

Canadian Team to Improve
Community-Based Cancer Care
along the Continuum
(CanIMPACT)

Improving Coordination Between Primary Care
Providers and Oncology Specialists:
Cases from Canada
(CanIMPACT Casebook)

Final Report, December 2015

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Improving Cancer Care Together


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Casebook of Canadian Initiatives for Improving Community-Based Cancer Care along the Continuum

December 2015

Improving Coordination Between Primary Care Providers and Oncology Specialists: Cases from Canada is a product of the program of research entitled, *Canadian Team to Improve Community-Based Cancer Care along the Continuum (CanIMPACT)*. The overall objective of the CanIMPACT Casebook was to profile Canadian initiatives that aim to improve or support continuity and coordination of patient care between primary care providers and oncology specialists. These initiatives have been implemented by individuals, groups or organizations across Canada and aim to overcome system challenges and ameliorate patient experiences and outcomes for breast and/or colorectal patients across the cancer care continuum.

We would like to extend our thanks and appreciation to our partners who offered nominations, to the research team who graciously contributed their time and effort to assist us in the development of the Casebook, and to the Canadian Institutes of Health Research for funding this body of work.

Best wishes,



Melissa Brouwers, PhD

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Canadian Team to Improve Community-Based Cancer Care along the Continuum (CanIMPACT)

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INTRODUCTION

CANADIAN TEAM TO IMPROVE COMMUNITY-BASED CANCER CARE ALONG THE CONTINUUM (CANIMPACT) PROJECT

CanIMPACT is a research study funded by the Canadian Institutes of Health Research. The study aims to develop an inter-disciplinary, multi-jurisdictional coordinated program of research and knowledge translation to enhance the capacity of community-based primary health care (CBPHC) to provide care to cancer patients, and to improve the link between primary care and specialty care along the cancer care continuum. The CanIMPACT Research Team is comprised of health professional scientists, research scientists with expertise in epidemiology, biostatistics, knowledge translation, quantitative and qualitative methods, knowledge users and individuals affected by cancer.

Additional information about the CanIMPACT Project is available online at <http://canimpact.utoronto.ca/>.

RATIONALE FOR CASEBOOK DEVELOPMENT

CBPHC is the first and most frequent point of contact for cancer patients within the healthcare system during most phases of cancer care, making coordination between CBPHC providers and oncology specialists vital to quality and outcomes of care. Coordination of care, however, is known to be problematic along all phases of the cancer continuum. Therefore, more research is required in order to understand the barriers to coordination of care and to develop sustainable models of shared care for cancer patients. The CanIMPACT Casebook speaks directly to these issues and its results will inform the larger CanIMPACT program of research.

OBJECTIVE OF CASEBOOK

The intent of the Casebook is to profile Canadian initiatives designed to improve or support continuity and coordination of patient care between primary care providers and oncology specialists. These include initiatives that have been implemented by individuals, groups or organizations across Canada in order to overcome system challenges and ameliorate patient experiences and outcomes. As one of the advisors to CanIMPACT is Australian, an Australian initiative was also included.

CASEBOOK “INITIATIVES”

The CanIMPACT Research Team defines a Casebook “initiative” as a program or project that is initiated by groups or individuals belonging to a recognized organization or institution, and is intended to resolve a cancer-related challenge or to improve some aspect of cancer care coordination, delivery, organization or patient care.

The following are examples of Casebook initiatives:

- A re-organization of care to improve the patient experience during transitions from one phase of care to the next
- Development of a tool to facilitate, for patients or providers, the delivery of roles and responsibilities among providers at different points of the cancer journey

- Implementation of educational training and resources in order to improve knowledge and skills in providing cancer care in the community
- Development of a communication strategy or system to improve coordination of shared-care between oncology specialists and primary care

SETTING THE CONTEXT - HEALTH CARE IN CANADA

Across all primary care systems in Canada is a direction towards more collaborative interdisciplinary practice models (e.g., Community Health Centres, Family Health Networks, Family Health Teams) as a means to improve quality of care and make family practice a more appealing specialty for trainees. Fee for service, capitation models, salary, and blended payment models are all used to remunerate primary care providers across Canada.

Common across all cancer programs in Canada is the commitment to provide care across the entire cancer continuum and for all cancer diagnoses. Better integration with primary care is also a common goal. Fee-for-service, alternative funding plans, and blended payment schemes define payment models for oncology specialists.

Below is a summary of some of the defining features of the cancer system in the jurisdictions profiled in this casebook: British Columbia; Alberta; Manitoba; Ontario; Québec; and Nova Scotia. A brief description of Australia's cancer care system is also included.

British Columbia

As an agency of the Provincial Health Services Authority, the British Columbia Cancer Agency (BC Cancer Agency) provides a comprehensive cancer control program for British Columbians. The BC Cancer Agency operates six regional cancer centres that provide assessment and diagnostic services, as well as treatment and supportive care. Each of the regional centres delivers cancer treatment based on provincial standards and guidelines established by the Agency.

Alberta

CancerControl Alberta (Alberta's integrated cancer system) was established as a division of Alberta Health Services (AHS) in 2013 to better align and integrate AHS cancer programs and services. Within CancerControl Alberta, the Cross Cancer Institute in Edmonton and the Tom Baker Cancer Centre in Calgary are provincial centres of oncology expertise. They provide services and care, carry out research, develop standards and guidelines and lend expertise to other cancer centres. The two provincial centres collaborate with four associate/regional cancer centres and 11 community cancer centres in Alberta.

Manitoba

Manitoba's provincially mandated cancer agency is CancerCare Manitoba (CCMB). CCMB partners with Manitoba's five Regional Health Authorities (RHAs), the University of Manitoba's Department of Medicine, Diagnostic Services Manitoba and volunteer funding agencies. CCMB has two tertiary locations in Winnipeg that provide various cancer treatments and supports. CCMB delivers cancer care at six hospitals within the Winnipeg RHA, and provides community-based cancer services at 17 health centres across the four additional RHAs in the province.

Ontario

Cancer Care Ontario is the provincially mandated cancer agency for Ontario responsible for advancing quality standards and evaluation. In 2006, Cancer Care Ontario established 14 Regional Cancer Programs (RCPs), corresponding with the province's 14 Local Health Integration Networks (LHINs). RCPs are networks of stakeholders, including regional cancer centres (RCCs), healthcare professionals and organizations involved in providing cancer prevention and care. Each RCP is led by a Cancer Care Ontario Regional Vice President, who also leads the RCC that is located in the LHIN area.

