

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

Consultative Workshop: March 31/April 1, 2016

Detailed Report

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EXECUTIVE SUMMARY

While cancer rates are growing, and healthcare spending as a percentage of GDP is growing globally, there are many breakthroughs in therapies, with more cancer survivors. The medical side of cancer care has been improving exponentially; insufficient attention has been paid to the processes of care.

CanIMPACT is a pan-Canadian, multidisciplinary research initiative studying the question of how to improve cancer care through refining the interventions and support available for patients in primary care settings. This initiative was created in recognition that primary care has an expanding role in cancer control, and that integration is key.¹ Funded by the Canadian Institutes of Health Research, beginning in 2013, the overall goal is to elucidate gaps in care, develop and test a strategy to enhance the capacity of primary care to provide care to cancer patients, and improve integration and coordination of care along the cancer care continuum. CanIMPACT's activities are divided into two phases: Phase 1 was foundational research to understand existing evidence, models of care, patient and provider experience, and provincial differences (an overview of CanIMPACT is presented in Appendix 1). Phase 2 will involve evaluation of an intervention which will be based on the findings from Phase 1 and recommendations from the Consultative Workshop.

The Consultative Workshop was held on March 31 and April 1, 2016, with the research team and other leading researchers, members of CanIMPACT's Patient Advisory Committee, and primary care and cancer specialist healthcare providers from across Canada (workshop attendees and their principle institutional affiliation and jurisdiction is presented in Appendix 3). The objective of the workshop was to establish and prioritize recommendations for improving integration of care between primary care and cancer specialists that would lead to a recommendation for a "doable, meaningful and testable" intervention to be evaluated in Phase 2.

Key insights from Phase 1 include:

- Relationships and communication are a critical part of all cancer experiences.
- Integration between primary care and specialist care is key for seamless coordination of care, timely referrals, provider and patient confidence, and system access; but there is no simple way to achieve this.
- Family doctors are at the centre of all effective care, but transferring responsibility to the primary care physician to initiate and drive relationships with specialists requires time, support, knowledge development, relationship building and resources that add to the pressure of burdened practices.
- Context is critical, and there are multiple variations: team based or solo family practice; rural vs. small urban vs. metropolitan; vulnerability of populations; provincial and regional policies and resources; access to technology and EMR.
- Supported change management and readiness for innovation are critical factors in any intervention.
- Funding models for physicians can be important factors to consider.
- Solutions that may work well in one context (e.g., professional patient navigator inside team-based primary care) may not transferrable or feasible in other settings.

At the Consultative Workshop, eight potential scenarios were workshopped, including a comprehensive evaluation framework, patient navigation based in primary care, electronic asynchronous consulting between primary care provider and specialists (further information is provided at www.champlainbaseconsult.com), online educational resources, a shared care team model, and various combinations of each of these elements (a synopsis of the scenarios is presented in Appendix 5).

Through the discussion, it became clear that the most useful study would be of a combination of different interventions, implemented and evaluated in different contexts. The group concluded that models of care such as “patient navigation” are not useful to test in isolation, since there are multiple factors at play. Moreover, the role of patient navigator might work well in a team-based practice with the resources to devote to it that is not a common scenario. Similarly, interventions such as online guidelines and other educational resources require enabling knowledge translation strategies to encourage providers to use the resources when they are already under pressure.

The ideal Phase 2 intervention would be the test of e-resources or a navigator role with rigorous examination of different enabling and contextual components, such as professional designation and experience of the navigator, leadership to facilitate change management, team engagement and electronic resources, and patient activation. The group asserted that navigation as a concept (rather than a specific navigation role) has been proven to be effective, but the navigator role based in primary care is dependent on context, particularly a team structure. The questions emerged: “How do we enhance patient navigation in any context? What is the value of eConsult and technology for navigation and resource sharing?”

