All.Can Canada

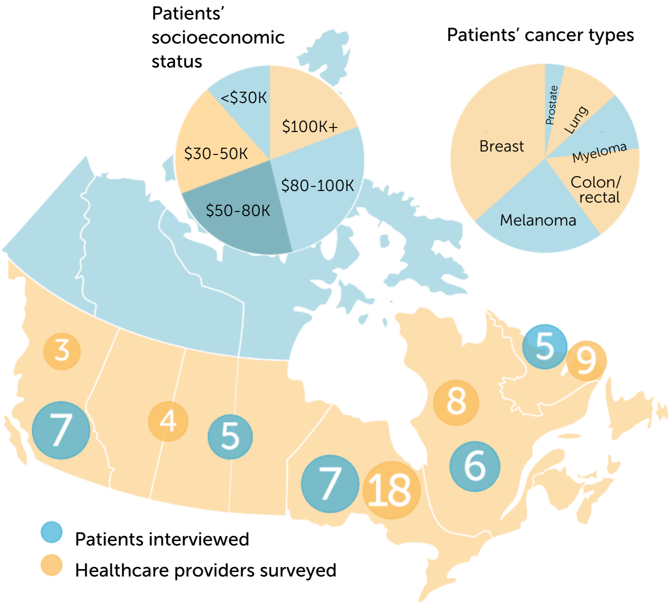
'Optimizing Diagnosis in Canadian Cancer Care' Research Report
Summary of Key Findings & Recommendations

About All.Can Canada

All.Can Canada is a national, multi-stakeholder platform for cancer care efficiency, with a preliminary aim of optimizing people's entry into cancer care through swift, accurate, and appropriately delivered diagnosis.

Understanding the Current Diagnosis Experience of Canadian Cancer Patients

As a first step, it was decided that a rigorous scan was needed to identify outcomes that matter most to patients, review promising practices in cancer diagnosis, and explore areas of inefficiency that represent opportunities for improvement.
The research included a literature review, **30** qualitative interviews with cancer survivors across Canada and a survey of relevant healthcare providers across Canada.



Findings: Phases of Diagnosis & Seven Outcomes Critical to a Quality Diagnosis Experience

Irrespective of cancer type, stage of disease or social determinants of health, patients with lived experience of cancer described the diagnosis process as taking place in three distinct phases:

EARLY PHASE	The period from when a person first tries to contact or interact 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

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Satisfaction with the diagnosis experience differed markedly by phase, with most people finding the early and middle phases to be the most challenging and the final phase to be quite a bit smoother.

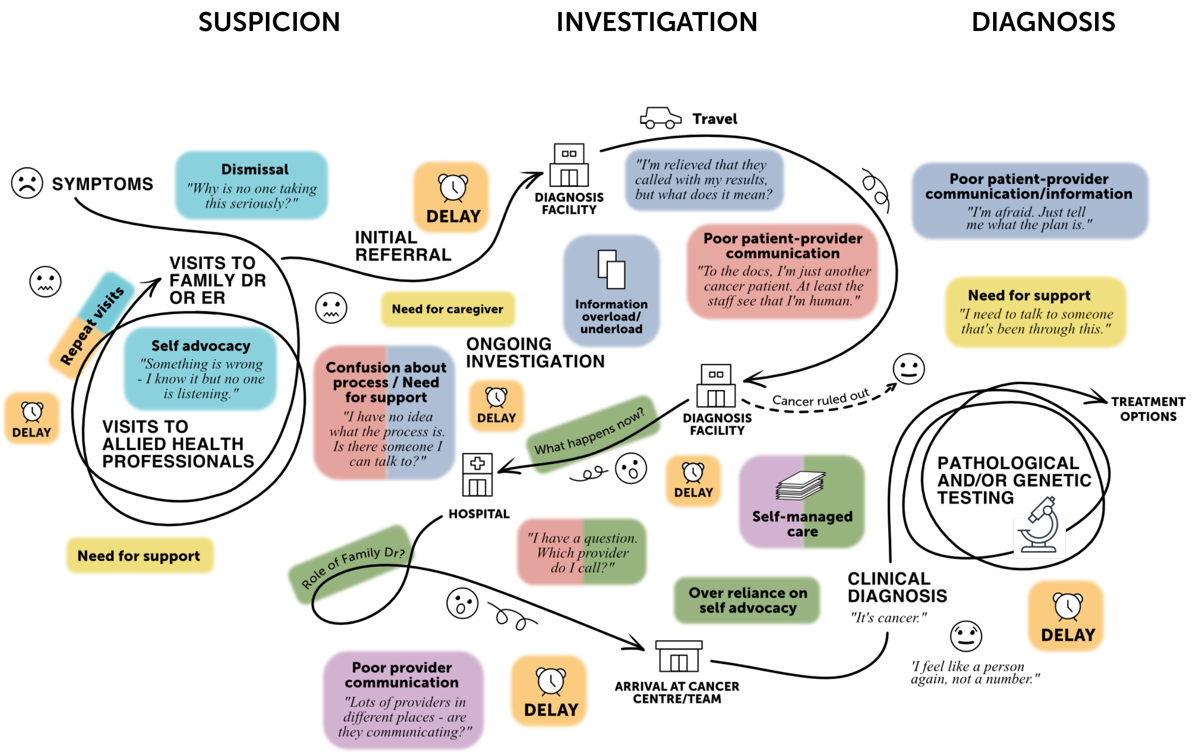
From the moment a person tries to interact with a healthcare provider over a suspicion of cancer to the point they receive their diagnosis, **seven outcomes are critical to a quality diagnosis experience.**