Québec

The province of Québec mandates the Ministère de la Santé et des Services sociaux (Ministry of Health and Social Services) to regulate and coordinate health care services in the province. As of April 2015, the Ministry of Health and Social Services shares this responsibility with integrated centres of health and social services. These integrated centres include networks of interdisciplinary cancer teams, which offer specialized cancer services across the province. Various cancer services are provided at local, regional and supra-regional levels.

Nova Scotia

Cancer Care Nova Scotia (CCNS), established by the Department of Health and Wellness in 1998, is Nova Scotia's provincial cancer agency. CCNS provides education regarding standards and best practices. Members of CCNS collaborate and provide leadership and expertise to health professionals and administrators who work as members of the Nova Scotia Health Authority.

Australia

Cancer Australia is an Australian Government agency, established to reduce the impact of cancer by leading national, evidence-based interventions across the cancer care continuum and providing expert advice on cancer care to governments and health care professionals. The Department of Health is responsible for administering many of the Australian Government's cancer programs, most of which are run through partnerships between the national government and territory and state governments.

METHODS

BUILDING THE PROFILES

RECRUITMENT AND NOMINATIONS

Requests for nominations were sent to clinical and research leaders across Canada. The first wave was initiated in June 2014. A template of the request for nomination can be found in Appendix A (Item 1). Leaders were asked to nominate initiatives that:

- Involved Canadian content or contributions;
- Were from groups or individuals belonging to a recognized Canadian organization; and/or
- Were a concerted effort to improve some aspect of cancer care coordination, delivery, organization or patient care.

The contacted individuals were able to nominate activities from their own or others' organizations or jurisdictions. They were asked to provide:

- The name of the nominated initiative along with a short description;
- A list of reports or supporting documents about the initiative (if available); and
- Names and contact information for primary and secondary initiative contacts.

Nominations received by the Research Team were screened based on the following eligibility criteria:

- Supported shared care between CBPHC and specialty care
- Related to diagnosis, treatment, survivorship and/or personalized medicine
- Focused on breast and colorectal cancers (not required, but preferred)

For the first wave, primary contacts of the included initiatives were contacted in November 2014. They were sent a request for participation via e-mail. A template of the request for participation letter is included in Appendix A (Item 2). Reminder e-mails were sent to non-responding primary contacts and/or secondary contacts in December 2014 and January 2015.

To ensure jurisdictional representativeness, a second wave of recruitment was initiated in February 2015 and a third and final wave was initiated in September 2015. These waves were targeted and purposeful to fill in the gaps.

DATA COLLECTION METHODS

A profile form developed by the Research Team was used as a structured guide for the telephone interviews. A template of the form is included in Appendix A (Item 3). The form consisted of a list of questions about the initiative. Nine questions requested general information about the initiative, such as implementation date, the targeted cancer diagnosis and the rationale for the development of the initiative. The form also included 12 detailed questions about initiative goals and development, roles and responsibilities of involved providers, barriers and facilitators to implementation, lessons learned, impact, resource and cost implications and evaluation results.

With the initial wave, initiative contacts who agreed to participate in the Casebook project corresponded with the CanIMPACT research assistant to schedule a telephone interview. Telephone interviews took place from December 2014 to March 2015. Calls lasted 25-45 minutes and were recorded with the permission of the interviewee(s). The research assistant used the telephone

interviews to complete profile forms for each initiative. The completed profile forms were sent to interviewees for verification shortly after each interview.

In the second and third waves of recruitment, the contacts were given the option of scheduling a telephone interview with the CanIMPACT research assistant or completing a profile form for their initiative themselves. All new nominees chose the latter option. Completed profile forms were received by the Research Team in early April (second wave) and October (third wave) and did not require a member-check/verification like the other forms.

CREATION OF PROFILES

The information provided in the profile forms, along with any supplementary material provided by nominators or nominees, was combined and organized into a “profile”. Along with a summary of contact information and general facts about the initiative, the profiles consist of the following sections:

- Overview
 - Stage of Cancer Care Continuum

The cancer care continuum encompasses all stages of cancer care (i.e. screening, diagnosis, treatment, survivorship or end-of life care) as well as transitions in care. Cancer care is coordinated by a multidisciplinary team of health care professionals, including both specialists and primary care providers. Casebook profiles are organized into one of three categories, based on the targeted stage of the cancer care continuum:

 - *“Pre-treatment” → screening, diagnosis, and/or transitioning from diagnosis into treatment*
 - *“Post-treatment” → transitioning from treatment to survivorship/follow-up care*
 - *“Across the cancer continuum” → initiatives that span the continuum by addressing multiple stages of care (e.g. navigation; education)*
 - Level of Implementation
 - *Local/Regional → the initiative is implemented on a local or regional scale, therefore the initiative provides cancer programs and services to patients living in a specific town, city or region*
 - *Provincial → the initiative is implemented on a provincial scale, therefore the initiative provides cancer programs and services to patients across the province*
 - *“Other” jurisdiction → the initiative is implemented in multiple provinces, or is implemented in a country other than Canada*
- Rationale and development
 - Issue or challenge that prompted the initiative
 - Developers of the initiative
 - Goal and objectives
- Description
 - Program or project activities
 - Types of providers involved and their responsibilities
 - Resource and cost implications
- Evaluation
- Barriers and Facilitators
- Lessons Learned
- Future Directions
- Additional Notes

For the first and second wave initiatives, profiles were sent out to interviewees/initiative contacts between May and June 2015 for review. Reminder e-mails were sent to non-responders in early June 2015 and the deadline for response was early July 2015. For the third wave initiatives, profiles were sent out to contacts in September for review; the deadline for response was early November. As needed, contacts were asked specific questions where there were gaps in information. Some profiles do not contain all of the aforementioned sections, as the information was not provided during the interview or review processes.

ANALYSES AND INTERPRETATION

Through discussion and exploration of thematic similarities, the Research Team organized the presentation of the profiles according to the following scheme: first by targeted stage of cancer continuum (pre-treatment, post-treatment or across the continuum) and then by level of implementation (local/regional, provincial and “other”). A detailed thematic analysis of the profiles, using an iterative process, was undertaken to identify similarities and differences in rationales, strategies used, collaboration between primary care providers and oncology specialists, barriers and facilitators, factors that influence success, and areas of concern.

RESULTS: Nominations, Representation and Profiles

NOMINATIONS

Across the first wave of recruitment, 159 requests were made and 32 nominations of interest were received. Of these, 26 met inclusion criteria and proceeded to data collection. Twenty of the initially nominated profiles were completed. One of the profiles was incorporated into another, resulting in a total of 19 profiles from the first wave of recruitment. Table 1 summarizes the process of the first wave of recruitment, by jurisdiction.