Building on the deliberative process, followed by voting of Workshop participants, the recommended intervention to be tested in Phase 2 is to **implement eConsult in the oncology setting to determine whether it improves relationships, communication, knowledge sharing and connections between family doctors and cancer specialists; and, to improve system navigation, evaluate eConsult in existing nurse navigator programs, if feasible.**

This intervention should target specific transition points, such as transition to survivorship care when patients are transferred from oncology care to primary care. The intervention will also explore different cost-effective models for the introduction of this innovative intervention. Possible jurisdictions include Nova Scotia and the Champlain LHIN in Ontario, where navigation is already part of the diagnostic assessment programs.

1. OVERVIEW OF CanIMPACT

CanIMPACT is a pan-Canadian, multidisciplinary research initiative studying the question of how to improve cancer care through refining the interventions and support available for patients in primary care settings. This initiative was created in recognition that primary care has an expanding role in cancer control, and that integration is key.¹ Funded by the Canadian Institutes for Health Research, beginning in 2013, the overall goal is to elucidate gaps in care, develop and test a strategy to enhance the capacity of primary care to provide care to cancer patients, and improve integration and coordination of care along the cancer care continuum. CanIMPACT is made up of healthcare professionals (family physicians and cancer specialists) researchers, patients, policy makers and knowledge users spanning seven provinces as well as international liaisons in Denmark, Australia, England and the United States. An overview of CanIMPACT is presented in Appendix 1.

The process has been as follows:

Phase 1: Foundational descriptive studies

- Qualitative study of stakeholder perspectives and contextual factors related to the coordination of care between primary care and cancer specialist care.
- A pan-Canadian environmental scan and systematic review to identify and understand the implementation of models of care designed to improve integration between primary care and cancer specialist care.
- Quantitative analyses of inter- and intra-provincial comparisons of breast cancer diagnosis, treatment and survivorship phases of care using administrative health databases in five provinces.
- A study of family physicians' experiences, desired roles and need related to cancer personalized medicine.

Phase 2: Intervention study

- **Consultative Workshop: Synthesis and formative knowledge translation and exchange**
- Testing an intervention
- Summative knowledge translation and exchange

This document summarizes the Consultative Workshop, which took place on March 31 and April 1, 2016. In this Consultative Workshop, the CanIMPACT team met with key Canadian and international stakeholders, including researchers, members of CanIMPACT's Patient Advisory Committee, and primary care and cancer specialist healthcare providers. Efforts were made to ensure a cross section of stakeholders, including nominated delegates from each province. (Workshop participants and their affiliations are listed in Appendix 3). The objective of the workshop was to establish and prioritize recommendations for improving integration of care between primary care and cancer specialists that would lead to a recommendation for Phase 2. Phase 2 will be focused on developing, implementing and evaluating a "doable, meaningful and testable" intervention.

2. OVERALL OUTCOMES FROM WORKSHOP: RECOMMENDATIONS FOR TESTABLE INTERVENTION

The main focus of the workshop was to review key findings from Phase 1 of CanIMPACT, along with two promising practices, in order to develop a testable intervention that would potentially improve the patient experience, patient outcomes, provider coordination, population health and system resources. (The full workshop agenda is presented in Appendix 2).

The first morning of the workshop included detailed presentations of context and evidence to inform the discussion about Phase 2, including keynote address focused on what Canada could learn from international experience with patient-centred approaches to improving cancer within primary care; the findings from each of the Phase 1 teams; two detailed examples of potential interventions, one involving a nurse navigator based in a family health team² and the other involving eConsult which is an innovative electronic approach to primary care/specialist communication³; and detailed visual representations of the cancer continuum from the health system and patient perspectives in the form of “gigamaps.” (Appendix 4 includes all presenter slides and Appendix 6 includes the gigamaps).

In the afternoon of the first day, potential interventions were presented (see Appendix 5) and the group broke into small groups to develop cases for these interventions, along with a few hybrids developed in the session. In the morning of Day 2, each small group presented their cases, and the group voted for each scenario along several key criteria (see Appendix 7 for the table of voting counts), and then used their assessments to inform a discussion to make a recommendation for a testable intervention.

