., Health Excellence Canada, Canadian Institute for Health Information, Canada Health Infoway, Canadian Association of Provincial Cancer Agencies).
- F. Work with professional colleges to **create opportunities for communication skills acquisition** to support excellent patient-provider communication throughout the diagnosis process.

Recommendation #3:

Ensure consistently available and accessible patient navigation for all cancer types and all jurisdictions throughout the cancer diagnosis process.

- A. Work with provincial and territorial governments, cancer control agencies, provider associations, and other stakeholders to **assign system-level accountability to primary care to coordinate the cancer diagnosis process during the early to middle phases**. Primary care providers need patient navigation capacity to proactively connect with other parts of the health care system and other systems on behalf of patients. This also requires the establishment of supportive accountability agreements with primary care providers.
- B. Work with cancer control agencies, and other stakeholders to **grow and expand patient navigation, multidisciplinary teams, and diagnostic assessment programs (DAPs)** within all jurisdictions across Canada to provide a clear point of entry into the cancer care system, assessment within a single location (or at least

coordination of assessment), and access to a multidisciplinary team that includes a clinical patient navigator.

- C. Work with provincial and territorial governments, provider associations, cancer control agencies, and other stakeholders to **grow and expand physician funding models that support integrated primary care and integrated cancer care and the achievement of patient-defined outcomes in cancer diagnosis.**

Recommendation #4:

Provide patients the right information at the right time and establish technological mechanisms to facilitate communication throughout the cancer diagnosis process.

- A. Work with professional colleges, provider associations, cancer control agencies, and other relevant stakeholders to **ensure the information provided to patients matches the information needed** at each phase of the diagnostic process. Specifically, upon entry to the middle phase, provide an overview of the diagnostic pathway. Throughout the middle phase of diagnosis, provide details of what to expect along each step of the diagnosis pathway *before* it occurs. At the final phase of diagnosis, give the patient an information kit that explains the type of cancer and its treatment(s) and includes a list of reliable sources of information along with a phone number of who or where to call to ask questions (and ideally connecting them with their patient navigator for the treatment phase of their cancer care).
- B. **Identify a national body to lead and coordinate the development of technological mechanisms** outlined below so that tools that support communication and coordination can be scaled and spread across jurisdictions (e.g. Canada Health Infoway, Health Excellence Canada, private-public partnerships).

- C. **Support the spread of user-friendly smart-phone applications** to enhance provider-provider and patient-provider communication and connection.
- D. **Improve on and spread user-friendly online portals** that are invoked the moment a patient enters the cancer care system and which can store clinical patient information, make personal health information accessible to patients, and support shared decision-making between patients and providers. Portals must link to existing EMRs and programs in clinics and both patients and providers need to have access to this information as part of a patient's medical history/file.
- E. **Scale virtual communication technology** to reduce appointment wait times, increase provider access, and ensure attendance of a support person at appointments during restricted times or otherwise. Establish guidelines around what can be effectively managed virtually and what requires in person consultation. Prepare patients for doing visits related to the cancer diagnosis process in a virtual environment.
- F. **Grow and expand telepathology** to make diagnostic care more accessible and faster for people living in rural and Northern Canada.
- G. **Remove barriers to digital equity through digital inclusion initiatives** to ensure individuals and communities facing barriers achieve access to digital devices, bandwidth and any other mechanisms required, e.g. electricity and freely available Wi-Fi, as well as meaningful adoption that enables underserved people to have the means and knowledge to use technology through easily accessible education and support.

Recommendation #5:

Expand availability and accessibility of psychosocial supports for people going through cancer diagnosis and create linkages between cancer care and supportive care.

- A. Work with national bodies such as the Mental Health Commission of Canada, the National Network for Mental Health, the Canadian Mental Health Association, Canadian Association of Psychosocial Oncology, and All.Can Canada Hub for Mental Health to **grow and expand psychosocial supports for people going through cancer diagnosis across Canada and across cancer types** and to create linkages to psychosocial supports as outlined below.
- B. **Increase provider awareness of existing psychosocial supports, including those provided by patient groups**, regionally and by jurisdiction and **create mechanisms for providers (including nurses, patient navigators, technicians, support staff) to easily connect patients with these supports.**
- C. **Embed psychosocial supports** into community-based primary care services, diagnostic facilities, and hospital settings.
- D. **Provide funding for travel and other needed diagnostic process supports** for people living in rural, remote and Northern Canada.

Recommendation #6:

Develop a patient-centred quality framework to measure, benchmark, and improve the efficiency and effectiveness of cancer diagnosis.

- A. **Work with key stakeholders (e.g. Canadian Institutes for Health Information, Canadian Partnership Against Cancer, Canadian Cancer Society) to build on the cancer diagnosis quality framework** which originated from this research project to establish patient-reported experience measures (PREMs) and other metrics associated with each of the seven outcomes identified in this research, which are common to all cancer types, stage of disease and social determinants of health, to benchmark, compare, and improve across cancer populations and jurisdictions. Once a quality framework is established, develop tools to measure the patient experience in the cancer diagnosis process and use this information for reporting and to guide performance improvement. To this end, create a national dashboard with key metrics and data points of the diagnosis process.
- B. **As part of the cancer diagnosis quality framework, continue to establish wait time targets** within jurisdictions for various types of cancer with an eye toward establishing national targets.



Optimizing Diagnosis in Canadian Cancer Care

To address the challenges and leverage new opportunities in obtaining a swift, accurate and appropriately communicated cancer diagnosis, All.Can Canada embarked on a comprehensive assessment of how well Canada is doing in terms of ensuring people have optimized entry into cancer care. The purpose was to obtain an up-to-date picture of the current state of cancer diagnosis in Canada in order to identify priority areas and concrete actions to inform the work of policy makers and other stakeholders working or studying in cancer control.

Introduction

In May 2020, All.Can Canada commissioned research to obtain an in-depth understanding of the current state of cancer diagnosis in Canada. The impetus for the research grew out of an inaugural multi-stakeholder roundtable meeting in November 2019 convened by Save Your Skin Foundation (SYSF) and which was intended to draw upon prior research to orientate the mission and work of All.Can Canada. Participants at the meeting were patients, patient group representatives, health care professionals, former health technology assessment professionals, industry representatives, and researchers from across Canada. Participants at the meeting were patients, health care professionals, patient group representatives, former health technology assessment professionals, industry representatives, and researchers. The roundtable meeting built consensus on a priority area of focus plus next steps, and agreed to a preliminary governance approach for All.Can Canada through the establishment of a multi-stakeholder interim steering committee, supported by the Secretariat. The group achieved consensus on a preliminary area of focus to be:

Optimizing patient entry into Canadian cancer care systems, ensuring swift, accurate, and appropriately delivered diagnosis.

As a first step, it was decided that a rigorously conducted environmental scan should be conducted to assess the current state in achieving this goal across Canada.

Objectives

- To assess the current state of cancer care systems in Canada to ensure swift, accurate and appropriately delivered diagnosis as the entry point to the cancer care system
- To identify outcomes that matter most to different cancer populations, including performance indicators to assess success, to benchmark and to compare across cancer populations and Canadian jurisdictions
- To identify promising, good and best practices in cancer care diagnosis that could be adapted, spread and scaled
- To understand what works well, enablers, issues, barriers and gaps against identified outcomes
- To identify specific areas of inefficiency that represent opportunities for improvement towards achieving identified outcomes

Background

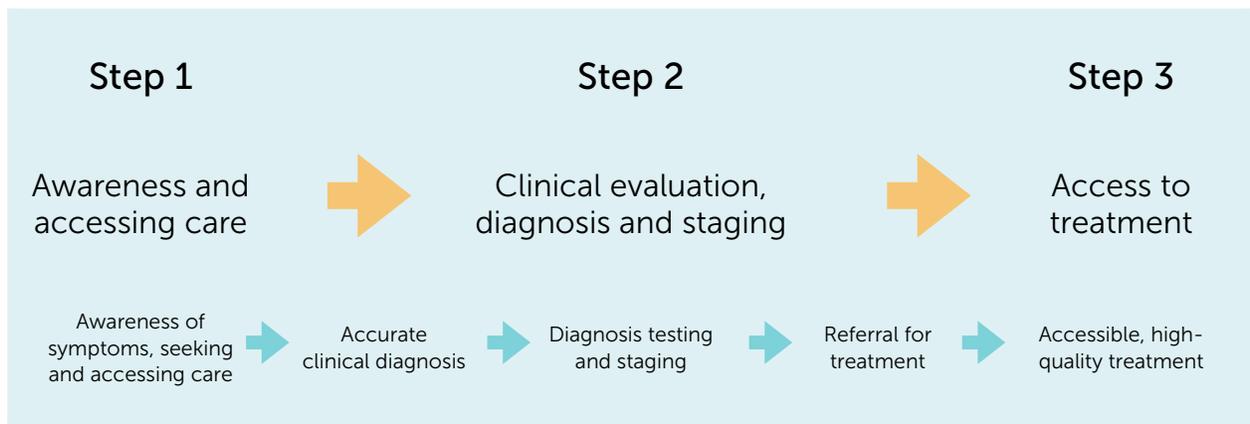
There are multiple phases of the cancer care continuum, from screening to pre/diagnosis through to treatment, post care, and palliative/hospice care. The diagnosis phase - *the time from when an individual presents to their health care provider with a symptom to the time a confirmed diagnosis is made (or cancer is ruled out)* - is depicted in Step 2 of the World Health Organization's three steps of early diagnosis (Figure 1).



Diagnosis refers to the time from when an individual presents to their health care provider with a symptom to the time a confirmed diagnosis is made (or cancer is ruled out).

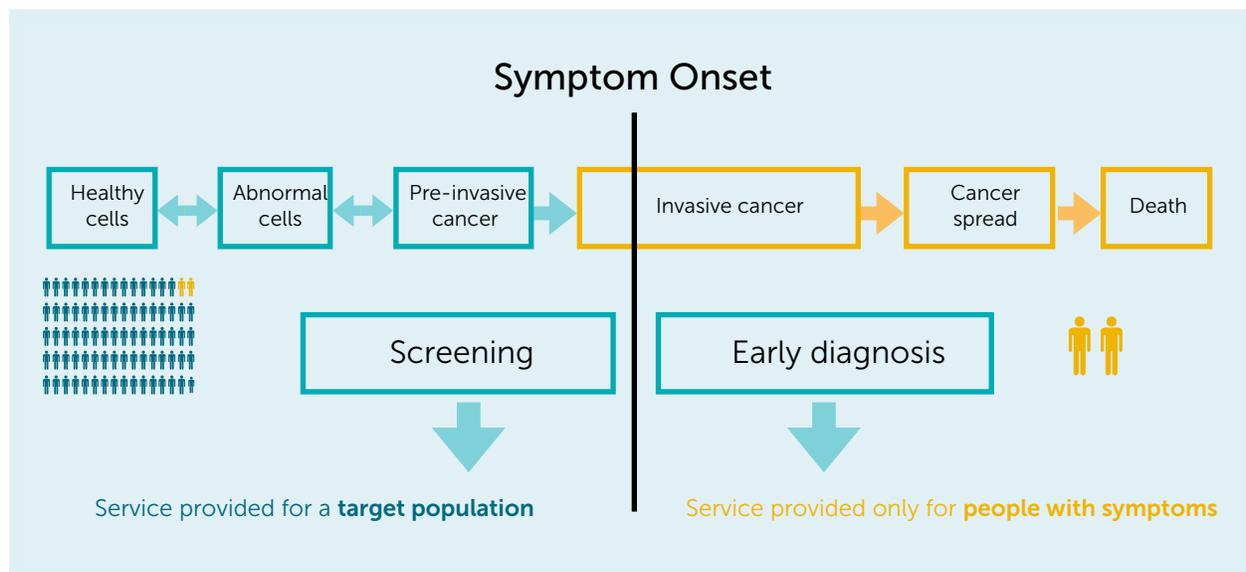
All.Can Canada

Figure 1. Elements of cancer early diagnosis (WHO, 2017)



The diagnosis phase focuses on people who have symptoms consistent with cancer which sets it apart from prevention and screening, which is targeted to whole, healthy populations.

Figure 2. Distinguishing screening from early diagnosis according to symptom onset (WHO, 2018)



Typically, the diagnosis phase begins with an evaluation by a primary care provider at the initial point of entry to the health care system, to establish if symptoms warrant investigation. The point at which patients enter the health care system will vary, but in Canada typically patients enter via their family physician or via hospital emergency rooms (ER). Patients with symptoms indicative of cancer are then referred to specialist care for diagnostic testing and confirmation of diagnosis (and then staging to assess whether and to where cancer may have spread) (WHO, 2017).¹

The diagnosis phase represents a complex stage of care which often requires patients to interact with several different parts of the health care system including primary care, laboratories, diagnostic imaging, specialist facilities and the health care providers and other staff that provide these services. Cancer care literature recognizes this phase as critically important, noting that to achieve the best possible outcomes for a cancer diagnosis, diagnostic testing should be swift, the interpretation of diagnostic tests should be accurate, and the results of diagnostic

¹ For the parameters of this environmental scan, the diagnosis phase ends once a diagnosis of cancer is confirmed and before staging begins.

tests should be appropriately communicated to the patient/caregiver (All.CanCanada, 2020). Diagnostic facilities should be easily accessible and integrated, allowing providers to work in a coordinated fashion to arrive efficiently and effectively at a final diagnosis.

While the benefits of a coordinated and efficient cancer care system are easily recognized, cancer diagnosis is not always a well understood, organized or seamless process (All.Can, 2019). Indeed, an international survey of nearly four thousand cancer patients and caregivers found diagnosis to be the area where patients felt there was the greatest inefficiency out of all aspects of their cancer care (All.Can, 2019). Studies have found that health care system-related factors such as the presence of a gatekeeper system (e.g., needing a referral from a GP for diagnostic tests or specialist care), referral patterns from primary to secondary care, access to primary care, diagnostic, and specialized services, size of wait lists, physician behaviour and practice routines, physician-patient communication, symptom-recognition skills, ability to interpret tests, and availability of materials and personnel can cause or exacerbate these inefficiencies, resulting in delays and inaccuracies in cancer diagnosis (Astrid Brousselle, 2017); (All.Can, 2019). A breakdown in one or more of these factors can cause considerable distress for patients and families as they wait for the outcome of their diagnosis process. To exacerbate diagnosis challenges, some patients are additionally affected by health inequities due to their sex, gender, sexual orientation, ethnicity, socioeconomic status, immigrant status, age, education, and/or geography (Astrid Brousselle, 2017). The impact of this is significant to the patient experience, and potentially to patient outcomes, as earlier diagnosis at a potentially curable stage may improve survival rates (CPAC, 2018).

About this Research

This research was conducted from June 2020 to March 2021.

Research Questions

The following key questions were used to guide the research:

- **How do patients define 'optimal' entry** - i.e., what matters most to patients during the pre-diagnosis phase? Do these desired outcomes differ by cancer type, stage of disease or social determinants of health (SDH)?
- **What indicators can we use to measure these desired outcomes?** Are common indicators available that can be used irrespective of cancer type, stage of disease or geographic location to assess success, to benchmark and to compare outcomes across cancer populations and jurisdictions?
- **What is the experience of patients when they enter the cancer care system?** What factors contribute to differing experiences, (e.g., cancer type, stage of disease, jurisdiction, SDH)? Does the achievement of desired patient outcomes differ by cancer type, stage of disease or SDH?
- **What opportunities for improvement exist**, across Canada and by jurisdiction, for improving on inefficiencies related to entry into cancer care systems in order to achieve desired patient outcomes? How do these opportunities vary across different population groups? Are there disparities across populations (e.g., by socio-economic status, gender, locality) that should be mentioned?
- **How can we optimize entry into the cancer care system in terms of swiftness of diagnosis, accuracy of diagnosis, and appropriate communication of diagnosis?** What existing good or best practices can we adapt, spread and scale? What factors would permit the extension of these practices broadly? Would these practices be beneficial, a) for all cancer types; b) for all stages of

disease; c) for all jurisdictions; and, d) across all population groups? What recommendations can be made for optimizing entry into Canadian cancer care systems to achieve swift, accurate and appropriately communicated diagnosis?

- **In what way, if any, has the COVID-19 pandemic disrupted or affected the current state of entry and/or exacerbated pre-existing inefficiencies in entry into Canadian cancer care systems?** Have people with different cancer types, stage of disease or SDH been impacted differently by these disruptions or inefficiencies? Are there promising, good or best practices in enabling entry into cancer care during the pandemic that should be looked at as lessons learned to be applied to our current and future diagnosis pathway?

Out of Scope

The following topics were out of scope for this research:

- Investigation of screening access and screening rates (organized screening programs)
- Investigation of patient awareness in identifying symptoms and subsequent health-seeking behaviour (i.e., before suspicion)
- Investigation of patient experiences after diagnosis
- Relationship between the diagnosis interval and survival rates

Approach

The research was carried out in three phases.

1. Literature Review

The first phase of the research involved us delving into the literature to: a) identify and catalogue practices underway in Canada that aim to reduce inefficiencies and enhance the individual's experience during the diagnosis phase; b) summarize what is known about how the social determinants of health impact the diagnosis experience in Canada; and, c) identify metrics currently used in Canada to measure the diagnosis phase. Among the complete body of literature retrieved were thirty-four practices designed to optimize the swiftness, accuracy and appropriateness of communication along the cancer diagnosis process. These practices are highlighted throughout this report and are summarized in Appendix A.

2. Patient Interviews

In the second phase of the research, we conducted thirty interviews with people diagnosed with cancer across Canada. The purpose of the interviews was to gather information about the patient's experience as they navigated the diagnosis phase, looking specifically at their experience with swiftness of diagnosis, accuracy of diagnosis and appropriateness of communication. The interviews allowed us to better understand, from the patient's perspective, what outcomes mattered most to them at each step of the diagnosis process, the challenges they encountered along the way, the factors that caused distress, and the practices currently in place that contributed to a more seamless and satisfactory experience. Selection of the interview participants was informed by the literature review and was stratified as much as possible to include: a) population groups for whom the social determinants of health are known, or suspected, to markedly impact their diagnosis experience and outcomes; and, b) patient groups whose diagnosis experience is not already being studied and/or for which there is not an existing body of work. People who had been diagnosed within the past 18 months were selected for inclusion in the interviews. See Appendix B for a snapshot of the thirty interview participants.

3. Provider Survey

In the third phase of the research, we conducted a survey of providers across Canada with whom patients are known to interact at key points throughout the diagnosis process to understand what they perceive to be the main inefficiencies, the factors they believe are essential for a quality diagnosis process, and what, if any, practices they have used or know of which they feel are exemplary and warrant follow-up. A total of forty-two providers completed the survey. See Appendix C for a snapshot of provider survey respondents.

Along with the thematic analysis of patient interview transcripts and the frequency analysis of the provider survey, information collected from the patient interviews and provider survey was analyzed together to identify common threads or categories across both of these sources. This type of comparison helped us to verify findings and to ensure that complementary concepts and information were properly identified and reported. Throughout this report, the information provided by patients and providers is integrated with the findings from the literature review. The report is structured around the seven outcomes identified by patients as being the most important throughout the diagnosis process. For each outcome, current inefficiencies are discussed, opportunities for improvement are presented, practice spotlights are featured, and benchmarks/indicators of success are suggested. Verbatim quotes from patient interviews are included for illustrative purposes and to add richness to the findings.

The research methodology and tools were developed in concert with the ethical requirements of human subjects' research, and included an independent review board (IRB) review of the design, instruments and materials created by the research team.

What We Learned

We recognize that the patient experience is an important dimension of quality care. In keeping with a person-centred approach to cancer care, the findings from this research are structured around what matters most to people as they navigate complex cancer diagnosis systems. We wanted the patient’s voice to be heard as an individual with an identity that goes beyond being just a cancer patient. Our intent is to emphasize that this person-centred lens should guide all efforts to improve diagnosis processes in Canada.