Table 1: First wave of Casebook nominations and inclusions, by jurisdiction

Jurisdiction	Nominations			Profiles
	Requests	Received	Inclusion Criteria Met	Completed
Northwest Territories	1	0	0	0
British Columbia	23	3	2	2
Alberta	28	11	9	5
Saskatchewan	3	0	0	0
Manitoba	13	3	3	3
Ontario	55	12	11	8
Québec	1	1*	0	0
Nova Scotia	2	0	0	0
Prince Edward Island	1	0	0	0
National/Interprovincial	32	2	1	1
Total	159	32	26	19

*Note: The nomination received from Québec was sent from a nominator that was from Ontario (not Québec).

Across the second wave of recruitment, requests were made to the Northwest Territories (n=1), Ontario (n=1), Québec (n=1), Nova Scotia (n=1) and Australia (n=2). Of these, three nominations were received (one each, from Québec, Nova Scotia and Australia). All three met inclusion criteria, and proceeded to data collection. The third wave of targeted recruitment identified one initiative from Ontario and one from Nova Scotia, resulting in a final sample of 24 initiatives. Twenty of the 24 completed profile forms were verified by interviewees.

CASEBOOK INCLUSIONS AND EXCLUSIONS

The nominated initiatives were reviewed based on the following inclusion criteria:

- Supports shared-care between specialists and primary care providers;
- Is related to/associated with the diagnosis, treatment, survivorship and/or personalized medicine stages of cancer care; and
- Is focused (solely or partially) on breast and/or colorectal cancer.

Six of the 32 nominations from the first wave of recruitment were excluded; four of which were specific to screening, or thoracic cancer (i.e. did not encompass breast and/or colorectal cancer). Furthermore, one nomination was focused on public education regarding prevention and one

project was specific to the development of a cancer biomarker health policy, neither of which fit within the scope of the Casebook. Seven of the 26 first wave nominations that met inclusion criteria were not profiled in the Casebook. Of these seven, four had already been nominated (i.e. were duplicates), one initiative was combined with another, and two initiative contacts declined to participate (one contact felt that his/her initiative did not fit within the scope of the Casebook and the other contact declined because his/her initiative was no longer active). All of the nominations received during the second and third waves of recruitment (n=5) met inclusion criteria and were profiled in the Casebook.

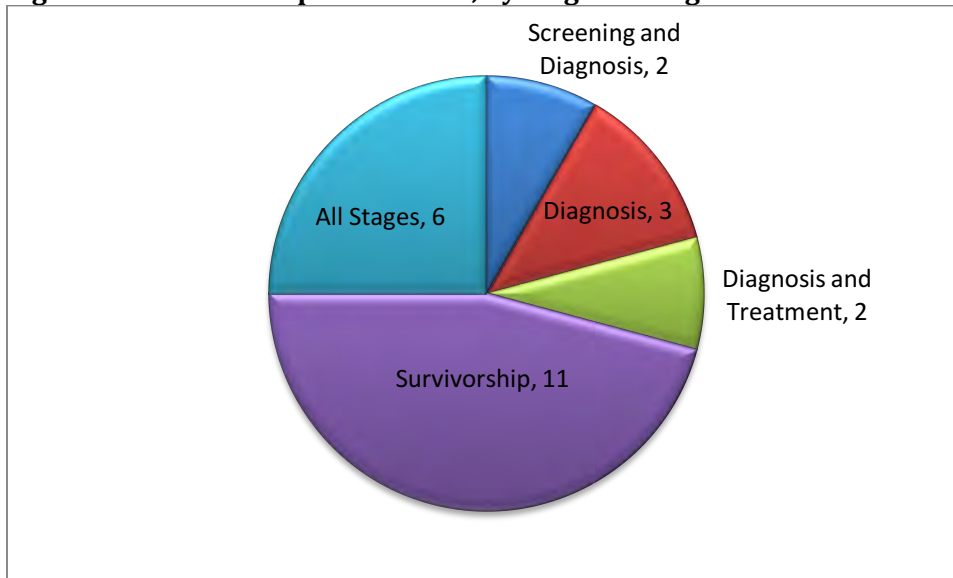
REPRESENTATION

When examining the completed profiles against the Casebook eligibility criteria, there was a broad representation of profiles in each of the following categories.

TARGETED STAGE OF CANCER CONTINUUM

Profiles were received from across the continuum with survivorship being most common (n=11; Figure 1).

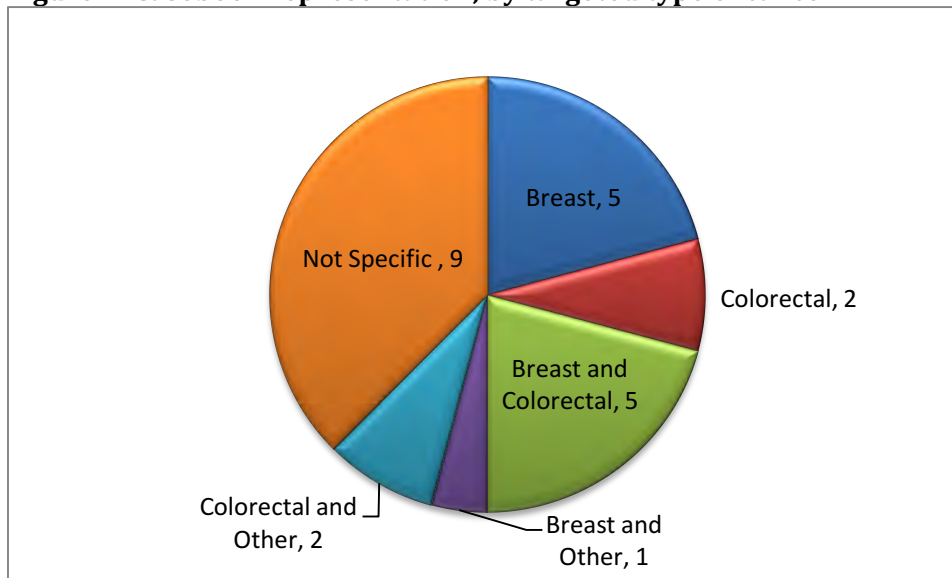
Figure 1: Casebook representation, by targeted stage of cancer continuum



TARGETED TYPE OF CANCER

With the exception of nine profiles, all others targeted breast and/or colorectal cancer (Figure 2).