Key insights from Phase 1 and the workshop discussion were:

- Relationships and communication are a critical part of all cancer experiences.
- Integration between primary care and specialist care is key for seamless coordination of care, timely referrals, provider and patient confidence, and system access; but there is no one simple way for this to be achieved.
- Family doctors are at the centre of all effective care, but transferring responsibility onto the primary care physician to initiate and drive relationships with specialists requires time, support, knowledge development, relationship building and resources that add to the pressure of already burdened practices.
- Context is critical, and there are multiple variations: team based or solo family practice; rural vs. small urban vs. metropolitan; vulnerability of populations; provincial and regional policies and resources; access to technology and EMR.
- Supported change management and readiness for innovation are critical factors in any intervention.
- Funding models for physicians can be important factors to consider.
- Today the evidence is not strong from evaluations to support any specific intervention(s).
- Solutions that may work well in one context (e.g., professional patient navigator inside team-based primary care) may not be transferrable to other environments.
- Possible study design should include participatory co-design with patients/family members as part of the team.

Section 4 outlines the possible scenarios that were workshopped in detail and then prioritized by the group. There were 8 scenarios in total, including a comprehensive evaluation framework, patient navigation based in primary care, eConsult and online educational resources, a shared care team model, and various combinations of each of these elements (see Appendix 5 for summary of scenarios).

Through the discussion, it became clear that the most useful study would involve a combination of different interventions, tested and implemented in different contexts. The group concluded that concepts such as “patient navigation” are not useful to test in isolation, since there are so many contextual factors. The recommendation for Phase 2 is a test of eConsult with rigorous examination of different enabling and contextual components, such as change management leadership and team engagement. The group asserted that navigation as a concept (rather than a specific navigation role) has been proven to be effective, but the navigator role is dependent on context. For example, in primary care it is dependent on having a family healthcare team structure. The questions emerged, “how do we enhance patient navigation in any context? Is there a value-added of eConsult for navigation and resource sharing?”

Building on the deliberative process, followed by voting of Workshop participants, the recommended intervention to be tested in Phase 2 is to **implement eConsult in the oncology setting to determine whether it improves relationships, communication, knowledge sharing and connections between family doctors and cancer specialists; and, to improve system navigation, evaluate eConsult in existing nurse navigator programs, if feasible.**

This approach will position the primary care physician/teams at the centre of seamless cancer care, while determining the value of enabling resources and how to best generate easeful uptake of electronic connections and resources. The intervention should target specific transition points such as the peri-diagnostic period and transition from active treatment to survivorship when patients are transferred from specialist care back to the care of the primary care practice. The intervention should also explore different cost-effective models for the introduction of this innovative intervention. Possible environments include Nova Scotia and the Champlain LHIN in Ontario, where navigation is already part of the process in some cancer care programs.

3. DETAILED INSIGHTS: PRESENTATIONS AND RESEARCH

The morning of March 31 was focused on presentations and knowledge sharing, with the intention of drawing on the Keynote address, the findings from Phase 1 and other key contextual factors to inform the shaping of the intervention for Phase 2. This section outlines key findings from those presentations.

3.1 Keynote Address: Stephen Taplin

Deputy Associate Director, Healthcare Delivery Research Program, Division of Cancer Control and Population Sciences, US National Cancer Institute

What can Canada learn from international experience with patient-centred, flexible approaches to improving communication, flow, knowledge and navigation for cancer within primary care?

Stephen Taplin reviewed the multi-level context of cancer care with examples about the most critical points in the continuum to improve care. He underlined that we are all policy makers, clinicians, and scientists, and are all also patients and family members who can build from our own experiences.

At a time when cancer rates are growing, and healthcare spending as a percentage of GDP is growing globally, there are many major breakthroughs in therapies, with more survivors. He noted that while technical care continues to improve, insufficient attention has been paid to the process of care. He advised workshop participants to look at cancer care in a multilevel context, including the connections and interactions between levels (i.e., individual patient, family and friends, healthcare provider, organization, local, state/provincial, national).

Specific suggestions included:

- Focus on the level in the process (e.g., policy, structure, culture, organization, individual) and the people related to that level; every level has a specific set of factors that affect care and possibilities.
- Move away from the focus on physicians and focus on providers as a team, and focus on teams as part of a community, not just an institution.
- Explore avenues proven to increase team productivity, such as:⁴
 - Daily huddles
 - Short all-team daily planning sessions
 - Visual displays to identify and track issues
 - Facilitate email and technology links between providers and patients
- Use Information Technology creatively.