Desired Outcomes

Across all phases of the diagnosis journey, from the earliest point at which an individual first tries to contact or interacts with a health care provider over a suspicion of cancer to the time a confirmed diagnosis is made, seven outcomes were voiced by people as being critical to the quality of the diagnosis experience:

1. **Swift**ness of the diagnosis process
2. **Validation** of concerns by primary care providers
3. Excellent **patient-provider communication**
4. Effective **provider-provider communication**
5. Better **information**
6. Integrated **psychosocial support**
7. **Coordinated and managed care**



To best support people with cancer and their families—from the moment they start wondering if they have cancer to post-treatment care—it is essential to treat them as individuals with a reality that extends beyond being a cancer patient. A health care system guided by a person-centred approach recognizes this and establishes a partnership among everyone involved—health care providers, patients and loved ones.

(CPAC, 2018).

Attainment of these outcomes resulted in a more satisfactory diagnosis experience, while failing to attain any one of these outcomes had a negative, and oftentimes detrimental, impact.

Three Phases of Diagnosis

Irrespective of cancer type, stage of disease or social determinants of health, those who had traversed the diagnosis trajectory described the process as taking place in three distinct phases:

Early phase: the period from when a person first tries to contact or interacts with a health care provider over a suspicion of cancer until the first referral to a diagnostic facility for testing

Middle phase: the period during which a person undergoes diagnostic testing to investigate a suspicion of cancer

Final phase: the period from when a person arrives at a dedicated cancer facility to the time they receive their cancer diagnosis

When preparing this report, we found this distinction helpful. Certain desired outcomes, while consistent throughout the diagnosis process, mattered more or less depending on which phase of the process a person was in. We also found that satisfaction with the diagnosis experience differed markedly by phase, with most people finding the early phase to be the most challenging and the final phase to be quite a bit smoother. Throughout this report, the terms early, middle and final phase

of diagnosis are used both to highlight gaps and inefficiencies at key points across the diagnosis journey and to help in the formulation of targeted recommendations.

Quality Indicators

There is an abundance of literature concerned with the quality of cancer care and the outcomes that one would expect to see in a high-quality cancer care system. The most comprehensive quality index in Canada, the Canadian Cancer Quality Index, is compiled by the Cancer Quality Council of Ontario and is devoted to measuring six quality domains in the post-diagnosis phase (i.e., Effective, Efficient, Equitable, Timely, Safe and Person-Centred) and at various points along the post-diagnosis cancer continuum. The Canadian Cancer Quality Index includes multiple indicators within each quality domain and the Council reports on select indicators in their annual performance report.

Considerably much less work has been done to measure quality in the *diagnosis* phase of cancer care. Our review of the literature found that wait times, patient satisfaction (an aspect of the patient experience) and stage of diagnosis, are the three most common indicators used to assess quality in the diagnosis phase.

1. Wait Times

Wait time refers to the time it takes for a patient to wait for a diagnostic test defined as the time from which the patient is ready for the procedure to the time the patient receives the service they are waiting for (Western Health, 2020). Wait time indicators use 'time-to' or 'time-from' variables assigned to specific milestones along the diagnosis pathway and are usually measured in median number of days. Wait time data is relatively easy to collect and the extent to which target wait times are met is a good indicator of a coordinated, efficient, and thus swift, diagnosis process.

Wait time indicators specific to a diagnostic milestone include:

- Time from symptom/suspicion to definitive diagnosis
- Time from abnormal screening/specialist referral to definitive diagnosis
- Time from symptom to provider evaluation
- Time from screening test to diagnostic resolution
- Time from diagnostic confirmation to patient notification

Extensive wait times have been found to induce worry and anxiety among patients, not only worsening the patient experience but also influencing patient outcomes for certain types of cancer (Neal, 2015). Wait time targets, therefore, are commonly used to specify the desired level of performance the system wants to ensure.

In Canada, there are no national established wait time targets for cancer diagnosis² but target wait times have been established by a number of jurisdictions and for various types of cancer.

In Ontario, the Ontario Wait Time Strategy³, initiated in 2004 by the province's Ministry of Health and Long-Term Care, was one of the first in Canada to include a target wait time for the period from the first cancer-related consult to the time of diagnosis. It was recommended that the wait time for 90% of all cancer surgeries be less than or equal to 14 days from consult to decision-to-treat (CCO, Target Wait Times for Cancer Surgery in Ontario, 2006). More commonly, within jurisdictions, wait time targets have been broken down by milestones along the cancer-specific diagnosis pathway as shown in Table 1.

² There are Canadian timeliness targets for certain types of cancers. For breast cancer, for example, the current Canadian timeliness targets recommend that 90% of patients should have abnormal screening results resolved within 5 weeks (if not tissue biopsy is required) or within 7 weeks (if a tissue biopsy is required). There is no explicit Canadian target for symptomatic patients (L. Jiang, Is being diagnosed at a dedicated breast assessment unit associated with a reduction in the time to diagnosis for symptomatic breast cancer patients?, 2018)

³ In November 2004, Ontario's Ministry of Health and Long-Term Care (the Ministry) announced Ontario's Wait Time Strategy. The strategy was designed to reduce wait times by December 2006 by improving access to healthcare services for adult Ontarians in five areas: cancer surgery, selected cardiac procedures, cataract surgery, hip and knee total joint replacements, and magnetic resonance imaging (MRI) and computed tomography (CT) scans.

Table 1. Target wait times by jurisdiction and cancer type

Indicator	Jurisdiction	Target Wait Time
All Cancers		
Referral from primary care – to - first specialist appointment	Ontario	14 days
Referral date – to - first available appointment for PET/CT scan	Ontario	10 days
Surgery – to - receipt of pathology report	Ontario	14 days
Breast Cancer		
Date of abnormal screening report or presentation of symptoms – to- date of final diagnosis	British Columbia	21 days
Visit to primary care – to - referral to specialist care	Manitoba	24 hours
Referral from primary care - to -first specialist appointment	Manitoba	14 days
Diagnostic mammogram/Ultrasound ordered – to – date of test	Manitoba	7 days
Mammogram/Ultrasound – to - Biopsy	Manitoba	7 days
Biopsy – to - pathology sign-off and reported	Manitoba	7 days
Lung Cancer		
Referral to DAP – to - diagnosis	Ontario	28 days
Primary care visit – to - primary care orders CT scan	Manitoba	1 day
CT scan ordered – to - CT scan complete	Manitoba	7 days
Referral or CT scan – to - diagnostic visit with specialist	Manitoba	10 days
Diagnostic visit – to - diagnostic procedures and pathology report back to specialist	Manitoba	14 days
Diagnostic procedures and pathology report – to - follow-up appointment with diagnostic specialist	Manitoba	4 days
Colon or Rectal Cancer		
Visit to primary care to referral to specialist care	Manitoba	24 hours
Referral received – to - endoscopy	Manitoba	13 days
Endoscopy – to - pathology sign-off and reporting	Manitoba	7 days

The [Quebec government report card](#) on the performance of the provincial cancer program, although limited in scope in that the report card mostly looks at wait times

for surgery and radiotherapy as well as some screening programs and cancer investigation procedures, is interesting insofar as it hones in on precise indicators related to selected cancers and publicly reports annually on provincial cancer program performance for these types of cancer. By presenting/explaining the indicators, and providing a detailed account of the results obtained across Quebec (data are presented by administrative region), the report card offers one example of a quantitative approach to evaluating and reporting on efficiency in the diagnosis phase. The report card also highlights some of the challenges related to collecting data which is instructive for other jurisdictions (Quebec, 2019).

While it was difficult for us to contribute to this body of work using our patient interview findings due to the varied experiences among patients and the subjective nature of the data, the interview findings did reinforce that the establishment of wait time indicators is needed and will help to attain one of the people, namely swiftness of diagnosis.

2. Clinical Outcome Measures

Stage of cancer at diagnosis and overall survival rates are both important indicators to assess diagnosis quality and there is an abundance of literature that examines the correlations between stage of cancer at diagnosis and wait times, stage of cancer at diagnosis and ethnicity, stage of cancer at diagnosis and socioeconomic status, and so on. Attributing stage of cancer at diagnosis and survival rates to an assessment of quality in the diagnosis phase of cancer care, however, is complicated. Certain types of cancers, for example, are asymptomatic until very late stage and so entry into the cancer care system is typically delayed. Further, individual factors outside of the control of the health care system (i.e., the health seeking behaviour and awareness of individuals) have been found to delay presentation.

3. PROMs and PREMs

There is an increasing body of literature dedicated to measuring patient-reported outcomes and patient-reported experiences. While the measurement of health status, quality of life and patient experience is not new, the advent of PROMs (patient-reported outcome measures) and PREMs (patient-reported experience measures) has brought the importance of adequately and accurately measuring patient reported outcomes and the patient experience into the forefront of cancer care.

PROMs and PREMs commonly take the form of self-reported questionnaires and examine the patient's health status, quality of life and impact of the process of care on various aspects of the patient's experiences, (e.g., communication, timeliness of assistance), throughout the trajectory of care. PREMs questionnaires, in particular, differ from the more familiar patient satisfaction surveys in that they report on the complexity of patient experiences, as opposed to reporting just subjective views (i.e., how well a patient liked their health care provider). Both PROMs and PREMs provide excellent insight into the quality of the care process during an intervention (Kingsley, 2016). However, the majority of work around PROMs and PREMs is currently concerned with the post-diagnosis period in cancer care; little to no literature was found discussing PROMs or PREMs in relation to the cancer *diagnosis* period. While there are a number of commonly used tools in Canada to measure aspects of the patient experience during



PROMs, patient-reported outcome measures, allow the efficacy of a clinical intervention to be measured from the patients' perspective while also allowing for the measurement of a patient's perceptions of their general health or their health in relation to a specific disease and are used to assess a patient's health status and quality of life during illness or while treating a condition such as cancer (Kingsley, 2016).

PREMs, patient-reported experience measures, allow the patient experience, defined as "the sum of an individual's perception, expectations and interactions related to their health and care throughout their cancer journey" (CPAC, 2018) to be measured from the patients' perspective.

the diagnosis phase, these typically continue to be limited to subjective measures of patient satisfaction alone, highlighting a significant gap in our ability to adequately measure the complexity of the patient experience throughout the diagnosis journey. Indeed, while 47% of providers surveyed believed benchmarks/targets and measuring performance against those benchmarks to be essential for a quality diagnosis process, only 19% reported having used benchmarks/targets in their practice.

PREMs offer an excellent measure of the quality of the diagnosis phase of cancer care and with an increasing focus on person-centred care over the past decade, attention to measuring PREMs is of the utmost importance. Throughout this report we utilize what we have gleaned from our patient interviews to begin the development of a collection of diagnosis PROMs and PREMs. Aligned with the seven desired outcomes, these measures are common to all cancer types, stage of disease and social determinants of health and can therefore be used to benchmark and compare the patient experience across cancer populations and jurisdictions. While these measures are admittedly a cursory start, they represent the beginnings of a quality framework for cancer diagnosis in Canada much like those which have been developed for the post-diagnosis phase of cancer care.⁴ Once this framework is fleshed out, tools can be developed to measure the patient experience in the diagnosis phase much like those which measure patient-reported experience in the post-diagnosis phase.

⁴ Numerous patient experience frameworks have been created to measure quality in the treatment phase of cancer care including: Health Quality Ontario's Patient Engagement Framework; Warwick Patient Experiences Framework; and, NHS Patient Experience Framework.



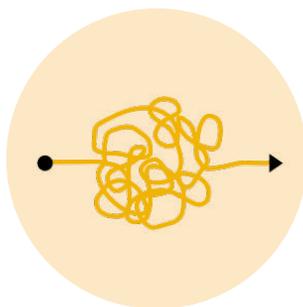
Outcomes

Outcome #1: Swift Diagnosis

Eliminating unnecessary delays in the cancer diagnosis process will positively impact a person's mental health and wellbeing and may improve health outcomes.

People undergoing investigation for a suspicion of cancer often do so under great personal stress. The impending possibility of a cancer diagnosis is accompanied by feelings of fear, exhaustion and uncertainty about one's future. Further, a swift diagnosis and thus early detection and treatment has been correlated with improved health outcomes for certain types of cancer (Hawkes, 2019), (Hanna, 2020), (CBoC, 2021).

While periods of waiting are inevitable throughout the diagnosis process as pathology reports are read and decisions about next steps made, unnecessary delays are unacceptable and take an immense toll on a person's mental health and wellbeing. Indeed, waiting for test results and encountering unnecessary delays in the diagnosis process were considered by many of the people in our study to be one of the most stressful parts of the cancer journey.



Current Inefficiencies

Through this environmental scan we learned that unnecessary delays abound throughout the current diagnosis process diminishing the realization of a swift diagnosis for patients. We learned at which points in the diagnosis process delays occur most often, the reasons for delays throughout the process, and the detrimental impact of these delays on both patients and providers. Current inefficiencies impacting swiftness of diagnosis are discussed below by phase of diagnosis.

As people cycle among primary care providers and allied health professionals in the early phase of diagnosis, delays of months or even years occur as people seek validation of their symptoms and subsequent referral. Delays are further compounded by unnecessary re-work due to referrals which 'fall through the cracks', necessitating that a person cycle back to the referring doctor for a re-referral.

As people progress along the diagnostic pathway during the middle phase of diagnosis, waiting is the norm -- waiting to be scheduled for an appointment, waiting in waiting rooms, and waiting for test results. For the most part, waiting is accepted by people as a normal part of the diagnosis process. At least for people in our study, this was not found to be terribly excessive. People did say, however, that waiting to find out what test results revealed was one of the most stressful parts of the cancer journey.



"Getting results quickly may not have much impact in terms of survival but I think in terms of quality of life and the diagnosis experience it's very important".

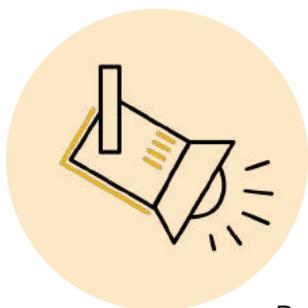
Female, 67, breast cancer survivor



Opportunities for Improvement

Rapid referral for diagnostic testing upon presentation of symptoms to a primary care provider expedites early diagnosis and has been found to have a positive impact on a patient's emotional wellbeing (Kate Absolom, 2011). Eight-four percent of providers surveyed believed rapid referral pathways that provide urgent access to diagnostic services were essential for a quality diagnosis process yet only 39% reported using rapid referral pathways.

Diagnostic centres, laboratories and technologies are in a position to fast-track early diagnosis if services are available and if providers within these facilities move quickly to interpret and communicate test results. Seventy-two percent of providers surveyed believed optimized roles for diagnostic centres, laboratories and technologies in fast-tracking early diagnosis was essential for a quality diagnosis process.



Practice Spotlights

Delays in the diagnosis process can be caused by numerous factors and are therefore remedied in a variety of ways.

Remediation strategies are discussed throughout this report according to the outcome to which it is most pertinent, and which, if addressed, will also serve to reduce delays in diagnosis. In this section, therefore, we highlight only those few practices found through our environmental scan which are designed to address delays associated with resource limitations.

An extensive **Primary Care Provider Support program in Quebec City** in the context of its breast cancer screening program entitled *Programme québécois de dépistage du cancer du sein (PQDCS)* involves a bank of doctors or nurse practitioners who sign up on a volunteer basis to assist patients who do not have a primary care provider. These volunteer health-care providers can then be called upon to prescribe diagnostic testing and to receive and review results in the case of an abnormal mammogram result obtained through the provincial breast cancer screening program. Though interesting, it does not appear that this program has been evaluated (Liens avec les médecins, 2020).

Specialized Nurse Practitioners (SPNs) in Quebec provide supplementary nursing and medical care that meets the needs of complex patients including the ordering of diagnostic examinations and medical treatment. SPNs support people in the diagnosis and management of disease, including cancer, and are situated in hospitals or in specialized oncology outpatient clinics (Specialized Nurse Practitioner, 2020).

Telepathology – or, ‘pathology at a distance’, uses telecommunications technology (i.e., computer software), to facilitate the transfer of pathology data between distant locations for the purposes of diagnosis (and research). Telepathology eliminates the need for patient travel to access care while helping pathologists do their job faster and more accurately. As of 2014, **Ontario** successfully realized the implementation of a telepathology network that connected northern sites to urban centres within the province. Building on the Ontario experience, the Multi-Jurisdictional Telepathology Project began in 2015, representing the first phase in the development of a Pan-Canadian Digital Pathology Network beginning across the provinces of **Newfoundland and Labrador and Manitoba** (Information, 2015). A multi-site laboratory, OPTILAB Montreal-CUSM supports 15 laboratories in **Quebec** spanning the territory from Montreal to Abitibi and plays a pivotal role in providing diagnostic support to several healthcare establishments, ranging from large academic health centres to smaller rural ones. The network is capable of connecting rural communities to pathologists located hundreds of kilometres away (McGill Publications, 2020).

A **telehealth clinic** was established in rural **Saskatchewan** for patients with a suspicion of lung cancer who live outside of large medical centres and so must travel long distances to be assessed by a lung cancer specialist. Patients are assessed at their nearest health centre by a nurse-clinician operating remotely in Saskatoon. The nurse-clinician reviews all cases with a respirologist before a diagnostic plan is initiated. Evaluation of the telehealth clinic reported high patient satisfaction levels and improved access to care -- a total travel distance saved by attending a telehealth visit per patient was 344 km and the mean wait time for assessment in the telehealth clinic was 6.8 days (D. Demchenko, 2015).



Benchmarks/Indicators of Success

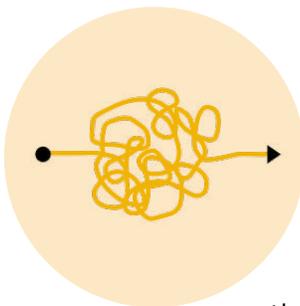
Swift diagnosis is one of our seven identified outcomes to attain if we are to have a quality cancer diagnosis process in Canada. Quality indicators associated with successful attainment of this outcome primarily involve:

- A. **Achievement of target wait times for diagnostic milestones** (e.g., referral for testing within x days; receipt of test results within x days; diagnosis received within x days of contacting or interacting with a health care provider over a suspicion of cancer)
- B. **Comparable wait times within jurisdictions**, irrespective of geography.

Outcome #2: Validation by primary care providers

Primary care providers need to take patient concerns seriously and initiate appropriate referrals.

People who first notice unusual and concerning symptoms, often indicative of a certain type of cancer, typically present first to a primary care provider (e.g., family physician) or to a hospital emergency room, or at times to an allied health professional (e.g., chiropractor, naturopath, physiotherapist). These providers, therefore, perform a critical role in the early phase of the cancer diagnosis process as they represent the first point of entry into the cancer care system for the majority of people. Validation of a patient's concerns by primary care providers is a critical first step toward initiating the diagnosis process.



Current Inefficiencies

For many people, the visit to the family physician to discuss concerning symptoms is not an affirming one. People in our study reported that their physician tended to minimize or dismiss their symptoms leaving them without answers or, in some cases, an inaccurate diagnosis accompanied by inappropriate prescribing of medications. Some people went on to visit an allied health professional to seek answers only to find the usual course of action was to be sent back to the family physician (with intermittent presentation at the ER as symptoms worsened).



"I showed the mole to my family doctor and he was like, it's not worrisome. I brought it up to a naturopath, same response. Went to a walk-in to get a referral to a dermatologist and even that doctor said no rush. So now here we are a year and a half later..."

Male, 43, stage 4 melanoma survivor

A lack of provider education and knowledge about cancer types and symptoms is delaying initiation of appropriate symptom investigation for many Canadians. All too often people interviewed who presented to a primary care provider with symptoms suspicious of cancer found that their concerns were minimized or even dismissed altogether. Coupled with a foreboding feeling about what may be happening to them, people either take it upon themselves to self-advocate and demand answers or, for those who are less willing or able to assert themselves, let things slide until symptoms become unbearable.

The early phase of diagnosis for many is characterized by multiple and repeat visits to primary care providers, unnecessary strain and costs to the health care system, delays in appropriate testing (possibly leading to poorer health outcomes) and personal worry about advancing illness. A recent study of lung cancer patients in Montreal, Quebec found that 29% of patients saw their family physician three times or more before being referred for investigation and 41% had visited the ER on at least one occasion (Satya Rashi Khare, 2021).