Figure 2: Casebook representation, by targeted type of cancer



IMPLEMENTATION LEVEL

There were 12 profiles focused on the provincial level and 12 profiles focused on the local-regional level (including one profiling a region in Australia).

PROFILES

Across the initiatives, several different tactics or strategies were used to improve coordination between primary care providers and oncology specialists. These tactics included enhanced navigation strategies (nurse, patient, nurse-patient), education initiatives (physicians, patient), electronic or information system enhancements, use of multidisciplinary care teams and multicomponent methods. The schema in Table 2 categorizes the initiatives according to stage of the cancer continuum (pre-treatment/post-treatment/across whole continuum), jurisdictional level (local/regional vs. provincial vs. other) and tactic or strategy type. The specific jurisdiction is identified for each initiative. Complete profiles of each initiative can be found in Appendix B according to profile number (e.g. 1, 2, 3, etc.).

Table 2: Organizational schema of profiles in CanIMPACT Casebook

Stage of Continuum	Jurisdictional Level	Tactic/Strategy Type	Initiative Number and Name	
PRE-TREATMENT (i.e. screening, diagnosis and/or transitioning from diagnosis into treatment)	Local/Regional	<i>Nurse/patient navigation</i>	1. Clinical Breast Health Program (AB)	
			2. Comprehensive Breast Care Program (AB)	
			3. Diagnostic Assessment Programs (ON)	
	Provincial	<i>Electronic communication/information systems</i>	4. eReferral (AB)	
			5. LEAN on cME (MB)	
			6. Ontario Breast Screening Program (ON)	
			7. Nova Scotia Breast Screening Program (NS)	
POST-TREATMENT (i.e. transitioning from treatment to survivorship/follow-up care)	Local/Regional	<i>Providing survivorship and primary care to “unattached patients”</i>	8. Survivorship Nurse Practitioner Program (BC)	
			<i>Multicomponent initiatives</i>	9. Juravinski Cancer Centre Well Follow-Up Clinics (ON)
				10. Optimizing a Cancer Survivorship Model for Northeast Ontario (ON)
				11. Wellness Beyond Cancer Program (ON)
				12. Transition Care Clinic (ON)
	<i>Electronic communication/information systems</i>	13. Well Follow-Up Care for Colorectal Cancer Survivors and their Circles of Care (ON)		
		14. Embedding Disease Pathway Management Published Pathways into Process of Care (ON)		
	Provincial	<i>Multicomponent initiatives</i>	15. Provincial Integrated Cancer Survivorship Program (AB)	
			16. Moving Forward after Cancer Treatment (MB)	
	“Other” jurisdiction	<i>Patient navigation and education</i>	17. Transition Volunteer Navigator Program (BC, NS)	
			18. Victorian Cancer Survivorship Program (AU)	
ACROSS THE CANCER CARE CONTINUUM (i.e. initiatives that address multiple stages of care)	Local/Regional	<i>Nurse/patient navigation</i>	19. Oncology Navigation Program (ON)	
			Provincial	<i>Nurse/patient navigation</i>
	21. Establishing Oncology Pivot Nurses in Québec (QC)			
	22. Community-Based Cancer Patient Navigation (NS)			
	23. Uniting Primary Care and Oncology (MB)			
	<i>Physician education</i>	24. British Columbia Family Practice Oncology Network (BC)		

RESULTS: Analyses

RATIONALES FOR INITIATIVE DEVELOPMENT

Challenges or issues related to the cancer care system prompted the development of the programs and projects profiled in the Casebook. Commonalities in rationales were identified based on the targeted stage of cancer care.

Pre-treatment

- An identified need to decrease wait times for diagnostic testing and delivery of treatment
- Provision of cancer education and support for newly-diagnosed patients and their families
- Delivery of high-quality cancer care (i.e. improvement of overall access, consistency, safety and coordination for transitions in care)

Post-treatment

- A shortage of oncology resources, coupled with an increasing population of cancer patients
- Limited communication and information sharing between specialists and primary care providers
- Lack of primary care/shared care for “unattached” patients
- A need to support patients’ capacity for self-management
- A need to support primary care providers’ capacity for follow-up care, including cancer care education and collaborative relationships with oncologists
- Maintain adherence to follow-up clinical practice guidelines to encourage ongoing surveillance and screening for cancer survivors

Across the cancer care continuum

- Provision of education and support to patients and primary care providers
- Improved communication and collaboration between specialists and primary care
- Improved access to safe and timely care

The aforementioned challenges and issues have been addressed through the implementation of unique projects and programs that have provided educational resources and supports for primary care providers and patients, clarified roles and responsibilities of care providers, and implemented standardized systems to transfer patient information and transition patients. The initiatives profiled in the Casebook were fundamentally developed to improve the quality of cancer care. Thus, through the implementation of distinct models of care, most program/project teams strive to:

- Improve access and continuity of care;
- Advance the efficiency of the cancer care system;
- Increase patients’ capacity to self-manage; and
- Increase primary care providers’ capacity to support cancer patients.

STRATEGIES

Different approaches have been implemented in an effort to coordinate and improve the interface between primary and specialty care. There are five strategies discussed in this section: nurse/patient navigation; multi-disciplinary care teams; electronic communication/information systems; education for primary care; and multi-component interventions.

1. Nurse/patient navigation

Nurse/patient navigation was implemented as a primary strategy by nine initiatives (profiles 1, 2, 3, 8, 17, 19, 20, 21, 22) and as a component of six other initiatives (4, 6, 7, 9,

13, 18). This strategy spans all stages of the cancer care continuum and has been implemented locally/regionally, provincially and cross-provincially. Patient navigators serve as a liaison between patients, the cancer care system, and often the primary care system. Their responsibilities involve providing patients with education and support, connecting them with cancer resources that are available in their communities, streamlining transitions in care and addressing logistical issues.

2. *Multi-disciplinary care teams*

The multi-disciplinary care team approach to cancer care was implemented by two provincial programs (6, 7) which both target the screening and pre-treatment phases of cancer care. Multi-disciplinary care teams consist of healthcare providers who are involved in a patient's cancer journey, both directly and indirectly. These providers work in diverse clinical environments and possess unique sets of skills. For example, they may include clerks or nurses who schedule tests and procedures, radiation technologists who perform diagnostic tests, and oncologists who consult with patients and provide referrals. The goals of these care teams can include ensuring that the best treatment and supportive care plan is determined and allocating clear responsibilities to the care team (e.g., most responsible physician).