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

*Outcomes correspond to the colours on the current state diagram below

Findings: The Current State of Cancer Diagnosis in Canada

Characterization of the current state of diagnosis in Canada is bleak and has been described by many as the most challenging period in the entire cancer experience. This map offers a snapshot of what the research found to be the current state of the diagnosis process for people in Canada.



Findings: The Future State of Cancer Diagnosis in Canada

Achieving an improved future state of cancer diagnosis doesn't mean we have to start from scratch. Through the research, numerous opportunities and existing practices were discovered that, if adapted and scaled for jurisdictional and regional needs, can be an excellent place to begin the realization of an optimized future state of cancer diagnosis in which the seven key outcomes are achieved for everyone.

This figure offers a snapshot of what the diagnosis journey *should* look like for people in Canada who are investigating a suspicion of cancer.

1. VISIT TO PRIMARY CARE

- Referral for testing is immediate
- Diagnostic pathway is explained

2. INVESTIGATION

- Occurs at one facility
- Patient navigator is assigned
- Information is provided and each step is explained before it begins
- Test results are explained and questions answered
- Communication is compassionate
- Providers are communicating and sharing information
- Mental health and peer supports are integrated

3. DIAGNOSIS

- Diagnosis is swift
- Information is provided about the type of cancer and the treatment pathway
- Communication is compassionate
- Mental health and peer supports are offered

Findings: Seven Outcomes Critical to a Quality Diagnosis Experience

	OUTCOME	ISSUES	OPPORTUNITIES	SPOTLIGHTS
1	Swiftness of the diagnosis experience	• Delays while seeking validation of symptoms and appropriate referral • Re-work when referrals 'fall through cracks' • Waiting for appointments and test results	• Rapid referral pathways • Optimized roles for diagnostic centres, labs and technologies	• Primary Care Provider Support Program, Quebec City • Specialized Nurse Practitioners (SNPs) in Quebec • Telepathology and telehealth
2	Validation of concerns by primary care providers	• Multiple repeat visits to GP and ER • Symptoms minimized or dismissed • Lack of provider education/knowledge about different cancer types	• Optimize role of primary care providers through educational programs • Use of electronic clinical decision support/risk assessment tools • Enhance provider-provider communication	• Standardized Care Pathways • Manitoba IN SIXTY Initiative • Cancer Care Ontario pathways maps

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	OUTCOME	ISSUES	OPPORTUNITIES	SPOTLIGHTS
3	**Excellent patient to provider communication**	• Patients struggle to navigate web of providers and diagnostic facilities • Diagnoses given without compassion, next steps not explained	• Communication skills training/guidelines for providers • Online portals to give patients access to information and shared decision-making	• Guidelines for the Investigation of Patients with Symptoms Suggestive of Cancer. • The Nova Scotia Health Authority has developed the Serious Illness Conversation Guide
4	**Effective provider to provider communication**	• Poor provider-provider communication • Missing/overlooked test results, repeat testing • Misdiagnoses • Cancellations • Mistrust and confusion	• Technology to facilitate sharing of a patient's health information	None identified
5	**Better information**	• Lack of information about diagnostic pathway and treatment trajectory for patients • Too much or too little information given • Information given at wrong time	• Appropriate information given at each point during diagnosis: • EARLY – diagnosis pathway • MIDDLE – info for each test/procedure • FINAL – staging, treatment trajectory	None identified
6	**Integrated psycho-social support**	• Lack of available, accessible psycho-social support • Support is not offered	• Psycho-social support offered to patients in early phase of diagnosis • Available and accessible psycho-social support	None identified
7	**Coordinated and managed care**	• No dedicated care coordinator • Difficulty navigating system • Lack of financial and logistical support for patients in remote/rural areas	• Assign a dedicated care coordinator or system navigator • Use multidisciplinary teams and Diagnostic Assessment Programs • Conduct diagnostic process in single facility	• Patient Navigators, Care Coordinators • Diagnostic Assessment Programs (DAPs) • Multidisciplinary Teams