Cycling among primary care providers in the early phase of diagnosis can go on for months or even years as symptoms are continually dismissed or misdiagnosed. Poor communication between providers only serves to exacerbate delays and mistakes as each different provider hears only a snippet of a person's story.



“After I was diagnosed my wife took my pain meds back to the pharmacy to dispose of. They looked in the bag and said ‘your husband was given all of these different drugs over a period of two months? This is unbelievable’. They were shocked. They just dispense it right on doctor’s orders. They never did any analysis of what I was taking.”

Male 52, stage 4 myeloma survivor

The need to self-advocate to have one’s concerns heard and symptoms to be taken seriously enough to warrant investigation is unkind and exhausting for people who are coping with the looming threat of being diagnosed with a serious illness. When they looked back on this phase of their cancer journey, people in our study expressed anger at the mistakes made and the lack of accountability of the health care system; those in the later stages of cancer progression wondered if the delays due to provider error had resulted in poor health outcomes. That the anger and frustration is largely directed toward the family physician stems from the understanding that the family physician plays a pivotal role for patient entry into Canada’s health care systems.



“Front line providers are the ones who need to set the ball rolling for diagnosis. The way the system works you can’t go see a specialist without a referral from a GP. After the patient, they are number one in the diagnosis process”.

Female 39, breast cancer survivor

An apparent lack of family physician knowledge about different cancer types and their symptoms was deemed to be the culprit that led to delayed investigation according to those who were interviewed.

Validation of cancer concerns and symptoms by primary care providers differs by cancer type. Our study included people who had been diagnosed with breast, prostate, colorectal, lung, melanoma or blood type of cancer. We found that for people who had symptoms consistent with the latter four types of cancer (i.e., colorectal, lung, melanoma, blood), having one's concerns validated by a primary care provider was just that much more difficult even with the existence of standardized screening practices (i.e. colorectal cancer). In general, primary care providers appear to lack adequate knowledge of these types of cancers and there appears to be inadequate support of primary care providers to enhance their knowledge. People in our study rightly observed that 'there are standardized screening practices for breast, cervical, colorectal and prostate cancer, but not for other cancers like lung or melanoma'. For cancers that have established screening guidelines, the health care system was considered to be 'proactive' whereas for other cancers patients found the system to be disappointingly 'reactive'.



"Having gone through two types of cancer you can see the difference. Breast cancer is so smooth, like you get on the train and they tell you when to get off. There's a very prescribed procedure and its similar for all women... you have a lump, a, b, c, d is going to happen. With melanoma it's very different. Melanoma is so rare and not well understood and so there is a lot of uncertainty and that's reflected in the diagnosis experience. It's just not as streamlined.

Female 59, breast and melanoma cancer survivor

Validation of cancer concerns and symptoms by primary care providers also differs by age in that people's symptoms tend to be dismissed by primary care providers if the person does not fit the age profile for the type of cancer in question.



“Doctors have their knowledge and history of what they’ve seen. But they can’t rule out the random times or the anomalies. My GP really learned to take things seriously based on me being twenty-eight when I was diagnosed with breast cancer. Specialists tend to go with data and percentages. We need to ask the medical professionals to widen their scope on what is normal, especially for young people.”

Female 28, breast cancer survivor

The result is that many young people tend to get ‘stuck’ in the very early phase of cancer diagnosis and have to self-advocate hard to get their primary care provider(s) to initiate the appropriate testing. Many of the young people in our study who had been diagnosed at a later stage certainly questioned, and some emphatically believed, that the delay they experienced in the early phase of diagnosis had resulted in them being diagnosed at a later stage than would otherwise have been the case.



“The biggest thing I’ve heard in all of this is you’re young, you’re fine. I was twenty-nine when I got diagnosed. If people keep brushing it off, we’re going to miss a ton of stuff. That age discrimination and the lack of awareness from the doctors...that could be the difference between saving someone’s life or not”.

Female 30, melanoma survivor



Opportunities for Improvement

In order to recognize, and thus validate, a patient’s suspicion of cancer and initiate appropriate referral, providers must be supported with adequate knowledge of different cancer types and their symptoms and be clear about the associated diagnostic pathway.

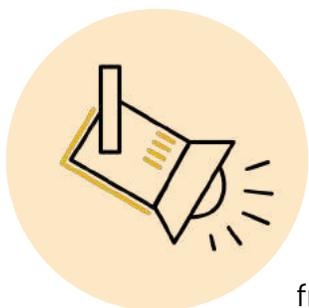
Both patients and providers consulted through this environmental scan asserted that optimizing the role of primary care providers as the first point of entry to the cancer care system is paramount. Indeed, 59% of providers surveyed believed optimized roles for primary care providers as the first point of entry to early diagnosis was essential for a quality diagnosis process.

Optimizing the role of primary care providers can be accomplished by supplementing post-secondary **programs to educate providers about cancer types, symptoms and diagnostic pathways** and through ongoing training for new and currently practicing providers. Providers themselves welcomed efforts to increase their knowledge; 59% of providers surveyed believed supports for primary care providers to inform them about cancer symptoms and the diagnosis process were essential for a quality diagnosis process yet only 7% reported using such supports. Optimizing the role of primary care providers is also accomplished through **supports to help primary care**

providers arrive at risk-informed decisions. Forty-seven percent of providers surveyed believed decision supports using technology (e.g., electronic cancer clinical decision support/risk assessment tools) were essential for a quality diagnosis process yet again, only 7% reported using such supports.

The focus of any efforts to optimize the role of the primary care provider should encompass primary care providers in clinics, community and hospitals settings and should extend to allied health professionals given that these providers unknowingly touch people's lives in different ways during the early phase of cancer diagnosis. Reducing fragmentation among providers by **enhancing provider-provider communication** helps to familiarize all providers with a patient's symptoms and symptom history and thereby lead to earlier initiation of an appropriate diagnosis pathway.

Finally, patient groups can do much to support a patient during all phases of diagnosis to lessen the burden of the patient having to self-advocate to obtain the care they deserve.



Practice Spotlights

Seizing opportunities to help primary care providers validate patient's cancer-related concerns does not require that we start from scratch. Quite the contrary, our environmental scan uncovered a few exemplary practices currently underway in Canada designed to fill the knowledge gap among providers. These practices are profiled below.

Standardized Care Pathways, also known as clinical pathways, integrated care pathways, care pathways or pathway maps, are a management tool for patient care during a specific phase of the cancer experience. Standardized care pathways are grounded in evidence-based best practices and constitute a tool for health care providers and administrators to facilitate mutual decision making and organization of care for cancer patients. Standardized care pathways are typically initiated following suspicious presentation of symptoms or detection of abnormalities via screening,

imaging or other procedures. Within the care pathways, the different tasks to be completed by the providers involved in the patient's care are defined, optimized and sequenced. Care pathways are specific to one type of cancer, are often represented as a visual process map, and often include target wait times for milestones along the care pathway to facilitate a swift diagnosis. Care pathways are usually organized by phase across the cancer care continuum, from screening to diagnosis and treatment.

Standardized care pathways that address the diagnosis process for different types of cancer have been implemented by a number of jurisdictions in Canada in an effort to fast-track the process and decrease wait times. While a complete catalogue of all care pathways currently in use in Canada was beyond the scope of our environmental scan, two examples from Manitoba and Ontario for which we were able to obtain detailed information are described below.

The **Manitoba IN SIXTY Initiative**, established in 2011 by the government of Manitoba, aims to ensure that patients with cancer go from suspicion to first treatment within 60 days -- the 60-day period defined as the date of the patient visit when a health care provider suspects cancer and thus initiates diagnostic testing or specialist referral up to the date of diagnosis. The start point can also include the date of an abnormal result from a screening test at a cancer screening program.

Determination of timelines along the care pathway was established by researching the provincial cancer registry and working backwards from diagnosis to determine the first point of suspicion. Using this information, an algorithm was built to establish milestones in the patient pathway. The analysis was undertaken by clinical advisors and for different types of cancers (P. Skrabek, 2015). To date, seven disease-site specific diagnostic and treatment care pathways with target timelines for milestones have been developed for breast, colon/rectal, haematology, lung, lymphoma, neck, and prostate cancer. Diagnosis pathways include a 60-day timeline model with target wait days for each milestone (visits, tests, procedures) along the diagnostic journey.

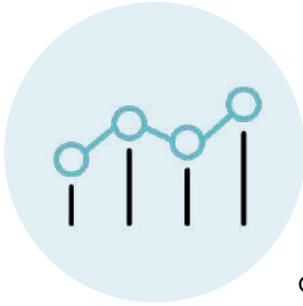
The care pathways include supporting information (emergency numbers, patient navigation and support services, information helpline), and communication guidelines for clinicians. The pathways are subject to rigorous and ongoing process improvement using value-stream mapping (a quality improvement tool) to represent the materials, work, patient and information flow and the queue time between

diagnosis processes. An electronic patient tracking system integrates systems and enables information sharing; patient's movements are monitored as they progress through the pathway to ensure that they are prioritized in order to meet wait time targets. The system monitors and reports patient progress compared to the expected pathway and variations from an expected path are identified, improved, optimized and stabilized with the end goal of ensuring an optimal patient experience.

Consistent with value stream mapping, key indicators used to drive the value stream include: wait time, cycle time and turn-around-time (TAT) (see footnote for indicator definitions).⁵

In Ontario, **Cancer Care Ontario pathway maps** have been developed for the management of patients with different types of cancer (e.g., breast, lung, colorectal, prostate, endometrial, oropharyngeal, thyroid, bladder, melanoma). Development is an iterative process that involves the participation of multidisciplinary groups including a clinical working group of disease-specific experts with regional and specialty representation, and various internal and external stakeholders. Pathway maps incorporate evidence from local, national and international clinical practice guidelines. Where evidence is insufficient, expert opinion from the working group is used to inform pathway map development. The pathway maps provide a high-level overview of the care that a typical cancer patient in Ontario should receive. They are organized by cancer type and phase of the cancer continuum (e.g., screening, diagnosis, treatment). The pathway maps are thoroughly reviewed internally and externally before being published. Formal reviews and updates of the pathway maps occur annually. Unfortunately, we were not able to find any literature describing how these pathway maps are currently being used in practice nor did we find any literature reporting on evaluation of these pathway maps (CCO, 2020).

⁵ Wait time – identified as one of 8 wastes by Quality Improvement specialists – wait time can be found both before and after a workstation, but also while the product is situated within the workstation; Cycle time - the time spent actually working (adding value) on the service; Turn-around-time (TAT) - the amount of time taken to complete a process or fulfill a request.



Benchmarks/Indicators of Success

Validation of patient concerns by primary care providers is one of our seven identified outcomes to attain if we are to have a quality cancer diagnosis process in Canada. Quality indicators associated with successful attainment of this outcome include:

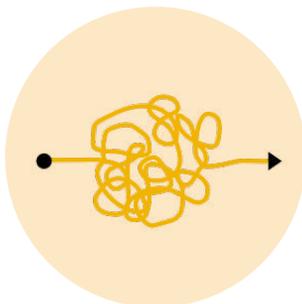
- A. Person perceives that **primary care provider validates their concerns**
- B. **Providers have knowledge** of different cancers, their symptoms and their diagnosis pathways
- C. **Referral for symptom investigation is appropriate**
- D. **All primary care providers and allied health professionals are aware of the person's symptoms and diagnosis trajectory**

Outcome #3: Excellent patient-provider communication

Providers and patients need to communicate effectively throughout the process of symptom investigation so that patients stay informed, remain in control and feel cared for.

Excellent communication between patients and providers is fundamental to a quality diagnosis experience. Excellent communication serves to keep the patient informed and able to ask questions and get answers, enables the patient to have a sense of control over what is happening to them, and allows the patient to feel like a human being who is facing a possible life altering illness, rather than 'just another cancer patient'.

At the time of communication of the cancer diagnosis, what mattered most to people was that the news was communicated in a compassionate and caring manner, that they were given the opportunity to ask questions and get answers, and that the treatment trajectory was explained. Simply put, excellent patient-provider communication, particularly in the middle and final phases of diagnosis, means that the patient knows why each test is being done, what the test results mean and what to expect next as they traverse a complex and disjointed cancer care system.



Current Inefficiencies

In our current state, communication challenges abound between providers and patients as people struggle to navigate a complex web of diagnostic facilities and providers while striving to be treated with the compassion and humanity they need to help them cope with what they are facing. Poor patient-provider communication not only leads to

confusion for the patient about the diagnosis process and what the tests and results mean, it can also have a detrimental effect on a person's mental health and wellbeing.



"We just had to have a brief discussion with the doctor about providing a letter for Employment Insurance. It was nothing. But then at the end of the discussion he tacked on that 'you should probably spend as much time with your child as you can'. Why would he say that? I'm telling you sometimes when we see this oncologist it feels like psychological terror".

Male 43, stage 4 melanoma survivor

The way a provider communicates with a patient may also impact health outcomes.



"Some doctors at the time of diagnosis give you hope. And some doctors take that away. And that caring contributes to how well you battle the disease".

Male 41, melanoma cancer survivor

Communication of a cancer diagnosis is usually given by an oncologist, a specialist or in some cases, a family physician. What matters most during the conversation is not *who* is delivering the news but rather, a) that the provider communicates the diagnosis in a compassionate and caring manner; b) that the patient is given the opportunity to ask questions and get answers; and, c) that next steps are explained.

Sadly, these needs are not always met and people are often left feeling afraid and 'in the dark'.



"The doctor came into the room and showed us a polaroid picture and told my husband that he has cancer. It was a shock to see that picture. And it said rectal cancer on it. And then she left and left the picture with us. For the doctor it's an everyday thing but for us it's a shock. My intuition is that my husband will die soon".

Caregiver for husband 54, colorectal cancer survivor

Providers surveyed recognized poor communication with patients as a serious shortcoming with 50% ranking patient-provider communication challenges among the top five inefficiencies in the cancer diagnosis process.



Opportunities for Improvement

Fortunately, excellent communication skills can be learned. Effective communication requires time -- to be able to have a proper conversation that allows for all questions to be asked and answered -- and requires that the provider use compassionate language and behaviour that demonstrates genuine caring and concern, which people understandably interpret to mean that they are getting the best care possible. From our interviews, for example, we learned that physically sitting down with a person to deliver the news was taken as an indication that the provider was going to dedicate time to the conversation; using words that were understandable when communicating test results was considered to be a sign of respect, and physical

touch (e.g., pat on the back, hand on shoulder) was appreciated as a demonstration of caring. Whether the encounter occurs in person, virtually or over the telephone, telling the patient what the next step will be and asking if they have any questions before ending the conversation is critical to excellent communication.

One of the current strengths in our diagnosis systems, and one that is best leveraged, is the behaviour of technicians and support staff within diagnostic facilities. We found that, from the patient's perspective, these people were most adept at responding effectively to a person with the compassion and caring they deserved. In contrast to doctors, these providers reportedly offered the person 'humanity when they needed it' and demonstrated through words and actions that they understood what an emotional and taxing experience the diagnosis process is.

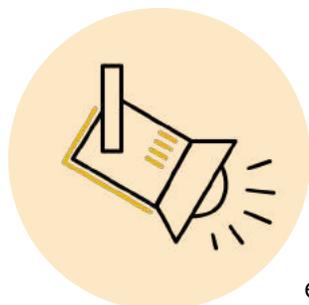


"The specialist just bustled in, said this looks like it could be cancer, you need to go for a biopsy, and then left. This was one of the most emotional moments in my life and I couldn't even tell you what he looked like. The tech was like, can I get you some water? Can I hug you? It was like humanity when I needed it. I get they're busy and time is tight but I just didn't feel taken care of by the doctors; I felt taken care of by the staff".

Female 40, breast cancer survivor

Another opportunity for improvement lies with technology. Online portals that give patients access to health information can support shared decision-making between patients and providers. While 44% of providers surveyed believed online portals to be essential for a quality diagnosis process only 16% reported having used them.

Additional opportunities for improvement, identified through our literature review, are profiled in the section below.



Practice Spotlights

Training and guidebooks to enhance communication skills are plentiful in almost all sectors where effective communication is essential to optimal performance or care. Our environmental scan uncovered a number of resources and tools being used by regional health authorities and provincial cancer agencies to enhance communication between patients and providers throughout the cancer journey. Two such practices, highlighted because they are designed specifically to enhance the appropriateness of communication of a cancer diagnosis, are described below.

Nova Scotia has developed a pre-diagnostic resource for providers entitled ***Guidelines for the Investigation of Patients with Symptoms Suggestive of [colorectal, lung] Cancer***. The resource is unique in that it is dedicated specifically to the diagnosis phase of care and includes not only an initial presentation algorithm, as other care pathways do, but also guidelines for enhancing the patient experience including a set of provider-patient communication guidelines. The resource is intended for family physicians, nurse practitioners, registered nurses, emergency department physicians, general internists, general surgeons, gastroenterologists and radiologists (NSHA, 2020).

The **Nova Scotia** Health Authority has developed the ***Serious Illness Conversation Guide*** which consists of a set of resources and tools designed to trigger conversations about serious illness. The primary goal of these tools is to assist with communication regarding care preferences between health care providers, patients and their families shortly after diagnosis of a serious illness and as illness progresses (NSHA, Library Services, 2020).



Benchmarks/Indicators of Success

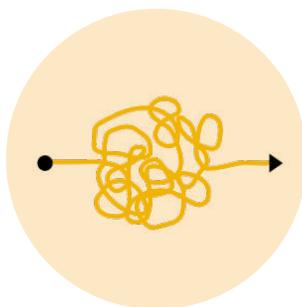
Effective patient-provider communication is one of our seven identified outcomes to attain if we are to have a quality cancer diagnosis process in Canada. Quality indicators associated with successful attainment of this outcome include:

- A. **Patient feels confident they understand all the information** providers tell them
- B. **Patient feels confident they understand their test results** and the implications of their test results
- C. **Patient always knows what the next steps in the diagnosis process are**
- D. **Providers possess skills to discuss serious illness with a patient**
- E. **Patient always knows how to reach their provider** if they have any questions

Outcome #4: Effective provider-provider communication

To ensure continuity of care in a discontinuous diagnosis system, providers must communicate effectively if they are to stay abreast of a patient's diagnosis trajectory and make informed and timely decisions about their care.

In Canada, provincial and even regional cancer systems are disjointed at best, this discontinuity being particularly rampant in the diagnosis stretch of the cancer care continuum. Throughout the diagnosis process people typically visit multiple facilities for various diagnostic tests and see a barrage of health care providers, most reporting encounters with three to five providers on average. To ensure that care is continuous, providers must communicate with one another in a timely and comprehensive manner so that all providers remain informed about a patient's diagnosis trajectory and can make informed and appropriate decisions about next steps.



Current Inefficiencies

Poor provider-provider communication abounds in current jurisdictional and regional diagnosis systems. In our study, patients and providers alike relayed many instances of poor provider-provider communication.



“One person at this facility is telling you that you need a biopsy and someone else at this other facility is saying you don’t...how can this be urgent and necessary in one clinic but not in another?”

Female 38, breast cancer survivor

The negative repercussions for patient care arising from poor provider-provider communication are many including:

- Missing or overlooked test results leading to repeat testing and delays
- Lack of awareness of prior diagnostic history leading to inappropriate or repeat testing
- Misdiagnosis
- Conflicting opinions among providers about what tests need to be performed
- Conflicting information to the patient about what tests need to be performed
- Cancelled tests due to conflicting opinions about what tests are required
- Cancelled tests due to scheduling confusion causing delays in diagnosis
- Confusion for the patient about next steps in the diagnosis pathway
- Distrust in providers and the diagnosis system
- Lack of timely follow-up and delayed diagnosis

Inevitably, the inefficiencies and gaps experienced by people due to poor provider-provider communication leads to a general distrust in the health care system.



“Meeting new providers when you already distrust the system makes you always worry, okay, is this one that’s going to fuck up and kill me?”

Female 52, breast cancer survivor

Providers themselves were frustrated by the broken chains of communication and used inefficient measures to try to manage it themselves, oftentimes spending time on the phone with their colleagues to clarify information and expedite procedures.