3. *Electronic communication/information systems*

Two initiatives implemented electronic communication/information systems as a primary strategy (4, 14). Four additional multi-component initiatives incorporated electronic systems into their strategy (7, 11, 15, 22). The implementation of these electronic systems is intended to support the efficient management and transfer of large volumes of information. More specifically, these systems are implemented to: aid communication between health care providers; safely track patients' journeys through the cancer care system; provide reminders and care paths; and speed up the transfer of patient information, specialist referrals and evidence-based recommendations.

4. *Education for primary care providers*

Three initiatives focus on the provision of education to primary care providers (5, 23, 24) while six initiatives incorporate primary care provider education into their models of care (2, 10, 11, 12, 13, 22). Examples of "education" include: providing primary care providers with electronic cancer-based resources, such as evidence-based surveillance and survivorship guidelines; hosting events to help build collaborative relationships between primary care providers and oncology specialists; and providing in-person consultations and education sessions to improve clinic work flow and to encourage timely referral to cancer care.

5. *Multi-component initiatives*

In order to produce a more comprehensive model of care, the developers of eight initiatives chose to implement more than one model (9, 10, 11, 12, 13, 15, 16, 18). The various approaches of these multi-component interventions include: providing patients, their families and primary care providers with cancer-related education and resources; conducting needs assessments with patients; creating survivorship care plans for patients and their primary care providers; providing patient navigation; encouraging and supporting communication between cancer care and primary care; and electronically transferring patient information.

ENGAGEMENT WITH PRIMARY CARE

Table 3 categorizes the level of engagement of primary care (low, moderate, high) for each initiative and elaborates on the nature of this engagement. A “low” categorization was assigned if an initiative had collaborated with primary care in **only one** of the following ways:

- Family physicians refer patients to the program
- Family physicians receive program- or patient-related information (e.g., survivorship care plans) from program providers
- Family physicians receive oncology-related education from specialists
- Family physicians are supported in their collaboration with specialists
- Family physicians were/are involved in developing program materials

If an initiative incorporated more than one of the aforementioned components into their model of care, they were categorized as having “moderate” primary care involvement.

Initiatives were classified as “high” only if they met **at least one** of the following criteria:

- The initiative is implemented in a primary care setting
- The initiative provides shared-care (i.e., between primary and specialty care) to patients

In summary, seven initiatives had a low level of engagement with primary care, 11 had a moderate level and six had a high level. It is important to acknowledge that this summary is based on the information that was collected during the interview process and therefore may not provide a completely accurate representation of the profiled initiatives’ level of primary care engagement.

Table 3: Level of primary care engagement

Initiative	Level of Primary Care Engagement	Description
1. Clinical Breast Health Program (AB)	Moderate	<ul style="list-style-type: none"> FPs refer patients to the program FPs receive updates on the progress of their patients
2. Comprehensive Breast Health Program (AB)	Moderate	<ul style="list-style-type: none"> FPs refer patients to the program FPs receive updates on the progress of their patients
3. Diagnostic Assessment Programs (ON)	Low	<ul style="list-style-type: none"> FPs refer patients to the program
4. eReferral (AB)	Moderate	<ul style="list-style-type: none"> FPs worked alongside specialists to design the referral process FPs provide electronic referrals for specialty care
5. LEAN on CME (MB)	Low	<ul style="list-style-type: none"> Program provides FPs with oncology education
6. Ontario Breast Screening Program (ON)	Moderate	<ul style="list-style-type: none"> FPs refer patients to the program Patients' screening results are shared with FPs
7. Nova Scotia Breast Screening Program (NS)	Moderate	<ul style="list-style-type: none"> Majority of patients report that their FPs encouraged them to get screened Patients' screening results and follow-up appointments are shared with FPs Diagnostic exams are booked through the program then forwarded to FPs, who inform their patients
8. Survivorship Nurse Practitioner Program (BC)	High	<ul style="list-style-type: none"> Program takes place in a primary care setting and nurses interact and collaborate with FPs on a daily basis
9. Juravinski Cancer Centre Well Follow-Up Clinics (ON)	Low	<ul style="list-style-type: none"> FPs receive copies of their patients' transition letters and SCPs
10. Optimizing a Cancer Survivorship Model for Northeast Ontario (ON)	High	<ul style="list-style-type: none"> FPs involved in the development of clinical pathways and educational materials for patients Primary care physicians help patients transition to their FPs after completion of treatment (i.e. shared care) FPs receive oncologists' discharge notes, patients' medical records and surveillance guidelines FPs have the opportunity to attend educational workshops
11. Wellness Beyond Cancer Program (ON)	High	<ul style="list-style-type: none"> FPs provide shared care with nurse practitioners FPs receive copies of their patients' discharge letters and SCPs
12. Transition Care Clinic (ON)	Moderate	<ul style="list-style-type: none"> FPs receive access to their patients' electronic care summaries FPs receive oncology-related education from specialists
13. Well Follow-Up Care for Colorectal Cancer Survivors and their Circles of Care (ON)	High	<ul style="list-style-type: none"> FPs were consulted and informed throughout program development Program provides shared care to patients Program provides FPs with patient information and oncology-related resources
14. Embedding Disease Pathway Management Published Pathways into Process of Care (ON)	Moderate	<ul style="list-style-type: none"> FPs involved in the development of clinical pathways FPs receive copies of their patients' SCPs and reminder letters for follow-up care
15. Provincial Integrated Cancer Survivorship Program (AB)	Low	<ul style="list-style-type: none"> FPs involved in the design and testing of mechanisms that embed follow-up guidelines into FPs' electronic medical records

Initiative	Level of Primary Care Engagement	Description
16. Moving Forward after Cancer Treatment (MB)	Moderate	<ul style="list-style-type: none"> • FPs involved in the development of program materials • FPs receive copies of their patients' SCPs
17. Transition Volunteer Navigation Program (BC, NS)	Low	<ul style="list-style-type: none"> • FPs receive information about the initiative
18. Victorian Cancer Survivorship Program (AU)	Moderate	<ul style="list-style-type: none"> • FPs receive copies of their patients' SCPs • FPs meet with patients to review their SCPs and to address their concerns
19. Oncology Navigation Program (ON)	High	<ul style="list-style-type: none"> • FPs involved in the development of program materials • Program takes place in a primary care setting and nurses interact and collaborate with FPs on a daily basis
20. Alberta Cancer Foundation Cancer Patient Navigation (AB)	Low	<ul style="list-style-type: none"> • FPs refer patients to the program
21. Establishing Oncology Pivot Nurses in Québec (QB)	Low	<ul style="list-style-type: none"> • FPs contact program providers to receive updates about their patients
22. Community-Based Cancer Patient Navigation (NS)	High	<ul style="list-style-type: none"> • Program provides shared care to patients
23. Uniting Primary Care and Oncology (MB)	Moderate	<ul style="list-style-type: none"> • Program provides FPs with oncology-related education • Program provides a platform for collaboration/communication between specialty and primary care
24. British Columbia Family Practice Oncology Network (BC)	Moderate	<ul style="list-style-type: none"> • FPs are involved in the development of program materials • Program provides FPs with oncology-related education and resources • Program provides a platform for collaboration and communication between specialty and primary care

Note: FPs refer to “family physicians” and SCPs refer to “survivorship care plans”. Please refer to the “Engagement with Primary Care” section on page 17 for information regarding the criteria for categorizing the initiatives as “low”, “moderate” or “high”.