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Findings: Quality Framework

Measuring the quality of the cancer diagnosis experience will demonstrate whether efforts are making a difference. Using shared and sound measures will help to make comparisons and improve across settings and jurisdictions. Indicators which can be used to measure the patient experience, commonly referred to as PREMs, are suggested in this table and are aligned with each of the seven desired outcomes identified through this research. 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 care. Once this framework is fleshed out, tools can be developed to measure patient experiences and outcomes in the diagnosis phase much like those which measure PROMs and PREMs in the post-diagnosis phase.

	DESIRED OUTCOME	MEASURES
1	Swiftness of the diagnosis experience	• Referral for testing within x days; Receipt of test results within 14 days; • Diagnosis received within x days of interacting with health care provider • Comparable wait times within jurisdictions, irrespective of geography
2	Validation of concerns by primary care providers	• Person perceives that primary care provider validates their concerns; • Providers have knowledge of different cancers and diagnosis pathways; • Referral for symptom investigation is appropriate; • All primary providers and allied health professionals are aware of person's symptoms and diagnosis trajectory
3	Coordinated care and management	• Patients assigned a single navigator for duration of diagnosis process; • Patients receive care from 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 loved ones for diagnostic services
4	Patient-provider communication	• Patient feels confident they understand test results • Patient knows what the next steps in the diagnosis process are; • Providers possess skills to discuss serious illness with patient; • Patient knows how to reach their provider if they have any questions
5	Provider-provider communication	• 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

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	DESIRED OUTCOME	MEASURES
6	Information	• Patient understands diagnosis pathway for their type of suspected cancer; • Patient understands each step along the diagnosis pathway; • People diagnosed with cancer understand what treatment trajectory entails; • People are satisfied with 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
7	Psycho-social support	• Psychosocial support is offered to patients in early phases of diagnosis; • Psychosocial support is available and accessible as needed

Recommendations

Finally, here is the set of six recommendations aimed at policy makers and those working in cancer control to improve the swiftness, accuracy and appropriateness of communication of diagnosis in Canada.

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.

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

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

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

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

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

This research represents an important step in understanding the current state of patient entry into Canada's cancer care systems. The research adds to the limited body of knowledge about inefficiencies and opportunities within the current systems of cancer diagnosis in Canada. Examined together, the findings are encouraging. We are not starting from scratch but there is much work to be done. The recommendations contained within this report serve to improve the diagnosis phase of the cancer care system such that it can not only absorb shock but also improve.

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Limitations

Patients with common types of cancer (ie. breast, colorectal) who were interviewed may already have experienced a more optimal diagnosis because of existing healthcare system practices. Additionally, the findings are not necessarily generalizable to Indigenous populations, recent newcomers, racialized people, and people residing in Nunavut, Northwest Territories and the Yukon.

As the provider survey was conducted through convenience sampling, the results of this survey are not necessarily representative of all provider groups across Canada. Responses to questions about inefficiencies could have been influenced by the COVID-19 pandemic when the survey was run.

Finally, the practices identified in the research were derived from published research and literature available on the Internet. Oftentimes the details afforded only a cursory glance into a practice, precluding us from determining generalizability, utility of practice application, and implications for policy development.

About All.Can & All.Can Canada

All.Can is an international, multi-stakeholder, not-for-profit organization working to improve the efficiency of cancer care by focusing on what matters to patients. In 2018, Save Your Skin Foundation agreed to establish the All.Can initiative in Canada (All.Can Canada) and, as Secretariat, bring the approach and lessons learned by the international group to Canada.

All.Can Canada (ACC) assessed the top inefficiencies in cancer care. Through the inaugural multi-stakeholder roundtable in 2019, ACC consulted with and gained consensus from representatives across the oncology ecosystem, including patients and patient group representatives. Based on this consensus, ACC committed to understand the current state of cancer diagnosis across the country, with a focus on ensuring swift, accurate, and appropriately delivered diagnosis.

As a result, an All.Can Canada **interim steering committee** was assembled with representation from all relevant stakeholder groups to support, guide, and oversee the progress of research into patients' entry into cancer care across Canada. The findings and recommendations are found in "**Optimizing Diagnosis in Canadian Cancer Care**."

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