Opportunities for Improvement

Perhaps one of the best ways to achieve effective communication among providers within our disjointed diagnosis systems is through electronic means. Technology of course has been found in so many ways to be a huge contributor to addressing system inefficiencies and here too, technology can improve these shortcomings. Indeed, 50% of providers surveyed believed technology was needed to support information sharing between providers. Providers believed technology, such as a smartphone app that could facilitate the sharing of a patient’s diagnostic information, to be essential for continuity of care yet only 10% of providers reported using such technology. Technology, therefore, represents a real but untapped opportunity for remedying inefficient provider-provider communication in our current diagnosis systems



Benchmarks/Indicators of Success

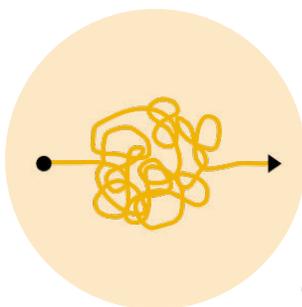
Effective provider-provider communication is one of our seven identified outcomes to attain if we are to have a quality cancer diagnosis process in Canada. Quality indicators associated with successful attainment of this outcome include:

- A. **Reduced re-work/re-referrals/rescheduling**
- B. Unnecessary **repeat testing eliminated**
- C. **Misdiagnosis avoided**
- D. **Clarity about the diagnostic trajectory** among providers and patients
- E. **Trust in providers** and the diagnosis system
- F. **Timely follow-up and swift diagnosis**
- G. Availability of **technology to collect and share information** among providers and patients
- H. Use of **technology to collect and share information** among providers and patients

Outcome #5: Better information

Clear and understandable information is needed by patients throughout the diagnosis process, the type and amount of information varying by individual and phase of the diagnosis journey.

Our understanding of the information needs of patients *following* a cancer diagnosis is quite advanced thanks to an abundance of excellent research in this area which spans a decade or more (Ankem, 2006). Much less is known, however, about a patient's information needs while they are undergoing investigation for a suspicion of cancer. Through our environmental scan, we learned a lot about what constitutes appropriate information for those undergoing an investigation of cancer. We learned what type of information people wanted, what was considered as too much or too little information, what information was wanted when, in what form, and by whom the information should be communicated. We also learned that what was currently happening in terms of information provision was often the opposite of what was wanted.



Current Inefficiencies

At the outset of the diagnosis process, people experience much uncertainty (and therefore anxiety) about what the diagnosis process entails. Knowing what to expect before one embarks on what may be a lengthy diagnostic process is critical to a person's mental health and wellbeing. People in our study who described initiation of their diagnosis pathway in a positive light attributed the quality of their experience to having had someone explain the pathway to them beforehand.



"My family doctor laid it out very well for me. Like, the next steps from here are this and now I'm going to send you for an ultrasound; the next step after that is a biopsy if there is something we need to look at. And he explained how the biopsy works, that they put a needle in, and there is a bit of pain...at that point I didn't even know what questions to ask for myself so for him to nudge me in the direction gave me an idea of what to expect going forward but he certainly didn't overwhelm me with information".

Female 40, breast cancer survivor

In the current state, people experience a dearth of information about the diagnosis pathway and the steps within it. Rather, people are catapulted into the diagnosis process with little understanding of what to expect. Many of the people in our study described the impact of not knowing what would be encountered as akin to 'being dunked into a series of pools whether you were ready for it or not', and described how it felt to be 'herded to the next test without even knowing what the last one's results meant'.



"I felt overwhelmed throughout the whole process, like a tumbleweed that was getting blown along with the wind".

Female 40, breast cancer survivor

Providers were cognizant that patients needed information – the problem was that they were largely unaware of what was appropriate information. Information was either given all-at-once resulting in ‘information overload’ or was not appropriate for the individual in terms of personality or learning style. Oftentimes people were either ‘given a bunch of papers to read and told to call if they had any questions’ or were left to their own devices to get the information they needed, relying most often on the Internet which at times led them down a ‘dark and scary rabbit hole’.



“Information needs to be tailored to me. Like I don’t want to read stuff about stage 4 cuz I don’t want to be stage 4. There’s a balance between too much and too little information”.

Female 30, melanoma cancer survivor

During communication of final diagnosis, people are either given an abundance of information or are simply given nothing at all. Information needs at the time of final diagnosis were found to differ from those in the middle of their diagnosis journey in that people wanted information about aggressiveness, size and staging since these are ‘the things most people understand about cancer’. Depending on the individual, information about prognosis and survival was also desired, especially for those whose first thought was ‘am I going to die?’. The second body of information people need at the time of final diagnosis is about the treatment trajectory; not a barrage of information but just enough so that they can ‘get on with it’.



“At that moment you don’t want to listen to a thirty-minute dissertation on what melanoma is. You just go holy crap, okay, what do we do about it?”.

Male 64, melanoma cancer survivor

Inappropriate responses to a person’s information needs only serve to intensify the assault on a person’s mental health and wellbeing. While the final diagnosis understandably comes as a shock for many people and can make it difficult for people to form their questions at that moment, providing good and appropriate information at that point in time is critical, including a clear and simple means for them to ask further questions as they arise.

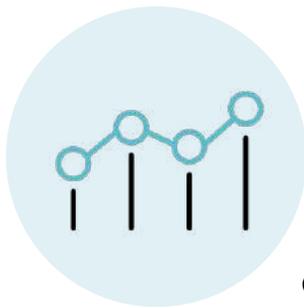


Opportunities for Improvement

Throughout the diagnosis process, information needs vary depending on the stage of the diagnosis process that the person is in. In the early phase of diagnosis, when a person is first referred for testing, information is needed about what the diagnosis pathway entails for their specific type of suspected cancer. The information should be just enough that the person understands the entire pathway but not so much that it becomes overwhelming. For many common types of cancer, the diagnosis pathway is standardized and therefore easily communicated to the patient.

In the middle phase of diagnosis, as people undergo multiple diagnostic tests and procedures, information about each step is needed and should be given *before* that step occurs so that the person has time to prepare for it and knows what to expect from that test and whether more tests may be needed, to ask questions and to have their questions answered. We also heard directly from people that getting information from the provider (rather than seeking it on their own) was desirable because it was more likely to be ‘safe and accurate’.

At the time the final diagnosis is communicated, people need information about aggressiveness, size and staging and about treatment next steps. Ideally, an information kit which explains the type of cancer and its treatment and includes a list of reliable sources to search along with a phone number of who to call to ask questions and when a reply can be expected is a good practice that enables a person to absorb and share information as they are ready.



Benchmarks/Indicators of Success

Better information is one of our seven identified outcomes to attain if we are to have a quality cancer diagnosis process in Canada. Quality indicators associated with successful attainment of this outcome include:

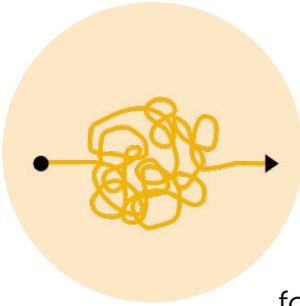
- A. **Patient understands the diagnosis pathway** for their type of suspected cancer
- B. **Patient understands each step** along the diagnosis pathway
- C. **People diagnosed with cancer understand what the treatment trajectory entails**
- D. **People are satisfied with the information they receive** from health care providers when they receive it.
- E. **People know who to ask if and when they have questions**
- F. **People feel their questions are satisfactorily answered**

Outcome #6: Integrated psychosocial support

To cope with the looming threat of a cancer diagnosis, psychosocial support must be integrated into patient care alongside diagnostic testing and medical procedures.

Our understanding of the psychological impact of cancer was unveiled decades ago with numerous excellent research studies documenting this impact on patients as well as other family members (C. Pitceathly, 2003). Today, there is a scattering of psychosocial support programs and services available to cancer patients nationally, provincially, regionally and locally, some specific to cancer type and each with a different focus whether it be mental health, financial support, employee assistance, family relations, peer support, and so on. While fragmented, people living with cancer can try to piece together a psychosocial support network if they are inclined to do so.

For those not yet diagnosed but who are undergoing investigation, a psychosocial support network is also needed. The constant emotional stress and worry over being potentially diagnosed with cancer coupled with the need to constantly self-advocate in a fragmented system while feeling like one is living inside a ticking clock takes a toll on people's mental health. Making decisions about courses of action with a partner, other family members or loved ones during an emotionally difficult time can stress relationships. The need to travel or take time off work for testing can tax people's pocketbooks, which induces further stress and anxiety. Psychosocial support must be integrated as part of a person's care right from the time the person is first referred for diagnostic testing.



Current Inefficiencies

Currently, a psychosocial support network is largely non-existent for people undergoing investigation for cancer and we found no evidence of any type of psychosocial support being integrated into the diagnosis process. If supports are a part of the cancer care process at all, they are often offered only after diagnosis. The 'fear of being left alone' after a cancer diagnosis, voiced by many of our interview participants, heralds the intense need for mental health and/or peer support at this critical juncture in the cancer journey.



"It's not just my breast that has cancer, it's my body and my brain you know. So, you have to treat the whole body, you can't just treat the affliction".

Female 40, breast cancer survivor

Many people with whom we spoke looked back on their cancer journey and realized that psychosocial support needs to be integrated right from the start, so that even 'if supports weren't used at that time they would be in place when needed'. Those who did not do this, and that was the majority of people in our study, found themselves unable to access services in a timely manner, being put on wait lists of up to six months which did them no good 'after the fact'. Particularly at the time of diagnosis, it is imperative that patients have robust supports in place.



“Ideally when you’re told you have cancer, you’re in a room with your oncologist, you have support people right beside them, there are people from the cancer agency right beside them, it’s all set up. But what really happens...it’s like, yeah, we’ll call ya...”

Male 41, melanoma cancer survivor



Opportunities for Improvement

The lack of integrated psychosocial support for people in the diagnosis phase represents a significant gap in cancer care especially given that we know that treating the whole body goes a long way to treating the actual cancer (Spiegel, 2012). Indeed, more than half (59%) of providers surveyed believed patient supports such as mental health and other individualized supports were essential for a quality diagnosis process and roughly one-third (36%) reported using these supports with their patients.



Benchmarks/Indicators of Success

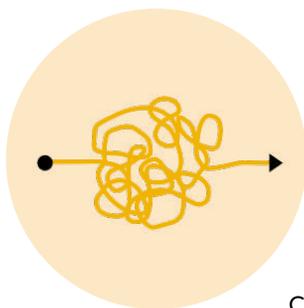
Integration of psychosocial support is one of the seven identified outcomes we must attain if we are to have a quality cancer diagnosis process in Canada. Quality indicators associated with successful attainment of this outcome include:

- A. **Psychosocial support is offered to patients** in the early phases of diagnosis
- B. **Psychosocial support is available and accessible** as needed

Outcome #7: Coordinated and managed care

A dedicated patient navigator to help navigate the diagnosis process would address inefficiencies and enhance patient experiences resulting in more timely and accurate diagnosis.

Canada's health care system is less a true national system than a decentralized, uncoordinated collection of provincial and territorial systems. Even within provinces, health care consists less of a system but rather of a number of processes and stand-alone providers that people are either fortunate and/or tenacious enough to access. Fragmentation and siloed services are the norm. For people undergoing investigation for a suspicion of cancer, this type of fragmented, uncoordinated system sets the stage for mismanagement and leaves a person to rely upon themselves to navigate a complex web of providers and diagnostic facilities.



Current Inefficiencies

Within jurisdictions or even regions, there is no role dedicated to coordinating a person's cancer diagnosis from beginning to end. Those who are able take it upon themselves to manage their own care, expending a lot of effort and energy to do so in our fragmented health care system. Coupled with the looming threat of a cancer diagnosis, managing one's own care can become incredibly burdensome and many without the skills or wherewithal to sustain it find themselves left 'floating' and 'muddling through' the diagnosis process by themselves. People in our study described various methods they had devised to manage their own care – journals, scrapbooks, electronic note taking – and told us that an online tool or phone-based app from which they could store and retrieve information would be very welcome.

When people did encounter someone who offered to help with care management, it was talked about 'like a breath of fresh air'.



“The techs and nurses were wonderful. Very clear about what the test was for, what they were looking for. They called before every appointment to remind me, what to prepare in terms of meds. It meant the world to get these calls because I was prepared for every test”.

Female 70, lung cancer survivor

The absence of a patient navigator was understood by both patients and providers surveyed to be a significant gap in the diagnosis phase of cancer care. Fifty-four percent of providers surveyed ranked lack of integrated and coordinated care among the top five inefficiencies in the diagnosis process, many urging the family physician to take on this role in an attempt to fill this gap. However, it is important to acknowledge that some people in Canada do not yet have access to primary care or do not have access to quality primary care (i.e. only walk-in clinic available). We learned, however, that while both providers and patients alike try to rely on the family physician to act as a touchstone throughout the diagnostic process, the success of this depends very much on the pre-existing relationship the physician has with the patient, with those having a close and long-standing relationship being more apt to assume this coordinating role to help mitigate some of the challenges encountered.

For people living in rural and remote areas of Canada, travel to diagnostic facilities was unavoidable at some point during the diagnosis process due to a lack of local specialized testing facilities, scantness of providers, and/or overcrowding of facilities due to the COVID-19 pandemic. The latter two issues, if not circumvented, likely result in delayed diagnosis. Financial and logistical support for patients living in rural and remote areas of Canada who travel regularly for investigation are lacking and must be provided to ensure equitable access. Indeed, 50% of providers surveyed

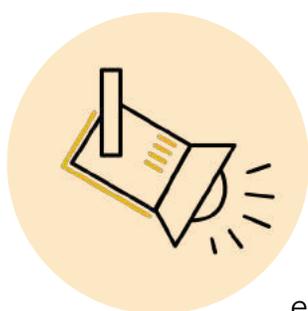
ranked lack of availability of diagnostic and specialized services to be among the top five inefficiencies in the cancer diagnosis system in Canada. ⁶



Opportunities for Improvement

Fortunately, providers and policy makers have recognized the need to improve coordination and care management within cancer care systems and have taken fruitful steps toward this end.

While these steps have introduced innovations and interventions into the cancer care system, most of these are introduced only post-diagnosis. There is much opportunity to integrate these measures throughout the diagnosis phase when the cancer care process begins. A notable exception is Diagnostic Assessment Programs, which have sprung up in many jurisdictions across the country. For patients, the arrival at one of these dedicated diagnostic facilities is accompanied by a sense of relief as things tend to move in a more coordinated fashion, swiftly and smoothly under one roof. This and other innovations intended to improve coordination of care are profiled in the next section.



Practice Spotlights

Our environmental scan uncovered a number of initiatives currently being used by provinces and regional health authorities to enhance coordination, collaboration and management of patient care throughout the diagnosis process. Initiatives for which we were able to obtain detailed information are profiled below.

⁶ Provider information was collected during the COVID-19 pandemic and so may not be entirely reflective of provider viewpoints during 'normal' times.

Patient navigation

Patient navigation within the cancer care system is a process by which a person with a suspicious finding or known cancer is guided through and around the cancer care system. Over the past decade, the patient navigator role has become increasingly essential as the person with cancer is now placed at the centre of cancer care. Also termed a 'pivot nurse', 'cancer coach', or 'care coordinator', patient navigators help ensure that people receive guidance and support as they proceed through the diagnosis process, and often help address health disparities by overcoming common barriers faced before and after a cancer diagnosis.

Almost all Canadian jurisdictions have a patient navigator program within their cancer centre, and many embed the navigator as part of their coordinated diagnostic program. Some Canadian examples are provided below.

- The *Cancer Navigation Program* is available across the **Northwest Territories** to help cancer patients navigate their cancer journey. In this program, patients with cancer and their support network are paired with registered nurse navigators who work closely with the patient/caregiver(s) and their health care team in order to offer assistance and direction through their cancer journey, including throughout the diagnosis phase (NWT, 2020).
- In **Manitoba**, Cancer Care Manitoba has established *Cancer Navigation Services*, a resource of health professionals available to assist people living in all five regional health authorities in Manitoba: Interlake Eastern, Northern, Prairie Mountain, Southern and Winnipeg. Each regional cancer program "hub" has a navigation team that includes nurse navigators, psychosocial oncology clinicians and community engagement liaisons (CCMB, 2020).
- The Juravinski Cancer Centre in Hamilton, **Ontario** established an Aboriginal Patient Navigator program so that Aboriginal patients can be paired with culturally

appropriate navigators who can fill language needs and address cultural gaps (Sciences, 2020).

- The **Ottawa** Regional Cancer Foundation established the *Cancer Coaching Program* for cancer patients and their families. Patients and families are directed to the program by clinicians, community partners, outreach and awareness campaigns, and by word of mouth. A medical referral is not required. Individuals have the option to enrol in the program online, select which cancer coach they want to be paired with, and can opt for in-person or virtual coaching (Foundation, 2020).
- In **Eastern Canada**, cancer patient navigators operate through the *Cancer Care Program of Eastern Canada* and are specially trained oncology nurses. The navigators offer practical support to patients and caregivers to help them understand and work through the services and challenges encountered on their cancer journey. The program also employs Aboriginal patient navigators to assist Aboriginal patients and caregivers by providing culturally relevant and language appropriate information and guidance (Health, 2020).
- A Peer Navigation Program situated in rural and remote communities in **Newfoundland and Labrador** offers information and support for women with women's cancers. The program trains peer navigators to meet the needs of rural and Aboriginal communities throughout the province. Women who are leaders in their communities take on the navigation role to support women with cancer and work with community groups and the patient's health care team to raise awareness about ways to make services more accessible and provide support to women throughout their cancer journey (Ledwell, 2015).

To date, there are no consistent role descriptions or competency frameworks for patient navigators across Canada and certification requirements and skill sets vary by jurisdiction. Achieving consistency and standards for the patient navigator role is a work in progress. Most recently (in April 2020), the Canadian Association of Nurses in Oncology (CANO) issued a position statement concerning the licensing requirements

of a patient navigator (i.e., that they be a specialized oncology nurse), and to clarify the role and its competencies (CANO, 2020). While the patient navigator efforts described here represent an excellent beginning, more work is needed to adequately and consistently integrate and standardize this role within cancer diagnosis systems. None of the people in our study reported being supported by a patient navigator and less than one-third (29%) of providers surveyed reported the use of patient navigators despite more than half (56%) believing them to be essential for a quality diagnosis process.

One of the best practices to ensure care is managed and coordinated is to conduct the diagnosis process in a single facility where things can move in a more coordinated fashion, swiftly and smoothly under one roof. Toward this end, many jurisdictions have established dedicated cancer centres or **Diagnostic Assessment Programs (DAPs)**. People in our study who were cared for within a dedicated cancer facility⁷ tended to be more satisfied with their diagnosis experience because a multidisciplinary approach was being used, the information they received was appropriate and forthcoming and care tended to be more compassionate.

While evidence-informed and standardized care pathways have been developed for a number of cancers, the challenge is to build the operational systems that deliver such care in a timely manner. A number of jurisdictions within Canada have implemented initiatives to coordinate diagnostic cancer services that improve the experience of patients with suspected cancer as they go through the diagnosis process.

Coordinated diagnostic cancer services differ from usual care in that they offer a single point of entry into the cancer care system, assessment is completed within a single location or via virtual means that coordinate diagnostic services across multiple institutions, and referrals for consultations and tests are centralized within the program itself rather than having to rely on the patient's primary care provider for each separate referral. This type of coordinated model of diagnostic care typically relies on standardized care pathways to guide providers while incorporating discrete interventions to reduce delays, minimize errors and enhance the patient experience

⁷ Although none of the patients in our study named a DAP per se, their description of the facility in which their diagnosis was completed led us to believe that many patients had in fact encountered such a facility at some point in their diagnosis process.

including: a single point of entry/access; fast-track/managed referral process; multidisciplinary teams; and patient navigators.

The structure and organization of coordinated diagnostic programs varies considerably across Canada and is necessarily influenced by the diagnostic process required for different cancer types, by the regional and geographic realities of each jurisdiction, and by the volume of cases. Some examples from across Canada for which we were able to find related articles or additional information are provided below.