BARRIERS AND FACILITATORS

Casebook interviewees disclosed various barriers and facilitators that were encountered by their project teams throughout the stages of initiative development, adoption and implementation.

Barriers

Barriers to development (unique to provincial initiatives)

- Limited funding/ budgetary constraints
 - *Limited availability of financial resources delayed program development.*
- Inadequate time to prepare for program implementation
 - *This resulted from technical issues that arose during development.*

Barriers to adoption

- Limited buy-in or support from primary care providers and/or specialists
 - *For example, specific to post-treatment, many oncologists were reluctant to transition their patients to primary care; they feared that primary care providers would not be equipped to provide survivors with the same quality and rigour of care as oncology specialists.*
- Reluctance of primary care providers to accept the responsibility of providing survivorship care to cancer patients
 - *Primary care providers felt incapable of providing the same level of high-quality cancer care as oncology specialists.*
- Lack of patient and/or primary health care provider awareness of the program
 - *This resulted in initially low participation rates in targeted communities or regions.*
- Lack of communication and collaboration between specialty care and primary care
 - *Many initiatives required the establishment of new and existing partnerships in order to be able to effectively provide services.*
- Uncertainty regarding the roles and responsibilities of the involved care providers
 - *This challenge often resulted from the implementation of a new model of care, which implied a change in practice.*

Barriers to implementation

- Lack of standardized guidance and orientation/training materials
 - *This encompassed a lack of provincial consensus regarding survivorship guidelines or standards of care (post-treatment only) and a lack of orientation materials and resources for newly introduced care provider roles, such as nurse navigators.*
- Reallocation of program resources
 - *The reallocation of program resources ensured that the appropriate supports for effective implementation were in place.*
- Limited communication between implementation sites
 - *This was primarily due to geographic dispersal of sites and ineffective means of communication.*
- Lack of integration between electronic medical record systems and limited access for care providers
 - *This issue resulted in a delayed transfer of information and sub-optimal provision of care.*

Common Facilitators

Facilitators to development

- Arranging community stakeholder meetings for the public and health care providers
 - *Meetings resulted in increased program awareness, clarification of roles and responsibilities of involved care provider and provided attendees with a venue to express their concerns.*
- Endowment of grants
 - *Financial support allowed for ideas for programs and projects to be developed.*
- A need for the program has been established
 - *Patients, survivors, family members and/or health professionals expressed a need for the services provided by the program.*

Facilitators to adoption

- The promotion of the initiative by clinical or program leaders
 - *This improved program credibility and encouraged support from other health care providers. Distinctively, the adoption of pre-treatment initiatives was encouraged by evidence of program success; evidence included clinical measures of success as well as patient and provider satisfaction.*
- Incentives (unique to provincial initiatives)
 - *Incentives included free access to electronic communication/information systems and free admittance to educational lectures and events.*

Facilitators to implementation

- Having a motivated and skilled project team in place
 - *A valuable team encouraged effective collaboration within the group and resulted in strong clinical design and primary care engagement.*
- Development of new electronic information systems
 - *This enabled effective communication between providers, and effective transfer of patient information and resources for primary care providers.*
- Use of existing resources
 - *This facilitated program sustainability.*

AREAS OF CONCERN FOR CURRENT STATE OF INITIATIVES

Technical issues associated with electronic systems

Electronic systems were primarily established to address challenges associated with communication and information sharing; however, the implementation of electronic solutions came with its own set of challenges. The developers of eReferral (AB; 4) an electronic referral system, and the Wellness Beyond Cancer Program (ON; 11), which implements a process management tool to track patients, emphasized the need for project teams to be aware of technical complexities associated with electronic solutions prior to attempting to develop and implement. The Moving Forward after Cancer Treatment (MB; 16) project team required technical support to be able to integrate reports into electronic medical records. Additionally, Embedding DPMS into Process of Care initiative (ON; 14) and Well Follow-Up Care for Colorectal Cancer Survivors and their Circles of Care (ON; 13) interviewees described the challenge of aligning electronic interfaces in order to meet their goal of optimizing electronic processes for, for example, issuing survivorship care plans and recall prompts to primary care providers, and allowing primary care providers to update patient records. In order to ensure that an electronic system is reliable and sustainable, thorough development and testing is required.

Limited complete evaluations

A program evaluation is a valuable tool for measuring the effectiveness of a program. Eleven profiled initiatives have complete formal evaluations (1, 2, 6, 7, 8, 11, 12, 13, 18, 20, 22); however, not all evaluative data was released at the time of the interview or during subsequent correspondence with the Research Team. The majority of the remaining 13 project teams are either in the process of developing an evaluation framework or collecting data for a formal evaluation. It was therefore difficult to gauge the effectiveness of many of the profiled initiatives and to identify which could serve as effective models of care for cancer care organizations with similar goals and objectives.

The Transition Care Clinic (ON; 12), the Victorian Cancer Survivorship Program (AU; 18), the Well Follow-Up Care for Colorectal Cancer Survivors and their Circles of Care program (ON; 13) and the Oncology Navigation Program (ON; 19) are being used as models to guide the development of other programs. The Transition Care Clinic (ON; 12) evaluation demonstrated that the implementation of the program resulted in resource utilization savings and improved symptom screening results. The implementers are now developing a business model based on this initiative. The Victorian Cancer Survivorship Program (AU; 18) project evaluation demonstrated that the implemented model of care had a positive impact on the program providers as well as the program users. Other cancer care teams in Victoria are using this model as a template to develop and implement their own versions of cancer survivorship programs. The evaluation model implemented as part of the Well Follow-Up Care for Colorectal Cancer Survivors and their Circles of Care program (ON; 13) is intended to be piloted in palliative care by the South East Regional Cancer Centre and the Kingston General Hospital. Lastly, an evaluation of the Oncology Navigation Program (ON; 19) is currently incomplete; however, the initiative is being used as a model for the establishment of navigation programs within the North Perth Vascular Health Team and the North Huron Family Health Team.