British Columbia

In **British Columbia**, *Rapid Access Breast Clinics (RABCs)* serve as a single point of entry for patients with a suspicion of breast cancer in Vancouver, B.C. Established in 2009, the first Rapid Access Clinic (RABC) was established at Mount Saint Joseph Hospital, Vancouver. Soon after, three additional rapid-access clinics spread throughout the Vancouver area, each of which operates as a single facility to fast-track patients throughout the diagnosis referral process. The clinics rely on a navigated care model to coordinate all aspects of the diagnosis process in an attempt to reduce time to surgical consultation. The model consists of both clerical and nurse navigation whereby clerk navigators facilitate movement of patients along clinical pathways and nurse navigators provide communication, information and emotional support. Shortly after establishment of the four RABCs, the fast-track referral model was implemented by several existing breast diagnostic radiology facilities in the greater Vancouver area, each of which adopted a policy of facilitated radiology booking – i.e., completing a diagnostic work-up for suspicion of breast cancer without requiring additional requisitions. Evaluation of the RABCs reported in 2018 demonstrated that the RABCs shortened the wait time for breast cancer diagnosis compared with usual care (i.e., time from presentation to surgeon evaluation was 35 days for RABC patients with breast cancer symptoms vs. 81 days for usual care and was 40 days for RABS patients with abnormal screens vs. 72 days for those in usual care) (E. McKevitt, 2018).

Alberta

The province of **Alberta** has implemented coordinated diagnostic services at both the provincial and regional levels.

- *The Breast Cancer Diagnostic Assessment Pathway (End-to-End Pathway)* was initiated by the province of Alberta in 2017 to coordinate and facilitate the patient diagnosis journey. The initiative is led by the Cancer Strategic Clinical Network™ (SCN) in partnership with the Provincial Breast Health Initiative with Cancer Control Alberta and the Surgery SCN. Its initial mandate is to target three breast cancer pathways, supported by new patient education materials and a provincial measurement and reporting framework. The initiative is intended to support the breast cancer community by designing and implementing care pathways that include timely and appropriate diagnostic assessment of breast abnormalities. The pathway uses an automated textbox system embedded in all imaging reports to the patient's primary care provider that prompt the provider to arrange for immediate referral to a cancer diagnostic facility or specialist. Within the diagnostic facility a nurse navigator reviews reports and schedules all consultations to move the patient along the care pathway. The nurse navigator also provides pre-consultation education to the patient and serves as a contact for further questions throughout the diagnosis process. As this initiative is still in its early stages, a Provincial Breast Health Steering Committee continues to be in place to oversee and guide the work. Membership includes representation from the public, expert clinicians, primary care, and administrators from the zones and provincial programs. Evaluation of the breast cancer End-to-End Pathway reported in 2019 found shortened wait times throughout the diagnosis process (suspicion to biopsy was 6 days; biopsy to pathology report was 5 days; suspicion to surgical consult was 21 days) and improved patient experience (using measures of patient anxiety level and wait time satisfaction) as a result of the program (Alison Laws, 2019). The coordinated pathway also improved communication and notifications to primary care

physicians and the breast health programs, prompted an immediate referral to a surgeon and initiated early patient navigation during the diagnosis period (CSCN, 2019). The SCN and partners continue to improve upon the breast End-to-End Pathway and are currently working on implementing a colorectal and lymphoma diagnosis pathway for patients with these suspected types of cancer.

- Alberta's *Thoracic Oncology Program (ATOP)* operates two rapid access clinics in Edmonton and Calgary for patients with suspected chest malignancies. The clinics are staffed by a team of nurse practitioners, interventional respirologist and thoracic surgeons with extensive experience and expertise in the diagnosis and treatment of lung cancer. Patients have access to a multidisciplinary team of specialists throughout the diagnosis process. To fast-track the referral process, incoming referrals are reviewed by dedicated nurse practitioners who initiate intake of information and preliminary evaluation. Patients are then booked into one of the clinics to see a nurse practitioner or a respirologist within one week of referral to discuss a diagnosis plan. Referrals deemed more appropriate for thoracic surgery are forwarded directly to the thoracic surgeons to reduce delays in evaluation and treatment. The fast-track referral process eliminates the administrative delays which occur when test results are sent to the patient's family doctor for processing and referral. The clinics are supported by Alberta Health Services, the Cancer Care Strategic Clinical Network (SCN) and Cancer Control Alberta. While no formal evaluation of the clinics has been completed, ad hoc reports said that wait times from the first appointment at the clinic in Edmonton Alberta to diagnosis dropped from 66 days to 52 days (AHS, unknown).

Saskatchewan

Developed by a team of urologists, oncologists, other health care providers and patients, the **Saskatchewan Prostate Assessment Pathway** offers coordinated diagnostic testing for men at risk of prostate cancer, an algorithm for physicians to help evaluate the need for diagnostic testing and guidelines to help providers decide on the best care pathway for patients with suspected prostate cancer. Primary care providers can refer patients directly to either centre without urologist consultation. At the centre, urology nurse navigators support patients, provide information on tests and treatment options, and facilitate patients' journey from assessment to diagnosis and treatment. The nurse navigators provide education before a biopsy (and after, if pathology is positive for early-stage prostate cancer). With the primary care provider's permission, nurse navigators can convey biopsy results to patients. The nurse navigators are experienced urology nurses with specialized training about prostate cancer diagnosis and treatment. Prostate assessment centres have been developed in Regina and Saskatoon (Authority S. H., 2020).

Ontario

In 2007, Cancer Care Ontario began the implementation of its Diagnostic Assessment Program (DAP) throughout the province of **Ontario**. The purpose of the DAPs was to improve the quality and accessibility of diagnostic care for patients, advance a person-centred approach in diagnostic care, drive integrated care delivery among services and providers, and maximize the value of care delivered. DAPs provide a single point of access to the cancer diagnosis process, coordination of diagnostic tests and appointments, engagement of multidisciplinary expertise, improved availability of resources for both patients and referring physicians, and psychosocial support. The primary intended outcome of the program is to improve the patient experience through shorter wait times for diagnosis (CCO, 2009).

CCO works with regional partners across Ontario to develop and support regional DAPs. As of 2020, 27 DAPs have been implemented primarily for lung, colorectal and prostate cancer. Evaluation of Ontario DAPs has consistently reported the effectiveness of the DAP model in reducing wait times and optimizing the patient diagnosis experience. In 2014, Cancer Care Ontario reported that DAPs are responsible for reducing Ontario wait time from referral for suspicion of lung cancer to the time of diagnosis by 20% (approximately 46 days in 2010 to 37 days in 2014) (CCO, 2014). DAPs have been shown to improve the patient experience with 73% reporting positive emotional support outcomes, 78% reporting positive patient assistance outcomes, and 98% reporting overall satisfaction with the diagnosis process (CCO, 2014). A study of Ontario DAPs by Jiang et al. (2015) found that diagnostic assessment units were associated with a reduced time to diagnosis for screen-detected breast cancer patients (L. Jiang, Effect of specialized diagnostic assessment units on the time to diagnosis in screen-detected breast cancer patients, 2015), and a 21% reduction in the diagnostic interval for symptomatic patients (L. Jiang, 2018).

Some examples of Ontario DAPs for which we were able to find related articles or additional information are described below.

- Ontario's *Time to Treat Program* at Toronto East General Hospital is designed for patients with suspicion of lung cancer. The program employs a single point of entry via a clerical nurse navigator who coordinates care of patients during the diagnostic work-up. The navigator utilizes a Lung Cancer Pathway diagnostic algorithm to book the patient to see an appropriate specialist and facilitates communication between and among physicians and patients. Upon entry to the program, diagnostic equipment is blocked for the patient in order to reduce wait times. All follow-up appointments are coordinated through the clerical navigator. Multidisciplinary teams with representation from radiation oncology, thoracic surgery, medical oncology, pathology, radiology, and respirologist services meet weekly to discuss cases. The program has established target wait time intervals which include: 5 or fewer working days for referral for a

specialist consult; and, fewer than 10 working days for CT scan. Local family practice units, radiology department, and potential referring physicians from the Toronto East General Hospital community are educated about the Time to Treat Program to encourage referrals. Evaluation of the Time to Treat program reported a reduction in the time from suspicion of lung cancer to diagnosis from 128 days to 20 days. (CPAC, 2018).

- The *Ottawa Hospital Cancer Assessment Clinic* integrates multiple regional and hospital-based cancer diagnostic processes into one coordinated system in order to integrate the patient journey from regional health facility to the tertiary care centre. The model was developed in collaboration with a team of patient and family advocates alongside regional clinical and non-clinical stakeholders. Multidisciplinary diagnostic assessment centres for patients with suspicion of thoracic, colorectal, breast or prostate cancer operate regionally under the umbrella of the central cancer assessment clinic, with the central clinic being the single point of access for patients. Within the centres, lean optimization of diagnostic procedures and patient education include coordinated referral review and integrated services supported by a patient navigator. Program developers are committed to continuous quality improvement and, as such, performance data is displayed on a corporate dashboard to create a transparent view of the patient journey and flow. An evaluation reported in 2017 found that the coordinated model has resulted in the region reaching Ontario's provincial time to diagnosis target⁸ for 80% of referrals (J. Pantarotto, 2017).
- The *Kingston Cancer Centre Breast Assessment Program (BAP)* aims to provide patients with timely access to care from detection of a breast abnormality to diagnosis and treatment. BAP offers a single-entry point to care and a multidisciplinary team of health care professionals providing services in diagnostic imaging, surgical consultation and intervention, nursing services, social work, pastoral care, nutritional services, supportive

⁸ Cancer Care Ontario established a target of <28 days from referral to diagnosis for lung cancer patients.

patient and family centred care, patient navigation, co-ordination of care and health teaching to help patients make informed treatment decisions. People with a suspicion of breast cancer are referred to the BAP by their family physician or by the Ontario Breast Screening Program (KHSC, 2020).

- The *Lung Diagnostic Assessment Program (LDAP)* is the main clinical pathway by which patients with suspected lung cancer are evaluated at *Kingston Health Sciences Centre* in Ontario. The LDAP piloted a Standard Triage Process (STP) for patients referred to the LDAP in 2018 which included: routine interdisciplinary triage, standardized care pathways including pre-ordered staging tests where appropriate, and a new Small Nodule Clinic. Pre- and post-STP evaluation results found the mean time from referral to diagnosis for patients had improved from 39.9 days before the STP to 30.7 days after the STP was implemented and that the proportion of patients meeting the Ontario's 28-day target increased from 39.3% to 51.3% (M. Mullin, 2019).
- The *Lung Diagnostic Assessment Program (LDAP)* in the Hamilton, Niagara, Haldimand and Brant communities offers a coordinated approach to assessing and diagnosing patients and provides necessary physical and emotional support. There are three hospitals that participate in the LDAP including St. Josephs Healthcare Hamilton, Niagara Health and Brant Community Health Care system. All referrals are made to a central fax line where a nurse will call the patient within 48 hours of referral. The Lung Diagnostic Assessment Program (LDAP) coordinates all tests required to make a diagnosis or rule out lung cancer (Hamilton, 2020).
- Toronto, Ontario's *Lung RAMP program* (Lung Rapid Assessment and Management Program) allows patients who are suspected of having lung cancer to obtain consultation and diagnostic investigation through a streamlined process. Nurse navigators manage care from the start and wait times for each step of the diagnosis process are specified.

- *Rapid Diagnostic Units at Sunnybrook Health Sciences Centre* in Toronto, Ontario, have been established for patients with a suspicion of breast, prostate or melanoma cancer. The clinics feature a nurse navigator who guides and supports each patient through the assessment process. Patients benefit from the collaborative expertise of specialists and surgical oncologists. Prostate biopsy is performed with 72 hours of referral (Centre, 2020).

Quebec

The province of **Quebec** has implemented coordinated diagnostic assessment programs to address the needs of Quebec residents with a suspicion of lung cancer.

- The *Diagnostic Assessment Program* in Quebec City was established in 2008 by the l'Institut Universitaire de Cardiologie et de Pneumologie de Québec, a public academic hospital, for patients with suspected lung cancer. Referrals are received from family physicians or other centres in the eastern Quebec area. Referrals to the program are triaged by a respirologist within one working day, and necessary tests are prioritized and organized quickly by a nurse navigator with access to dedicated investigation booking slots. An evaluation of the DAP reported in 2017 found average wait times from referral to diagnosis were 21 days which fell within the acceptable wait time target for the province based on Ontario's recommended target of ≤ 28 days (C. Labbe, 2017).
- *Rapid Investigation Clinic (RIC)* in Montreal, Quebec was established in February 2010 at the McGill University Health Centre to coordinate and accelerate the workup of patients with suspected lung cancer. The RIC operates twice a week and is staffed by a rotating pulmonary physician and nurse clinician. The nurse-clinician monitors the investigation progress, assists with coordination of care, and provides patients with the necessary psychosocial support. Procedures that allow simultaneous diagnosis and

cancer staging are favoured. The RIC was evaluated between February 2010 and December 2011 to determine the impact of the clinic on timeliness of lung cancer diagnosis and treatment. The primary desired outcome was to reduce the time between first contact with a local physician for suspected lung cancer and first treatment. The evaluation found that the time from suspicion to diagnosis was on average 14 days shorter in the RIC patients (compared to a control group) (Nicole Ezer, 2017).

Newfoundland

The Thoracic Triage Panel (TTP), a multidisciplinary, coordinated diagnostic program was established in St. John's **Newfoundland** in 2014. The program was created in order to reduce delays in lung cancer diagnosis which were being experienced in the traditional, primary care provider-led referral process. The key components of the coordinated program include nurse navigation, weekly multidisciplinary meetings, and regular communication with the primary care provider. The nurse navigator coordinates patient care and acts as the contact person for patients and clinicians involved in the program. A working group of thoracic specialists including radiology, respirology, medical and radiation oncology, thoracic surgery, and pathology meets weekly to review new and ongoing cases, to determine optimal course for diagnosis and treatment and to coordinate appropriate investigations and referrals. Communication with the primary care provider occurs via standardized forms at time of referral, initial review by the TTP, and discharge from the program. The program was evaluated one year after establishment to determine if referral to a Thoracic Triage Panel (TTP) expedites lung cancer diagnosis and treatment initiation and leads to more appropriate specialist consultation. Evaluation found a decrease in wait times for patients referred to the TTP, specifically, a 25.5-day reduction for wait time from first abnormal imaging to biopsy, and a 38-day reduction for wait time from first abnormal imaging to treatment initiation. The percentage of specialist consultations

that led to treatment was also greater for patients referred to the TTP (Reducing Wait Time for Lung Cancer Diagnosis and Treatment: Impact of a Multidisciplinary, Centralized Referral Program, 2018) (Jessica L. Common, 2018).

Cancer Care Ontario, with support from the Canadian Cancer Society (CCS) and the Canada Health Infoway (CHI) developed an electronic tool for **Ontario** DAPs to guide clinical practice, facilitate patient tracking, support the care team and enhance patient engagement during the diagnostic phase of care. This tool, known as the **Diagnostic Assessment Program-Electronic Pathway Solution (DAP-EPS)**, is built according to validated clinical diagnostic pathways and uses shared care decision-making models to provide relevant and timely patient-focused information, navigational support and workflow management tools. The DAP-EPS also enables the collection of data to monitor DAP processes and assess the impact of the DAPs on the efficiency and effectiveness of diagnostic care. Evaluation of the DAP-EPS in 2014 found widespread acceptability and uptake among patients and providers (CCO, DAP-EPS Benefits Evaluation Final Report, 2014). A DAP-EPS effectiveness evaluation has not been completed.

While the DAP concept is gaining popularity within jurisdictions; 41% of providers surveyed believed centralized and coordinated diagnostic services in a single location (tests, appointments, providers) were essential for a quality diagnosis process, more work is needed to embed DAPs within jurisdictions and regions as only 32% reported of providers surveyed reported using DAPs in their practice.

Multidisciplinary Teams

Cancer diagnosis can be complex and, given the wide range and numbers of health-care professionals involved in a cancer diagnosis, an enormous potential for poor coordination and miscommunication exists. To address these issues, cancer care centres are increasingly providing care by multidisciplinary teams (MDTs).

The MDT approach in Canada is not unique to the cancer care system and has been used as a model in multiple jurisdictions to address the needs of patients with various chronic conditions such as diabetes, mental health, asthma, and heart disease. The members of such teams come from different specialties or disciplines and, for cancer care, typically include surgeons, radiation and medical oncologists, experts in diagnostic imaging, and pathologists. Other important members of the multidisciplinary team are nurses, nurse navigators, genetic counsellors, physical therapists, hospital pharmacists, and social workers. Members of multidisciplinary teams often meet as a group to discuss each patient and consider all the different aspects of treatment and services. Within cancer care diagnosis, MDTs are intended to improve coordination, communication, and decision making between health-care team members and patients, and hopefully produce more positive outcomes along the diagnostic pathway.

The one example of an MDT for which we found detailed information is Edmonton. Alberta's *Multidisciplinary Melanoma Clinic (MMC)* staffed with dermatologists and surgical/medical oncologists, aims to see a patient within 1-2 weeks of referral and complete initial diagnosis and treatment planning within just a few weeks. The clinic benefits both patients and providers who, through the use of multidisciplinary teams (MDTs), have the ability to tap into the expertise of others and quickly define a coordinated strategy for the patient.

Today, most organized and coordinated cancer diagnostic services incorporate MDTs into their programs. MDTs also operate more informally by regularly bringing together individuals who have important roles to play in patient triage, coordination of diagnostic tests, and assessment of the informational and psychosocial needs of the patients (CPAC, 2018). MDTs work either in-person or remotely through various technological means.

While MDTs are being used sporadically throughout jurisdictions more work is needed to formalize the use of MDTs. The introduction of DAPs is a good start toward this end. Indeed, more than half (53%) of providers surveyed believed formal

multidisciplinary teams operating from one location and working together daily to participate in and support the diagnosis process were essential for a quality diagnosis process yet only one-quarter (26%) reported using formal MDTs in practice. More often, informal MDTs are being used with nearly half (45%) of providers surveyed reporting use of informal MDTs.

E-management tools that can store and retrieve information (i.e., test results, provider contact information, appointment calendars) efficiently will minimize the effort and energy required to manage care. Online portals are used by some jurisdictions to centralize information including, for example, MyChart in Quebec; Netcare in Alberta and the University Health Network in Toronto, Ontario.



Benchmarks/Indicators of Success

Coordinated and managed care is one of our seven identified outcomes to attain if we are to have a quality cancer diagnosis process in Canada. Quality indicators associated with successful attainment of this outcome include:

- A. **Patients are assigned a patient navigator** for the duration of their diagnosis process
- B. **Patients receive care from a multidisciplinary team**, ideally as part of a DAP or similar coordinated cancer diagnosis program
- C. **People have access to online tools** or apps to help manage care
- D. **Availability of telepathology services** and/or **reimbursement of travel costs** for patients and their loved ones for diagnostic services

Impact of the COVID-19 Pandemic

Measures introduced during the COVID-19 pandemic both exacerbated and mitigated inefficiencies in cancer diagnosis and can serve as lessons learned for the future.

The COVID-19 pandemic that hit globally in March 2020 overwhelmed Canadian health care systems and resulted in alterations and disruptions that were felt by everyone across the nation. Recent reports from the Quebec Ministry of Health documented the impact of the first wave shut-down of services on cancer patients, stating that a minimum of 4,119 patients had gone undiagnosed between March to June 2020 because of gaps in screening and access to facilities (Montreal, 2021). For people who were engaged in investigating a suspicion of cancer amidst this tumultuous time, the extent of the disruption was well voiced in our study, the fallout depending largely on when, during the multiple waves of the pandemic, a person entered the diagnosis process.

Challenges

Alterations to and disruptions in the health care system introduced new barriers that would not otherwise have been encountered were it not for the pandemic.

Challenges reported by patients included:

- ✘ Fear of travelling outside of one's own 'bubble' to attend a distant cancer clinic for diagnostic testing
- ✘ Fear of using public transportation to get to appointments as was done pre-COVID

- ✘ Needing to self-advocate, or what was described as 'doing all the heavy lifting because the providers are pinned under the rocks of COVID'
- ✘ Fear of existing mistakes in the diagnosis system being compounded due to COVID
- ✘ Worry of contracting COVID while in hospital
- ✘ Lack of access to or interest in online supports for older adults
- ✘ Poor patient-provider communication because doctors were masked
- ✘ Lengthy wait times for specialist appointments (upwards of 4 months in some jurisdictions) due to lack of personnel (Nova Scotia)
- ✘ Shut down of community support programs in some jurisdictions (Quebec)
- ✘ Lack of family support while in hospital amid unhelpful and overwhelmed nursing staff
- ✘ Cancelled procedures and tests in the height of the first wave of the pandemic
- ✘ Increased mistakes or missed paperwork (e.g., medication forms not submitted) because the 'system is overwhelmed and everyone is just focused on COVID'
- ✘ Lack of guidance from diagnostic facilities and cancer centres about continuation of service

Challenges reported by providers included:

- ✘ Timely access to primary care physicians and diagnostic facilities
- ✘ Limited access to primary care providers
- ✘ Limited access to diagnostic facilities
- ✘ Difficulty/discomfort among patients diagnosing certain types of cancer (i.e., skin cancer) by virtual methods
- ✘ People delaying presentation to the medical system; reluctance to seek care and routine screening
- ✘ People presenting later due to hospital closings and cancelled surgeries

- ✗ Longer wait times for testing due to limited workflow and specialist inability to travel to distant areas (for fly-in doctors)
- ✗ Delays with hospital-based appointments or procedures
- ✗ Patients unable to bring advocates or family members to appointments

Enablers

At times the alterations and disruptions in the health care system served as enablers of care.

Enablers reported by patients included:

- ✓ Use of virtual communication for appointments
- ✓ Hospitals being quiet and therefore 'less chaotic' so appointments were 'more calming because you weren't being wheeled through a hall full of people'
- ✓ Provider work-arounds allowed family/caregiver support to participate in appointment via telephone or virtually

Enablers reported by providers included:

- ✓ Improved access to care due to virtual options
- ✓ At times we heard conflicting stories about how the pandemic impacted people's diagnosis experience and deduce that, depending on when during the multiple pandemic waves and lockdowns people interacted with the health care system, an inefficiency or gap in the system may have been either exacerbated or minimized:
 - Perceived prioritizing of patients in the earlier stages of cancer because 'those are the ones who can be saved' versus perceived prioritizing of more urgent, later stage cases

- Delays in getting appointments with family physicians and with diagnostic facilities due to COVID-19 protocols versus reduced delays to see primary care providers because 'even though they had shortened hours, people with a suspicion of cancer were prioritized'
- Extensive wait times (upwards of 3 hours) after arrival for appointment versus reduced waiting because of the fewer number of people scheduled and in the waiting room

Key Take-Aways

- A. **Virtual Communication.** The option of communicating with providers via virtual technology is a welcome addition to clinical practice. Virtual communication reduces wait times for appointments and/or test results and enables the presence of a support person amid a pandemic or other restriction.
- B. **Optimized role of primary care provider.** Primary care providers play an important role as a first line of defence during a pandemic or other catastrophic health care event and should be relied upon to act quickly and remove obstacles as much as possible.

Discussion

This environmental scan has unveiled inefficiencies and gaps in our current state of cancer diagnosis in Canada. Achieving a more desirable future state requires adapting, spreading and scaling what we already know and innovating to fill gaps that cannot be addressed by existing practices.

Our Current State

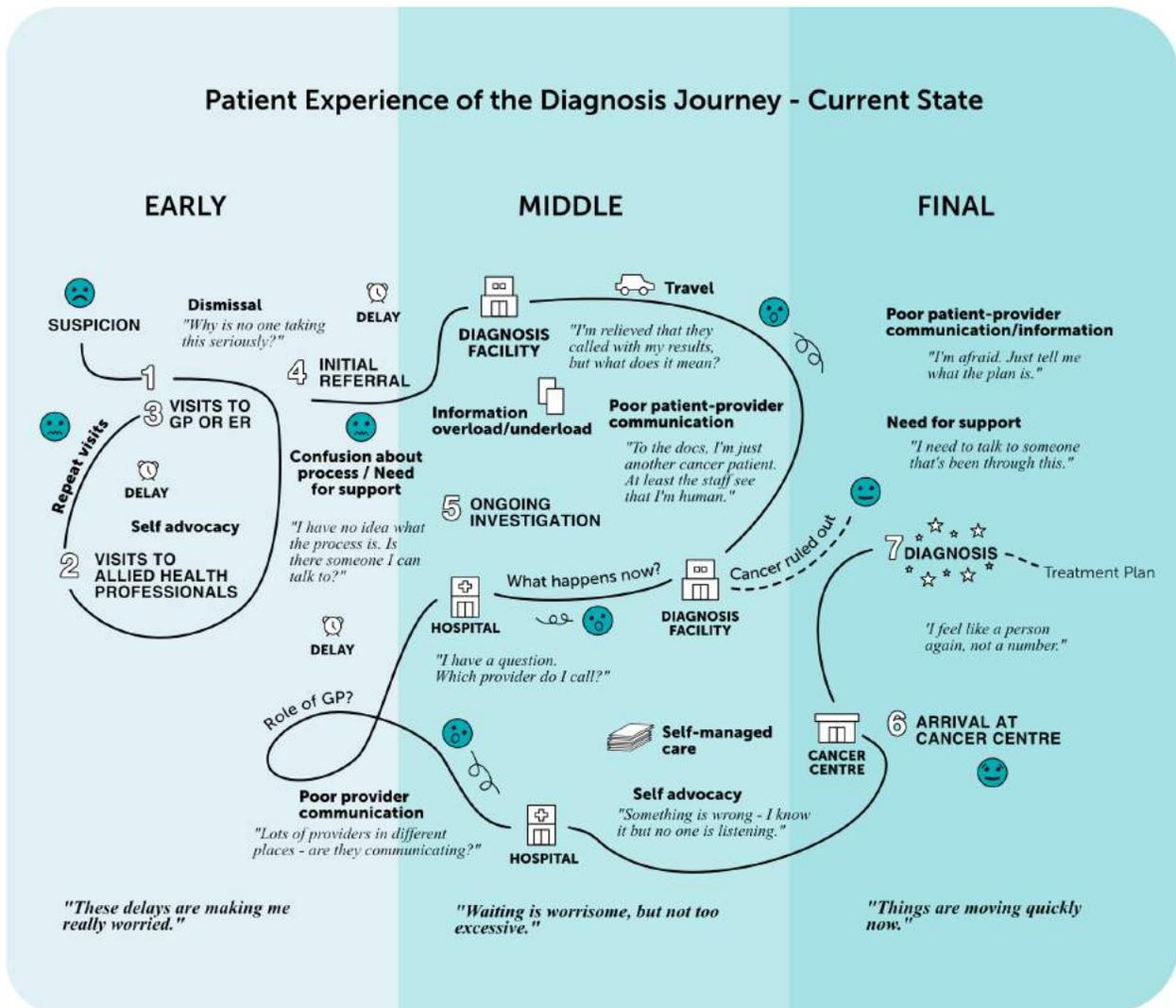
Our characterization of diagnosis in Canada is bleak and has been described by many as the most challenging period in the entire cancer experience. People continually face challenges in the *early phase* of diagnosis as they try to have their concerns validated and appropriately investigated. Perhaps the best word to characterize the current state of the *middle phase* of cancer diagnosis is overwhelming. Time and time again, people in our study used this word when describing the multiple facilities and providers they were forced to navigate on their own. What mattered most to people throughout their diagnosis journey was oftentimes the opposite of what actually happened. The degree to which desired outcomes are currently being achieved varies

Outcomes Indicative of a Quality Diagnosis Process

1. **Swiftness** of the diagnosis process
2. **Validation** of concerns by primary care providers
3. Excellent **patient-provider communication**
4. Effective **provider-provider communication**
5. Better **information**
6. Integrated **psychosocial support**
7. Coordinated and managed care by a **dedicated patient navigator**

considerably by phase of the diagnosis process, and to some extent by type of cancer, age and geographic location of the patient. Figure 3 offers a snapshot of what the current diagnosis journey looks like for people in Canada who are investigating a suspicion of cancer. The nature of cancer diagnosis systems varies across jurisdictions, but one thing is clear -- we have a lot of work to do to achieve the seven outcomes which people identified as being the most important for a quality diagnosis process. Existing strengths and practices need to be shared, modelled, spread, and scaled. Inefficiencies and gaps need to be addressed, and barriers and restrictions to excellent care need to be removed.

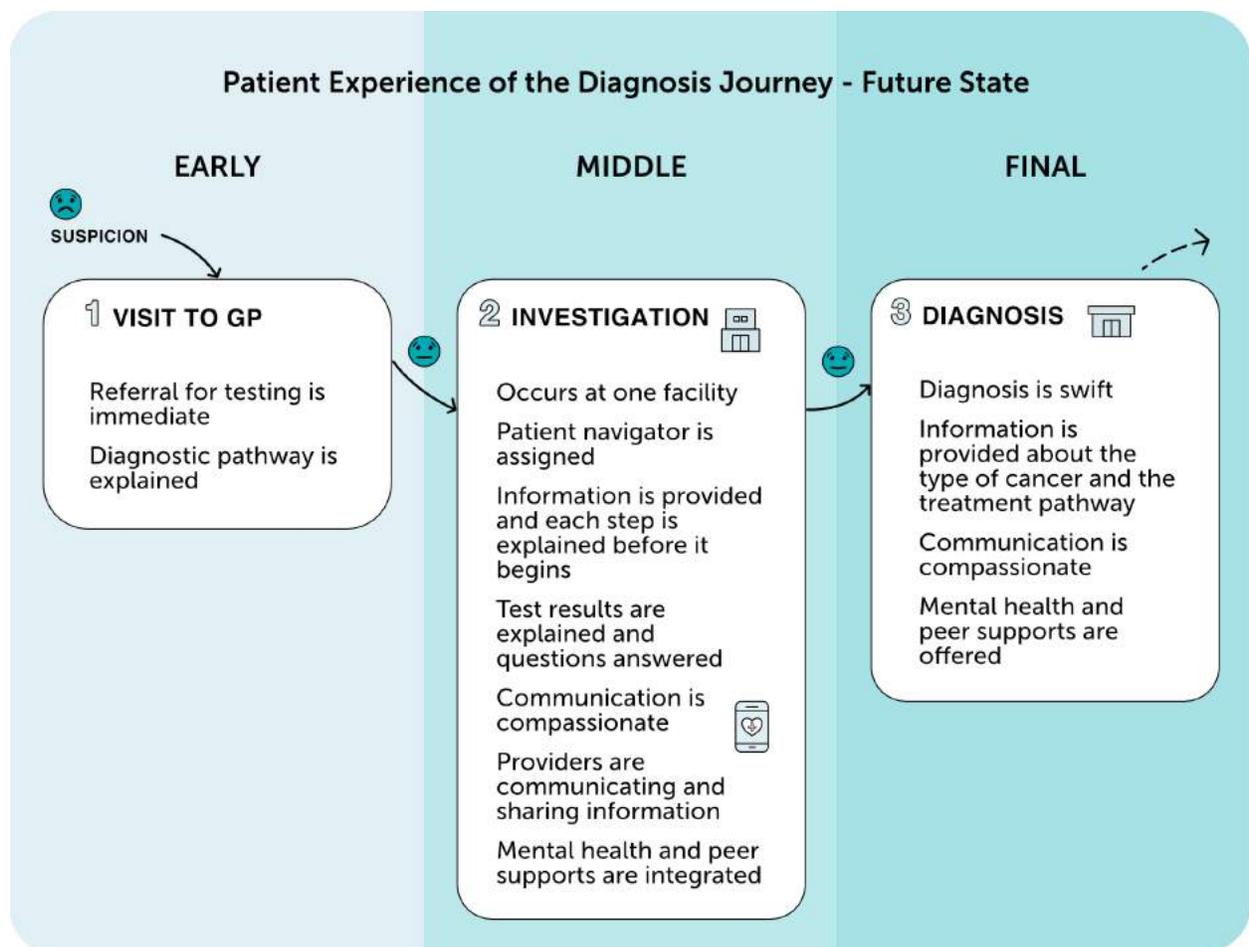
Figure 3. Patient Experience of Cancer Diagnosis in Canada – Current State



Toward a Better Future

Achieving a future, more desirable state of cancer diagnosis does not mean we have to start from scratch. Through our environmental scan, we learned about numerous opportunities and existing practices that, if adapted, spread and scaled for jurisdictional and regional needs, can be an excellent place to begin the realization of a future, more desirable state of cancer diagnosis in which desired outcomes are achieved for everyone. Figure 4 offers a snapshot of what we envision the diagnosis journey *should* look like for people in Canada who are investigating a suspicion of cancer.

Figure 4. Patient Experience of Cancer Diagnosis in Canada - Future State



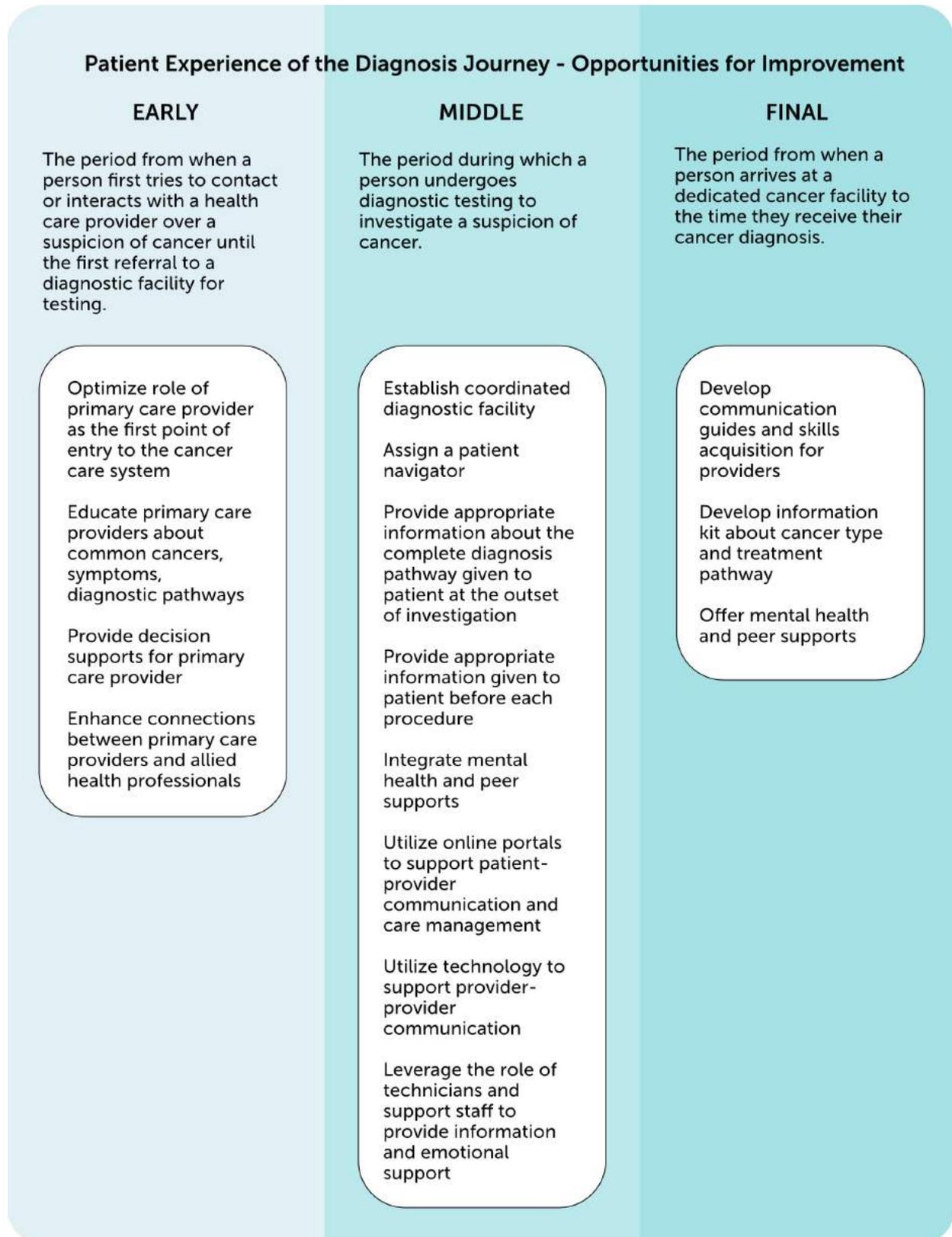
How do we achieve this?

There exists an overarching opportunity for improving early cancer diagnosis and that lies with the primary care provider as they are typically the first point of entry to cancer diagnosis systems. Optimizing the role of the primary care provider involves education, decision supports and enhanced connections between providers and allied health professionals.

Many of the challenges encountered, particularly during the middle phase of the diagnosis process could be mitigated by the presence of a patient navigator – a single person assigned to coordinate a person’s entire diagnosis process from beginning to end. Almost everyone in our study told us that throughout their diagnosis experience the absence of a dedicated patient navigator was one of the biggest gaps in their care. People referred to this person as a pivot nurse, a navigator, and a care coordinator. Regardless of the terms used, the message was clear that this role is critical and is an unmet need in our current diagnosis systems. Other opportunities, many of which can be rectified by a patient navigator, include ensuring investigation occurs at one facility if possible, providing information before each step begins, training providers to communicate with compassion and to share information, and integrating psychosocial support, particularly mental health and peer support, from the get-go.

The advent of a dedicated cancer facility early on in the patient’s diagnosis process enables many of the inefficiencies and gaps in care to be addressed and the subsequent challenges stemming from them to be eliminated. Getting people to a dedicated diagnostic or cancer centre as early on in the diagnosis process is best. Figure 5 summarizes the opportunities for improvement by phase of the cancer diagnosis process.

Figure 5. Opportunities for Improvement



Building on Our Efforts

Existing practices identified through our literature review were designed to address many of the inefficiencies and gaps unveiled in this environmental scan and so represent a good place to start working toward achieving our future state. Both people living with cancer and providers who participated in our environmental scan had encountered one or more of these practices along their diagnosis journey so we know they are being implemented, albeit in varying degrees, locally, regionally and provincially. The effectiveness of many of these practices has yet to be determined and it is the responsibility of policy makers to devise strategies to ensure that practices with proven effectiveness become scaled and integrated into Canadian cancer diagnosis systems. Table 2 summarizes what we know about current practices related to each of the seven outcomes identified by people living with cancer as being critical for a quality diagnosis process.

Table 2. Current practices by desired outcome

Desired Outcome	Current Practice(s)
Swiftness of the diagnosis process	<ul style="list-style-type: none"> • Primary Care Provider Support programs • Specialized Nurse Practitioners • Telepathology • Establishment of Wait Time indicators
Validation of concerns by primary care providers	<ul style="list-style-type: none"> • Guidelines for the Investigation of Patients with Symptoms Suggestive of [colorectal, lung] Cancer • Serious Illness Conversation Guide
Excellent patient-provider communication	None to report
Efficient provider-provider communication	None to report
Better information	None to report
Coordinated and managed care	<ul style="list-style-type: none"> • Patient navigators • Diagnostic Assessment Programs/Rapid Investigation Units • MDTs • E-management tools (e.g., online portals)

Monitoring Our Progress

Measuring the quality of the cancer diagnosis experience will tell us if our efforts are making a difference. Using shared and sound measures will help us to make comparisons across settings and jurisdictions. Measures which can be used to measure the patient experience, commonly referred to as PREMs, are suggested in Table 3 and are aligned with each of the seven desired outcomes identified through this environmental scan. The measures in the table are common to all cancer types, stage of disease and social determinants of health and can therefore be used to benchmark and compare the patient experience across cancer populations and jurisdictions. While this indicator table is a cursory start, it represents the beginnings of a quality framework for cancer diagnosis in Canada, much like those which have been developed for the post-diagnosis phase of cancer care⁹. Once this framework is fleshed out, tools can be developed to measure the patient experience in the diagnosis phase much like those which measure PREMs in the post-diagnosis phase.

⁹ Numerous patient experience frameworks have been created to measure quality in the treatment phase of cancer care including: Health Quality Ontario's Patient Engagement Framework; Warwick Patient Experiences Framework; and, NHS Patient Experience Framework.