Varying levels of engagement with primary care

The Casebook was intended to highlight projects and programs that initiate and/or support collaboration between primary care providers and oncology specialists. Table 3 describes the level of primary care engagement of all of the profiled initiatives. In regards to the seven initiatives categorized as “low”, their only interaction with primary care is through the receipt of referrals, or through the transfer of patient information/ provision of cancer care or program-related education. The majority of initiatives (i.e. 11) were categorized as moderately engaging with primary care, as they had more than only one point of contact with primary care providers. Lastly, the six initiatives categorized as “high” are all implemented in a primary care setting and/or provide shared care to patients. The Research Team expected that the role of primary care in the majority of the profiled initiatives would be very strong; however, the collected data illustrated that there are varying levels of involvement of primary care in the profiled initiatives and that most initiatives engage primary care on a moderate level.

DISCUSSION

The CanIMPACT Casebook profiles 24 initiatives, representing seven jurisdictional perspectives, aimed to improve coordination between primary care providers and oncology specialists. Key rationales that guided initiative development included: a need to facilitate communication and collaboration between primary care and specialty care; a need to support primary care providers' capacity for survivorship care; as well as an overall need to improve access to high quality care. The following strategies were implemented by the initiatives in order to address the issues or challenges that prompted their development: nurse/patient navigation; multi-disciplinary care teams; electronic communication/information systems; education for primary care providers; and multi-component initiatives. The level of primary care involvement was unique to each initiative; the majority of which had a moderate level of primary care involvement. Some common facilitators across initiatives included the provision of financial resources and/or repurposing of existing resources, having a motivated and skilled project team, and promoting the initiative by clinical/program leaders. Common barriers were related to incompatibility among electronic and information systems, a failure to share and standardize processes across close jurisdictions, employment of common strategies for common purposes and suboptimal evaluation of these initiatives. Based on the information provided in the profiles, suboptimal evaluation of initiatives, technical issues associated with electronic communication/information systems, and insufficient engagement with primary care, were identified as the primary areas of concern for the current state of initiatives.

CASEBOOK INSIGHTS AND ACTION

Insights

Engage stakeholders in development

Various approaches to successful stakeholder involvement are evident in the profiled initiatives. Community stakeholder meetings, held prior to implementation, can be used as an opportunity to ask community agencies to partner with the program, with the goal of enhancing patients' access to resources (20). The engagement of stakeholders from the very beginning stages of project development helps to plan appropriate program activities and to establish timelines (14), while including clinicians and physicians in the development process helps to ensure continued collaboration throughout implementation (9, 13, 24) and improves program credibility (5). However, it is important for the project team to consider stakeholders' areas of expertise and skill sets, as well as their schedules and resulting time constraints, when planning their involvement in a project (19). Overall, stakeholder engagement in the development of initiatives encourages greater buy-in and supports initiative adoption and implementation.

Encourage initiative champions

Initiative "champions" are administrative, managerial and clinical champions who openly promote and support the initiative. Their assistance can be crucial to program success (21). They emphasize program benefits and address the concerns of providers who are initially reluctant to participate (8, 9, 12, 19). Their support creates awareness, encourages buy-in and presents the program or project as being valuable in a targeted region/province (2, 3, 11, 16, 20, 22).

Consider the patient perspective

An understanding of patient values and opinions is required to create an effective patient-centered program (12, 15). A program team must acknowledge that patients of the same disease type are not homogeneous (i.e. they experience unique risks and needs) and that non-medical aspects of care influence patient health and should be addressed during program planning (10). Furthermore, encouraging patient feedback post-implementation can assist the initiative team through review and revision, to ensure continuous program improvement (11). Finally, patient-centered initiatives should have a goal of ensuring that the needs of their targeted patient groups are met (19).

Define roles and responsibilities of involved stakeholders

Health care professionals must be provided with a clear description of what *their* roles and responsibilities are, as project or program members (20). Initiatives that aim to cause a change in practice may instigate pushback from providers who may not view what is being proposed as being a part of their responsibility (18). However, shifts in obligation have had a positive impact on health system outcomes. For example, having non-surgical physicians treat cases of breast cancer that do not require surgery have decreased overall wait times (2). Lastly, the responsibilities of newly-introduced roles should be clearly communicated to all program staff (i.e. individuals responsible for the daily operations of the initiative), as their own roles are likely to be affected (8, 11, 22).

Plan for evaluation

Initiatives that had identified measurable outcomes as being critical for establishing program effectiveness (19) and for encouraging continuous improvement (8, 18) were either in the process of completing, or had completed, program evaluations. Presenting results that indicate success, such as positive patient experience and improved clinical efficiency, were important for generating buy-in from stakeholders (3). Some initiatives produced an evaluation as a requirement of their accreditation status (5) or as a requirement of their funding agency (20). Producing a complete formal evaluation demonstrating significant results can also be essential for securing permanent funding once a pilot project has been completed (1) or for expanding the program on a provincial scale (22).

Consider the complexities of large-scale initiatives

Unique considerations are required for initiatives implemented on a large scale. For example, establishing a centralized advisory committee may help facilitate progress (16) and ensure that a project team works within an established provincial framework (15). In addition, implementing the program at all oncology centres across a province can promote consistency in care and increase program awareness (21). Provincial standardization provides an overall organized and consistent approach to implementation (3), resulting in the provision of standardized resources and tools to providers who deliver the initiatives as well as their patients (10, 20). Therefore, provincial standardization is advantageous; however, there must be flexibility embedded in the standardized practices to allow for local contextualization (3, 20). Interestingly, one initiative recognized that an incremental implementation facilitated success (7); because an initial large-scale implementation would have been much more challenging to manage, the team was driven by opportunity and evolved and expanded over time. Finally, receiving funding from a provincial funding agency is advantageous, as it supports the development and implementation of large-scale initiatives (1, 10, 11, 13, 14, 15).

Action

Based on the insights described above, the Research Team developed a list of recommended actions.

Integrated KT and Governance

A consistent barrier and significant limitation reported in the profiles was the lack of appropriate leadership, engagement among stakeholders, and governance. To address these problems, it is recommended that a fully integrated KT strategy with updated and refined governance is employed while designing and implementing the next stages of the CanIMPACT program of research.