Table 3. Suggested patient reported experience measures

DESIRED OUTCOME	MEASURES
Swiftness	<p>Referral for testing within x days; Receipt of test results within 14 days; Diagnosis received within x days of contacting or interacting with a health care provider over a suspicion of cancer; Comparable wait times within jurisdictions, irrespective of geography</p>
Validation by primary care providers	<p>Person perceives that primary care provider validates their concerns; Providers have knowledge of different cancers, their symptoms and their diagnosis pathways; Referral for symptom investigation is appropriate; All primary providers and allied health professionals are aware of the person's symptoms and diagnosis trajectory</p>
Coordination and care management	<p>Patients are assigned a single coordinator for the duration of their diagnosis process; Patients receive care from a multidisciplinary team; People have access to online tools or apps to help manage care; Availability of telepathology services and/or reimbursement of travel costs for patients and their loved ones for diagnostic services</p>
Patient-provider communication	<p>Patient feels confident they understand all the information providers tell them; Patient feels confident they understand their test results and the implications of their test results; Patient always knows what the next steps in the diagnosis process are; Providers possess skills to discuss serious illness with a patient; Patient always knows how to reach their provider if they have any questions</p>
Provider-provider communication	<p>Reduced re-work/re-referrals/rescheduling; Unnecessary repeat testing eliminated; Misdiagnosis avoided; Clarity about the diagnostic trajectory among providers and patients; Trust in providers and the diagnosis system ; Timely follow-up and swift diagnosis; Availability of technology to collect and share information among providers and patients; Use of technology to collect and share information among providers and patients</p>
Information	<p>Patient understands the diagnosis pathway for their type of suspected cancer; Patient understands each step along the diagnosis pathway; People diagnosed with cancer understand what the treatment trajectory entails; People are satisfied with the information they receive from health care providers when they receive it; People know who to ask if and when they have questions; People feel their questions are satisfactorily answered</p>
Psychosocial support	<p>Psychosocial support is offered to patients in the early phases of diagnosis; Psychosocial support is available and accessible as needed</p>

Recommendations

Inefficiencies and gaps in optimizing patient entry into diagnosis systems in Canada abound and there are many opportunities for improvement. Action must be taken by policy makers and those working in cancer control in Canada to improve the cancer diagnosis process for all Canadians.

In this section, we present a set of key recommendations to improve the swiftness, accuracy and appropriateness of communication of the diagnosis process in Canada. Where appropriate, sub-recommendations or enablers that facilitate achievement of the broader strategic goal are identified and, where appropriate, tied to diagnosis phase – early, middle and final, in order to adequately address the different inefficiencies and gaps that present challenges at key points along the diagnosis trajectory. This approach will be instructive for policy makers and other stakeholders when crafting solutions to address the gaps and inefficiencies. Recommendations have been written so that they remain relevant given the uncertain, but potentially major and long-lasting, impacts on the health care system of the COVID-19 pandemic.

Recommendation #1:

National convening and coordination of the efforts of various stakeholders in implementing these recommendations are required, with patients and patient representatives providing meaningful leadership in any ongoing multi-stakeholder implementation efforts.

Recommendation #2:

Create opportunities to enhance primary care provider knowledge of cancer types, associated symptoms, and established diagnosis pathways.

Regulated health professionals, i.e., nurses, physicians and allied health professionals, are the first providers encountered in the early phase of diagnosis as people begin to explore and seek validation for their symptoms. These providers are in a position to fast-track early diagnosis if they move quickly to recognize symptoms, interpret test results, and initiate appropriate diagnostic pathways.

The environmental scan identified a need for provider education, knowledge, and tools about cancer types and symptoms to reduce the delayed initiation of appropriate symptom investigation for Canadians. Multiple and repeat visits to primary care providers, emergency rooms, and allied health professionals during the early phase of diagnosis unnecessarily strain and cost the health care system while delays in appropriate testing compound a person's anxiety about advancing illness.

Efforts to optimize the role of the primary care provider should encompass primary care providers in clinics, community, and hospital settings and should be extended to allied health professionals. Priority should be given to family physicians and primary care nurse practitioners as they play pivotal roles for patient entry into the cancer care system, as a touchstone during the middle phase of diagnosis, and as a first line of defence during a pandemic to act quickly and remove obstacles as much as possible.

- A. **Catalogue currently available cancer training/education in order to improve upon and better integrate knowledge into relevant post-secondary medical and continuing education programs** for practicing providers including knowledge of cancer types, symptoms, and diagnostic pathways.

- B. Work with professional colleges to **offer knowledge mobilization and awareness raising opportunities** for practicing providers.
- C. Work with provincial cancer systems to **ensure awareness and utilization of established standardized diagnostic pathways and guidelines** by all providers working in cancer control, including primary care providers and allied health professionals, through a common repository of diagnostic pathways.
- D. Work with provincial cancer systems, researchers, cancer patients, and other stakeholders to **develop new standardized diagnostic pathways and guidelines** for more types of cancers that are added to the common repository.
- E. **Develop electronic decision supports** for primary care providers to enable them to assess risk for various types of cancers (e.g., standardized clinical decision support/risk assessment algorithms). Work with key national organizations in Canada to ensure the work is done, standardized, and knowledge is translated and adapted from one province/territory to another (e.g. Health Excellence Canada, Canadian Institute for Health Information, Canada Health Infoway, Canadian Association of Provincial Cancer Agencies).
- F. Work with professional colleges to **create opportunities for communication skills acquisition** to support excellent patient-provider communication throughout the diagnosis process.

Recommendation #3:

Ensure consistently available and accessible patient navigator for all cancer types and all jurisdictions throughout the cancer diagnosis process.

Within jurisdictions or even within regions, diagnostic services and the diagnostic process are rarely cohesive and there is no consistently available and accessible role

dedicated to coordinating a person's diagnostic process from beginning to end, leaving people to rely upon themselves to navigate a complex and fragmented system. Meanwhile, primary care represents an important but under-utilized sector within the cancer diagnosis process. Overall, the lack of patient navigation represents a significant gap, leading to system-level waste and inefficiencies and abysmal patient experiences.

This research found that patient navigators go by many different titles (e.g. care coordinators, cancer coaches, pivot nurses). However, the role refers to someone assigned to the patient who is available and accessible throughout the diagnosis process from beginning to end and who is responsible for effective patient-to-provider communication and information sharing; clinical patient navigation; connecting the patient with other needed supports, including psychosocial supports; and consistent, accurate, and timely provider-to-provider communication.

- A. Work with provincial and territorial governments, cancer control agencies, provider associations, and other stakeholders to **assign system-level accountability to primary care to coordinate the cancer diagnosis process during the early to middle phases**. Primary care providers need patient navigation capacity to proactively connect with other parts of the health care system and other systems on behalf of patients. This also requires the establishment of supportive accountability agreements with primary care providers.
- B. Work with cancer control agencies, and other stakeholders to **grow and expand patient navigation, multidisciplinary teams, and diagnostic assessment programs (DAPs)** within all jurisdictions across Canada to provide a clear point of entry into the cancer care system, assessment within a single location (or at least coordination of assessment), and access to a multidisciplinary team that includes a clinical patient navigator.
- C. Work with provincial and territorial governments, provider associations, cancer control agencies, and other stakeholders to **grow and expand physician funding models that support integrated primary care and integrated cancer care and the achievement of patient-defined outcomes in cancer diagnosis**.

Recommendation #4:

Provide patients the right information at the right time and establish technological mechanisms to facilitate communication throughout the cancer diagnosis process.

Providers and policy makers alike have long recognized the need to improve coordination and care management within cancer care systems using relevant patient-facing information as well as enabling communication technologies and have taken fruitful steps toward this end. While these steps have introduced innovations and interventions into the cancer care system, most are introduced post-diagnosis. There is much opportunity to enhance coordination in the diagnostic phase of the cancer care continuum using what we already have. Efforts to improve should always focus on patient navigation support, reducing silos, enhancing communication, and better information.

- A. Work with professional colleges, provider associations, cancer control agencies, and other relevant stakeholders to **ensure the information provided to patients matches the information needed** at each phase of the diagnostic process. Specifically, upon entry to the middle phase, provide an overview of the diagnostic pathway. Throughout the middle phase of diagnosis, provide details of what to expect along each step of the diagnosis pathway *before* it occurs. At the final phase of diagnosis, give the patient an information kit that explains the type of cancer and its treatment(s) and includes a list of reliable sources of information along with a phone number of who or where to call to ask questions (and ideally connecting them with their patient navigator for the treatment phase of their cancer care).
- B. **Identify a national body to lead and coordinate the development of technological mechanisms** outlined below so that tools that support communication and coordination can be scaled and spread across jurisdictions (e.g. Canada Health Infoway, Health Excellence Canada, possible private-public partnerships).

- C. **Support the spread of user-friendly smart-phone applications** to enhance provider-provider and patient-provider communication and connection.
- D. **Improve on and spread user-friendly online portals** that are invoked the moment a patient enters the cancer care system and which can store clinical patient information, make personal health information accessible to patients, and support shared decision-making between patients and providers. Portals must link to existing EMRs and programs in clinics and both patients and providers need to have access to this information as part of a patient's medical history/file.
- E. **Scale virtual communication technology** to reduce appointment wait times, increase provider access, and ensure attendance of a support person at appointments during restricted times or otherwise. Establish guidelines around what can be effectively managed virtually and what requires in person consultation. Prepare patients for doing visits related to the cancer diagnosis process in a virtual environment.
- F. **Grow and expand telepathology** to make diagnostic care more accessible and faster for people living in rural and Northern Canada.
- G. **Remove barriers to digital equity through digital inclusion initiatives** to ensure individuals and communities facing barriers achieve access to digital devices, bandwidth and any other mechanisms required, e.g., electricity and freely available Wi-Fi, as well as meaningful adoption that enables underserved people to have the means and knowledge to use technology through easily accessible education and support.

Recommendation #5:

Expand availability and accessibility of psychosocial supports for people going through cancer diagnosis and create linkages between cancer care and supportive care.

From the moment a person begins to wonder if they have cancer to the time a final diagnosis is reached, waiting for test results, needing to self-advocate, and unnecessary delays due to provider or system error coupled with the looming threat of a cancer diagnosis take an immense toll on a person's mental health and wellbeing. We know that treating the whole body goes a long way to treating the actual cancer (Spiegel, 2012) yet a psychosocial support network is lacking in our current cancer care systems.

Currently, there is a lack of affordable and accessible psychosocial supports consistently available to people across jurisdictions who are going through the cancer diagnosis process and those that do exist need to be better coordinated, integrated and proactively offered to patients. Integrating psychosocial supports into patient care alongside diagnostic testing and medical procedures requires the creation of linkages between cancer care systems/providers and supportive care services/providers. Stakeholders are diverse and may include patient advocacy groups, mental health providers, personnel in diagnostic facilities, and employee assistance or financial aid programs.

- A. Work with national bodies such as the Mental Health Commission of Canada, the National Network for Mental Health, the Canadian Mental Health Association, Canadian Association of Psychosocial Oncology and All.Can Canada Hub for Mental Health to **grow and expand psychosocial supports for people going through cancer diagnosis across Canada and across cancer types** and to create linkages to psychosocial supports as outlined below.
- B. **Increase provider awareness of existing psychosocial supports, including those provided by patient groups**, regionally and by jurisdiction and **create**

mechanisms for providers (including nurses, patient navigators, technicians, support staff) to easily connect patients with these supports.

- C. **Embed psychosocial supports** into community-based primary care services, diagnostic facilities, and hospital settings.
- D. **Provide funding for travel and other needed diagnostic process supports** for people living in rural, remote and Northern Canada.

Recommendation #6:

Develop a patient-centred quality framework to measure, benchmark, and improve the efficiency and effectiveness of cancer diagnosis.

There is an abundance of literature concerned with the quality of cancer care in Canada and the outcomes that one would expect to see in a high-quality cancer care system. This work is confined, for the most part, to the post-diagnosis phase of the cancer continuum. Measuring quality in the diagnosis phase is relatively new and is currently limited to just three indicators – wait times, patient satisfaction, and stage of cancer at diagnosis.

To adequately capture the achievement of patient-defined outcomes and experiences in the diagnosis process, better measures are needed to ensure that the sum of an individual's perceptions, expectations and interactions related to their health and care are measured from the patient's perspective. Adequately measuring the complexity of the patient experience throughout the diagnosis experience will require research and a person-centred lens.

- A. Work with key stakeholders (e.g. Canadian Institutes for Health Information, Canadian Partnership Against Cancer, Canadian Cancer Society) to **build on the cancer diagnosis quality framework** which originated from this research project to establish patient-reported experience measures (PREMs) and other metrics

associated with each of the seven outcomes identified in this research, which are common to all cancer types, stage of disease and social determinants of health, to benchmark, compare, and improve across cancer populations and jurisdictions. Once a quality framework is established, develop tools to measure the patient experience in the cancer diagnosis process and use this information for reporting and to guide performance improvement. To this end, create a national dashboard with key metrics and data points of the diagnosis process.

- B. **As part of the cancer diagnosis quality framework, continue to establish wait time targets** within jurisdictions for various types of cancer with an eye toward establishing national targets.

Conclusion

This environmental scan represents an important step in understanding the current state of patient entry into Canada's cancer care systems, with a focus on ensuring a swift, accurate and appropriately delivered diagnosis. The research has added to the limited body of knowledge about inefficiencies and opportunities within the current systems of cancer diagnosis in Canada.

Some of the patient participants and all of the providers surveyed for this research experienced the diagnostic process amid the COVID-19 pandemic so this research is one of the first of its kind to help us understand in what way, if any, the pandemic exacerbated pre-existing inefficiencies in Canadian cancer care systems and, perhaps, what measures introduced during the pandemic should be examined more closely as potential lessons that should be applied to our current and future state.

Examined together, the findings are encouraging. We are not starting from scratch but there is much work to be done. Viewed from an antifragility¹⁰ lens, the recommendations contained within this report serve to improve the diagnosis phase of the cancer care system such that it can absorb shock and improve. The recommendations' calls for healthcare reform recognize health as an important economic driver in our struggle to deal with the long-term economic fallout of the COVID-19 pandemic.¹¹

Limitations

The research for this environmental scan is not without limitations.

First, the practices identified in the environmental scan were derived from previously published peer-reviewed research and literature which was published on the Internet. Oftentimes the details we were able to extract afforded us only a cursory glance into

¹⁰ Antifragility is defined as a system that can absorb shock and get better (Taleb, 2014).

¹¹ (McKinsey, 2020).

a practice, precluding us at times from determining generalizability, utility of practice application, and implications for policy development. While many of the practices included in this scan may indeed be exemplary, without further details or evaluation data about these practices, it is impossible for us to draw firm conclusions.

Next, recruiting people with common types of cancer for some of the patient interviews (i.e., breast, colorectal) means that care guidelines and wait time benchmarks may already be in place so we may be speaking to people for whom the diagnosis experience may already be more optimal because of existing healthcare system practices.

In addition, while every effort was made to recruit newcomers and racialized people, people residing in Nunavut, Northwest Territories and the Yukon, none of these people came forward to be interviewed and our findings are therefore not necessarily generalizable to these groups of people.

Indigenous populations (including First Nations, Inuit, and Métis) are not included in our patient sample and therefore the findings are not necessarily generalizable to Indigenous populations. Finally, while we detected some jurisdictional differences in participant experiences, our small sample size precludes us from drawing any conclusions about jurisdictional disparities.

The provider survey was conducted through convenience sampling despite attempts to alert various stakeholders to participate. Therefore, the results of this survey are not necessarily representative of all provider groups across Canada. Most likely there is a selection bias inherent in the data. For example, certain types of providers may be more likely to complete an online survey compared to others. Furthermore, there may have been multiple responses from providers within a single institution potentially biasing the results towards a certain direction. This does lead to difficulties in generalizing the results beyond the respondents of the survey.

The survey was intended to gather information from a sample of providers who represented six jurisdictions within Canada to allow us to compare and contrast

perspectives in the hope of detecting any jurisdictional differences. While we were successful in hearing from providers from five of our six jurisdictions of interest, the sample size from each of these jurisdictions was small and we did not hear from anyone representing Nunavut, Northwest Territories, or the Yukon. Jurisdictional differences have therefore not been analyzed or reported.

Due to the small respondent sample, the provider survey data was not analyzed to compare and contrast the perspectives of those who worked in different fields, or who held different roles, within the cancer control arena.

Provider responses to the survey questions which asked about inefficiencies could have been strongly influenced by the shutdowns which were occurring during the COVID-19 pandemic during which time the survey was administered.

Areas for Further Research

Our understanding of the **impact of social determinants of health on the diagnosis experience** for Canadians is limited as the body of literature in this area is not well developed and the limitations of our patient interview sample afforded us only a cursory glance into this area. To gain a fulsome understanding of the impact of social determinants on health in the diagnosis experience further research is needed. In particular, further research into solutions to expedite and improve cancer diagnosis for Indigenous and underserved populations, specifically racialized and recent newcomers to Canada.

The environmental scan identified many points along the diagnosis pathway where delays occur and unveiled, to some degree, the **reasons for delays along the diagnostic pathway**. While there is a decent body of Canadian literature that examines the reasons for wait time delays during the diagnosis phase of cancer care, an in-depth analysis of this literature was beyond the scope of this environmental scan but remains an important area of study as it may unearth recommendations for

reducing wait times that may be generalizable across populations and jurisdictions (Astrid Brousselle, 2017), (A. Barisic, 2016), (J.O.A. Kim, 2016).

There is a small body of Canadian literature which reports on the design of, and process improvements specific to, coordinated diagnostic services which would be informative to help service and program developers learn from other's LEAN processes on **how to reduce re-work and bottlenecks along the diagnosis process** (J. Pantarotto, 2017), (C. Cotton, 2020), (G.N. Honein-AbouHaidar, 2017).

One challenge in the use of wait times as an indicator of system quality is purely administrative in that hospitals must have processes in place to collect data (CCO, Target Wait Times for Cancer Surgery in Ontario, 2006). Further, as wait time data is collected, it must be analyzed against established targets and quality improvement methods then used to improve flow and remove bottlenecks along the diagnosis pathway. This work opens up an entirely new body of literature concerned with the **design and optimization of diagnosis pathways** which is beyond the scope of this review and is the purview of quality improvement specialists. However, given the concerns over delays in the diagnostic interval in Canada, it is imperative that jurisdictions create the infrastructure necessary to regularly measure, compare and report the durations of care intervals for patients. Research into how best to create this infrastructure to support continuous quality improvement is needed.

Several studies in the peer-reviewed literature report a lack of knowledge and skills among primary care providers to be a significant barrier to a swift cancer diagnosis. Specifically, primary care providers may lack the knowledge and skills to correctly assess a patient's cancer risk and to take actions to reduce diagnostic delay (Tara C. Horrill, 2019) (CPAC, 2018). This review found very few interventions or practices geared toward supporting primary care providers, apart from standardized care pathways and centralized referral services, that support decision-making about which patients should be referred for investigation and to what specialist. We did find one resource developed by the Quebec government intended as a guide for family doctors that provides a detailed breakdown of symptoms and screening procedures in relation to different types of cancers (Cancérologie, 2017) and several other

documents and online tools also exist in the Quebec context to support doctors and dentists to identify cancer symptoms. Overall, however, practices are few and fragmented. **Strategies to support primary care providers to recognize cancer symptoms and facilitate appropriate referral** is an area for future research.

A comprehensive index for measuring the quality of the diagnosis phase of cancer care is lacking. Currently, three groups of indicators are used to measure quality and include wait times, patient experience (mainly patient satisfaction), and clinical outcomes (i.e., stage of cancer at diagnosis/survival rates). Of the three, wait time measures are most often reported in the literature. Wait time data is relatively easy to collect and provides a good measure of process efficiency along the diagnosis pathway. Wait time targets are usually established alongside the development of standardized care pathways, and there is much variation in targets between and even within jurisdictions. While all provinces and territories within Canada collect and report on wait times for various types of cancer, there has been little attempt to standardize wait time targets or to determine, from a patient perspective, how long is too long. Ontario established a provincial Wait Times Strategy in 2004 but to date seems to be the only province that has undertaken such an initiative. Part of the challenge in establishing targets and measuring wait times lies in definitions – i.e., ensuring that the key dates (i.e., first consult, decision-to-treat) are consistently defined. Lack of consistency in definitions and thus a lack of common indicators, precludes us from having national data with which to inform best practices.

Measurement of patient reported outcomes and the patient experience, beyond simple patient satisfaction indicators, are just now coming into fruition with the advent of patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs). Currently, this work is largely concerned with the post-diagnosis phase of cancer care to improve the quality of the patient experience as they transition through treatment, survivorship and palliative care. Using the seven common themes identified in this environmental scan, we can begin to evaluate the quality of the diagnosis experience. Indicators which can be used to measure the patient experience, referred to in the literature as PREMs, are suggested and are based on what mattered most to patients in each phase of the diagnosis process as

gleaned from the participant interviews. The indicators are common to all cancer types, stage of disease and social determinants of health and can therefore be used to benchmark and compare the patient experience across cancer populations and jurisdictions. While this indicator table is a cursory start, it represents the beginnings of a quality framework for cancer diagnosis in Canada, much like those which have been developed for the post-diagnosis phase of cancer care. We propose that, once this framework is fleshed out, tools can be developed to measure the patient experience in the diagnosis phase much like those which measure PREMs in the post-diagnosis phase.



Appendix A: Canadian Practice Spotlights

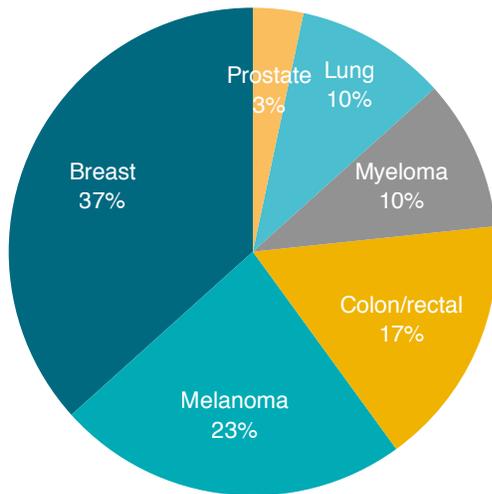
Name	Province	Scope	Cancer type(s) targeted					
			Breast	Colorectal	Prostate	Lung	Melanoma	Other
Standardized Care Pathways								
IN SIXTY	Manitoba	Provincial	✓	✓	✓	✓	✓	✓
CCO Pathway Maps	Ontario	Provincial	✓	✓	✓	✓	✓	✓
Discrete Interventions								
Centralized Referral Services								
CCMB Centralized Referral Service	Manitoba	Provincial	✓	✓	✓	✓	✓	✓
Cape Breton Cancer Centre 10-Step Referral Process	Nova Scotia	Regional	✓	✓	✓	✓	✓	✓
Multidisciplinary Teams (MDTs)								
Multidisciplinary Teams (MDTs)	Multiple	Provincial, territorial, regional	✓	✓	✓	✓	✓	✓
Edmonton Multidisciplinary Melanoma Clinic (MMC)	Alberta	Provincial						✓
Patient Navigator Programs								
Cancer Northwest Program	NWT	Territorial	✓	✓	✓	✓	✓	✓
CCMB Cancer Navigation Services	Manitoba	Regional	✓	✓	✓	✓	✓	✓
Juravinski Cancer Centre Navigation Program	Ontario – Hamilton	Regional	✓	✓	✓	✓	✓	✓
Cancer Coaching Program	Ottawa	Regional	✓	✓	✓	✓	✓	✓
Cancer Centre Program of Eastern Canada	Eastern Canada	Regional	✓	✓	✓	✓	✓	✓

Peer Navigation Program	Newfoundland and Labrador	Provincial	✓	✓	✓	✓	✓	✓
Technology								
Pan-Canadian Digital Pathology Network	Ontario, Newfoundland and Labrador, Manitoba	Multi-jurisdictional	✓	✓	✓	✓	✓	✓
OPTILAB Montreal-CUSM	Quebec	Regional	✓	✓	✓	✓	✓	✓
DAP-EPS	Ontario	Provincial	✓	✓	✓	✓	✓	✓
Rural Saskatchewan Telehealth Clinic	Saskatchewan	Regional				✓		
Communication Resources and Tools								
Guidelines for the Investigation of Patients with Symptoms Suggestive of Colorectal/Lung Cancer	Nova Scotia	Provincial		✓			✓	
Serious Illness Conversation Guide	Nova Scotia	Provincial	✓	✓	✓	✓	✓	✓
Primary Care Supports								
Programme québécois de dépistage du cancer du sein (PQDCS)	Quebec	Regional	✓					
Specialized Nurse Practitioner	Quebec	Regional	✓	✓	✓	✓	✓	✓
Coordinated Diagnostic Services								
Rapid Access Breast Clinics (RABCs)	British Columbia – Vancouver	Regional	✓					
Breast Cancer End-to-End Pathway	Alberta - Calgary, Edmonton	Provincial	✓					
Alberta Thoracic Oncology Program (ATOP)	Alberta - Calgary, Edmonton	Provincial				✓		

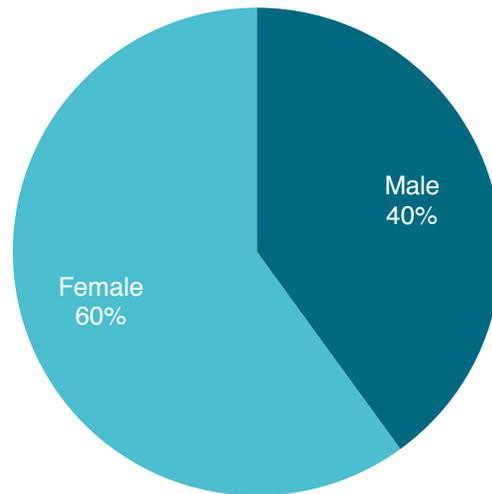
Prostate Assessment Pathway	Saskatchewan	Provincial			✓			
Time to Treat Program (DAP)	Ontario – Toronto	Regional				✓		
Ottawa Hospital Cancer Assessment Clinic (DAP)	Ontario - Ottawa	Regional	✓					
Breast Assessment Program (BAP)	Ontario – Kingston	Regional	✓					
LDAP Kingston Health Sciences Centre	Ontario – Kingston	Regional				✓		
Lung Diagnostic Assessment Program (LDAP)	Ontario - Hamilton, Niagara, Haldimand and Brant					✓		
Sunnybrook Health Sciences Centre Rapid Diagnostic Units	Ontario – Toronto	Regional	✓		✓		✓	
Diagnostic assessment program	Quebec - Quebec City	Regional	✓	✓	✓	✓	✓	✓
Rapid investigation clinic (RIC)	Quebec – Montreal	Regional	✓	✓	✓	✓	✓	✓
Thoracic Triage Panel (TTP)	Newfoundland – St Johns	Regional				✓		

Appendix B: Snapshot of Patient Participants

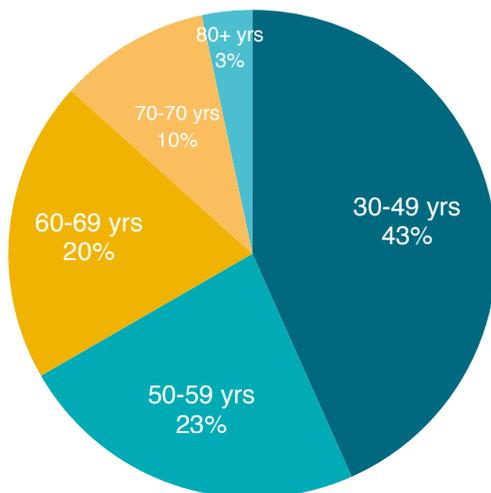
Type of cancer (n=30)



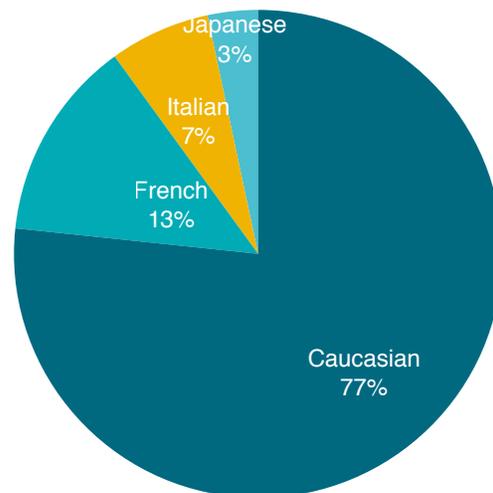
Sex (n=30)¹²



Age (n=30)



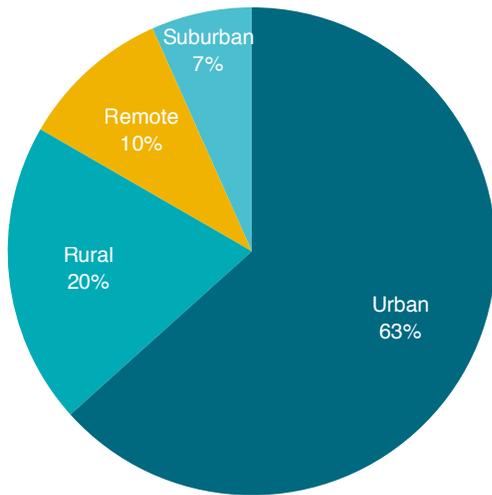
Ethnicity (n=30)¹³



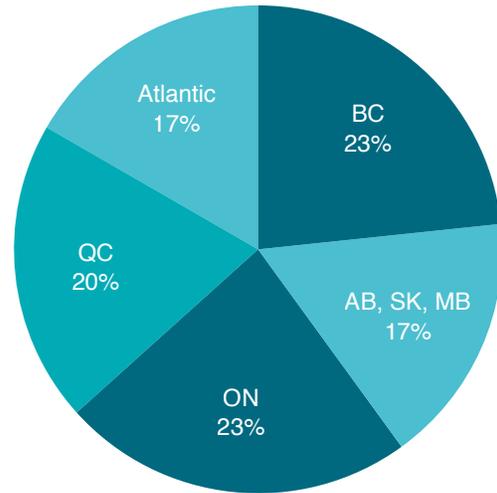
* The patient sample is described according to the sex of the person diagnosed with cancer; three women participated in an interview on behalf of a male patient and were therefore counted as male participants.

¹³ Every effort was made to recruit recent newcomers or racialized people for the study; no participants came forward to be interviewed.

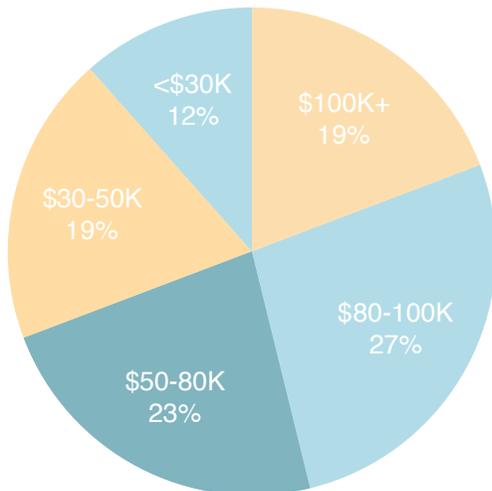
Geography (n=30)



Jurisdiction (n=30)¹⁴



Socioeconomic status (n=28)¹⁵

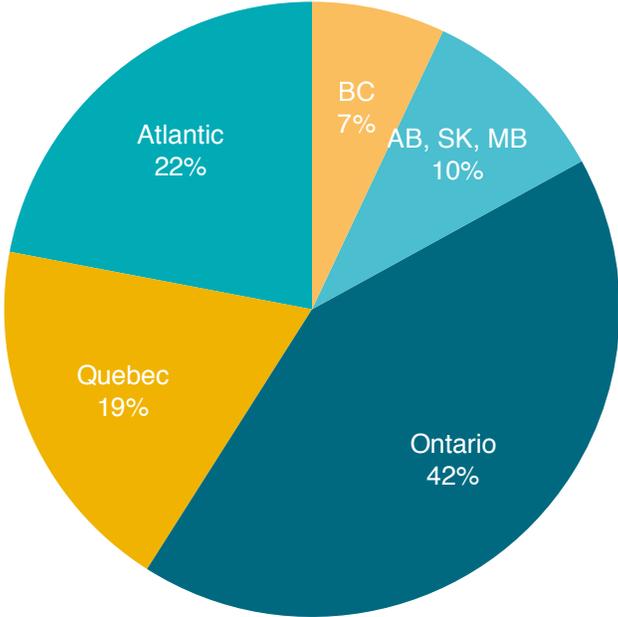


¹⁴ Every effort was made to recruit participants from Nunavut, NWT and Yukon; no participants came forward to be interviewed.

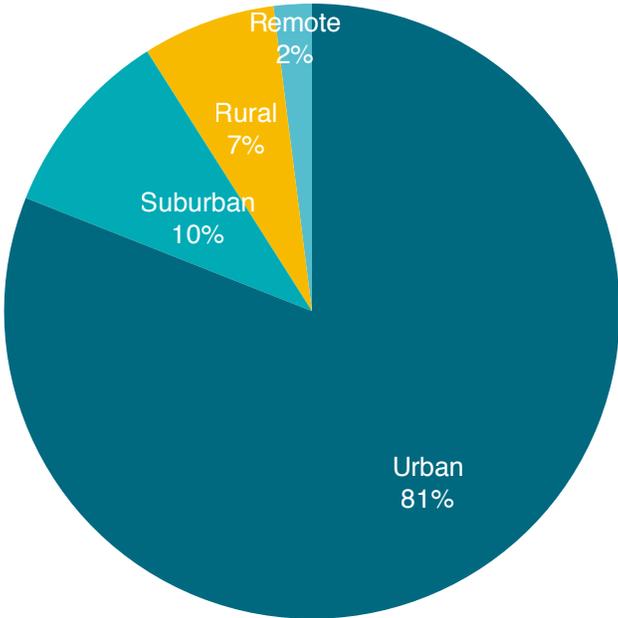
¹⁵ SES was determined by asking the person their total annual household income from all sources; two participants declined to answer the question.

Appendix C: Snapshot of Provider Respondents

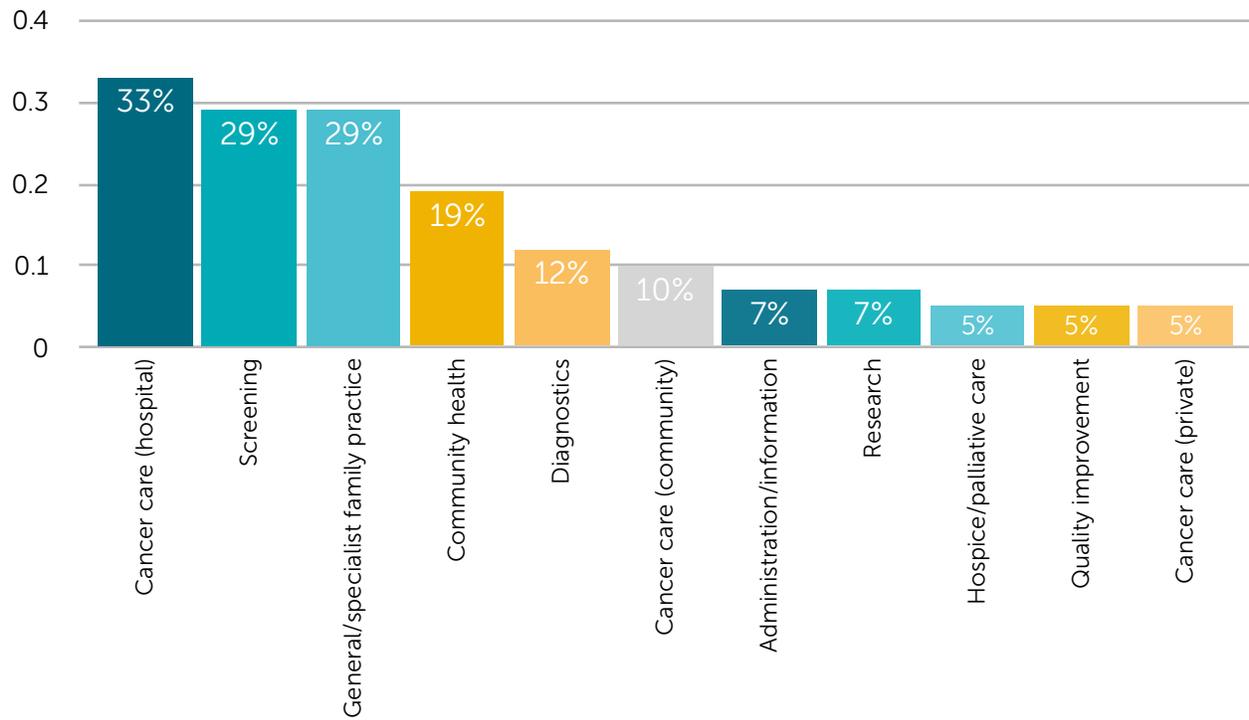
Jurisdictional representation (n=42)



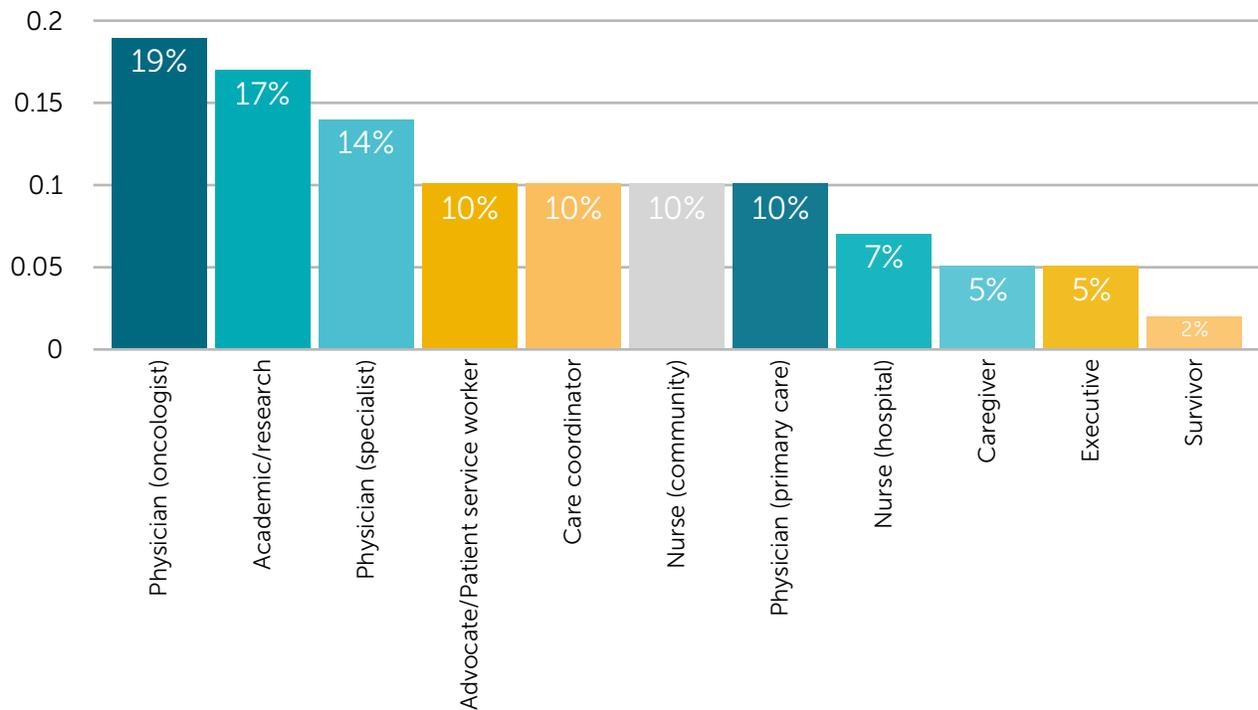
Geographic representation (n=42)



Field of work or study (n=35)



Primary role (n=30)



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