Specifically:

- Identify candidate community partners for participation and bring representatives to the table early. A proposed survey, to be administered before the Consultative Workshop, is a useful first step. However, it will be important to go beyond this strategy.
 - Be deliberate in choosing among candidate contexts for additional research inquiry (academic vs. non-academic; urban vs. rural; Ontario vs. other). While some contexts may be feasible, consider if this is where the most significant problems actually exist and where the research could have the most impact in advancing knowledge, patient experience or system outcomes.
 - Be deliberate among choice of lead(s) in the context chosen. How will CanIMPACT define local champion(s)? What are their role(s)? How are they chosen? Terms of reference should be prepared before confirming context.
 - To help work through the above suggestions, consider what line of inquiry that will define the second half of the project.
- Better optimize the expertise of the members of the CanIMPACT Patient and Family Advisory Committee to ensure their perspective is featured.
 - What is the specific role of the team in the second half the project? How will the committee extend its reach to more representative patients and families who receive cancer services? Is this a priority for the second half of the project?
- Does the CanIMPACT team collectively or through partnership have the appropriate suite of methodological and content skills to implement their next stages? Is there clear governance for the next stages so that the appropriate skill mix is present? This may require recruitment of new members to the team.

Protocol and Evaluation

The most striking limitations in the profiles were the lack of a comprehensive evaluation protocol and/or means to collect data to inform whether the efforts led to desired outcomes and were a good use of resources and time. This has made it difficult to optimize experiences that currently exist to take the most promising components to create a model for testing. To overcome these limitations:

- Be open to doing something different than what was originally proposed.
 - Should the goal be to test a new model? An existing model? The sustainability of a model?
 - Is there something out there that is “good enough” to use?
- Clearly defined goals for designing and implementing the next stages of the CanIMPACT program of research.
 - What is feasible given time and available resources?
 - What are the implications for subsequent stages past the 5-year mandate?
 - What are the implications for choice of goals?

- Pilot project vs. definitive study?
- Efficacy vs. effectiveness goals?
- What are the implications for choice of study design?
- What is the evaluation plan?
 - What design/outcomes are convincing for the purposes of pilot work for subsequent funding request?
 - What design/outcomes are convincing for the purposes of a definitive study to subsequently roll out in other jurisdictions?
- How can sustainability be built into the study design?

CHALLENGES IN CASEBOOK DEVELOPMENT

Limited representation from across Canada

The Research Team did not receive nominations from all regions of Canada. It appears that initiatives that improve or support continuity and coordination of patient care between oncology specialists and primary care providers are absent in regions of Northern and Atlantic Canada (excluding Nova Scotia), due to a lack of responses from stakeholders from these regions who had been invited to nominate initiatives. The Co-Investigators and Research Team brainstormed additional clinical and research leads in these two regions that might be able to nominate relevant initiatives and then followed up with new nominations. Additionally, the Research Team searched the Canadian Cancer Society Research Institute, the Canadian Institutes of Health Research and the Canadian Partnership Against Cancer funding databases to identify any relevant projects in Northern and Atlantic Canada that were funded within the last seven years. This search yielded two results from the Canadian Partnership Against Cancer; however, attempts to encourage project contacts to participate in the Casebook were unsuccessful. As there are limited initiatives in Atlantic provinces and Northern territories, it is challenging to identify which types of interventions could be successfully implemented in these regions.

Recent changes in Québec's health care system

Major changes within Québec's Ministry of Health and Social Services made it difficult to identify and contact clinical and research leads who would be able to nominate initiatives. Fortunately, one initiative from Québec was included in the Casebook. As the Canadian health care system is continuously evolving, the Casebook represents a "snapshot" of the initiatives nominated in the current primary and oncology care climates.

Lack of personalized medicine initiatives

One of the criteria for initiative inclusion in the Casebook was addressing at least one of the following stages of care: diagnosis; treatment; survivorship; or personalized medicine. It is important to note that personalized medicine was not targeted by any Casebook initiatives. Personalized medicine refers to diagnostic, prognostic and therapeutic strategies that are tailored to individual requirements. Personalized medicine-related initiatives were not included in the Casebook for several possible reasons: initiatives were not nominated; they are in very early stages of development; or they *have* been implemented but awareness of the programs is limited. The next phase of the CanIMPACT project may be influenced by the fact that Canadian personalized medicine initiatives were not nominated for inclusion in the Casebook.

Inconsistencies in regards to extent and quality of detail provided about initiatives

Key stakeholders across Canada were invited to nominate initiatives for inclusion in the Casebook. The Research Team anticipated that the stakeholders would: be aware of relevant initiatives; would nominate relevant initiatives; and that they would provide the most appropriate contacts for their nominations. It is likely that other initiatives that are similar to those profiled exist within Canada; however, they were not captured through the iterative nomination process. For example, although a number of initiatives that link breast cancer screening to diagnosis exist in Canada, only two initiatives (Nova Scotia Breast Screening Program (6) and Ontario Breast Screening Program (7) were *nominated, and thus included* in the Casebook.

The Research Team invited all of the nominated contacts to participate in a structured interview (all interviewees were presented with the same questions); however, varying levels of detail were provided by interviewees. Generally, the interviewee's position or role within the initiative was associated with the robustness of the information that was disclosed. For example, care providers and individuals involved in daily operations were likely to share the most detailed information about the responsibilities of program providers and of the barriers and facilitators that were encountered throughout program implementation. Therefore, it is important for Casebook readers to acknowledge that the Casebook *may or may not* provide a thorough representation of the profiled initiatives and of the current state of affairs, in regards to continuity and coordination of cancer patient care within Canada. The profiles and the results and conclusions of the Casebook were solely based on the information that was collected from initiative contacts during the interview process.

CONCLUSION

The CanIMPACT Casebook provides insights into Canadian efforts to improve the coordination of, and collaboration among, CBPHC and oncology specialists as a means to improve patient outcomes and cancer system performance. This project demonstrated a range of activities undertaken to achieve these goals. While inroads are being made, several gaps were uncovered that can serve as priority avenues for the CanIMPACT Team to pursue, namely, the need for a common rigorous, yet practical, evaluation framework to better enable proper assessment of these efforts, as well as more explicit protocolization of these efforts so groups are better able to learn from one another. The findings of the Casebook will be profiled at the CanIMPACT Consultative Workshop and used by the CanIMPACT Team to help choose, design, and execute the next stages of its program of research.