3.2 Qualitative Studies. (Leads: Bo Miedema and Julie Easley)

Community based primary care is the first and most frequent point of contact for cancer patients during most phases of cancer care. The qualitative study explored stakeholder perspectives and contextual factors related to coordination of care between community-based primary care and specialist care, through telephone interviews with 38 breast and colorectal cancer survivors and 58 health providers. (See Appendix 4 for slides).

Key findings include:

- Communication is at the center of all positive and negative experiences for both patients and providers, including access to information, education, leadership and relationships.
- Patients experience care as one entire connected experience, not as different phases, but they don't always know who is "in charge" of their care. Many patients express their experience not in terms of medical needs but in terms of their relationships.
- The system can be described as different "gears" (e.g., medical oncologist, patient, family physician, surgeon) which all need to work together; any glitch affects all other parts. A great deal of the coordination of care falls onto the family.
- Coordination of care is influenced by access to information, delays in medical transcription, access to all aspects of care and trust.
- Facilitators in the coordination of care include enhancing communication, building trust/relationships, improving access to care, establishing professional leadership, facilitating professional development and engaging the patient at all points of care.
- Family physicians wanted more education about survivorship.
- There is no "one size" solution to support all patients across Canada.

3.3 Knowledge Translation Subgroup (Lead: Melissa Brouwers)

This group conducted a systemic review of evidence and studied in-the-field practice about existing initiatives aimed to strengthen primary care-oncology collaboration. The in-the-field component has been published as a Casebook.⁵ (See Appendix 4 for slides)

Key findings include:

- There is no clear model or comprehensive assessment in either the published literature or casebooks about the most effective way to enhance collaboration, and no common evaluation strategies or metrics.
- Casebook themes include patient-centredness, nurse navigators, multidisciplinary teams, information/communication systems, education for primary care, and multicomponent interventions.
- Phase 2 of CanIMPACT could usefully contribute a robust evaluation framework (it would be important to have clear expectations – e.g., better communication, quality of life, length of life); clarity about the specific questions being tested in a navigation model, and a clear understanding of the intentions of online tools and resources (e.g., could we give people models and resources to develop their own solutions?)
- Phase 2 should ensure that research evidence is actionable, transferable and easy to use for the knowledge provider.
- There is no one solution that will work in every context, since what we are trying to improve differs from one region or context to another.
- Factors that will influence success include:
 - Effective engagement of stakeholders (integrated KT approach), particularly generating support and buy-in from primary care providers and generating awareness;
 - Good governance with clear roles and responsibilities;
 - Use of champions;
 - Commitment to evaluation;
 - Consideration of complexities of large-scale initiatives; and
 - Patient perspective.

3.4 Administrative Data Subgroup (Leads: Patti Groome and Marcy Winget)

This stream conducted inter- and intra-provincial comparisons in BC, Alberta, Manitoba, Ontario and Nova Scotia of the breast cancer diagnosis, treatment and survivorship phases of care, to focus on aspects that might be influenced by primary care and to identify subgroups of patients at risk of sub-optimal access/outcomes. (See Appendix 4 for slides).

Key Findings:

- The group reviewed several outcomes, including the use of primary and oncology services in all three phases, screen detection, diagnostic interval length, adjuvant chemotherapy use and emergency department use during chemotherapy, survivorship care guideline adherence and chronic and preventive disease care.
- The review concluded that primary care providers:
 - have a role in *care co-ordination* in diagnosis of symptomatic patients, avoidance of ED visits for treatment toxicity and improving surveillance guideline adherence during survivorship
 - need *information* about diagnostic and survivorship care paths and chemotherapy toxicity management
 - should be *providing culturally sensitive information* to immigrant patients about breast cancer screening
 - should be included in multi-disciplinary care to improve access to chemotherapy and toxicity management
 - may have the role in the diagnostic process of ensuring referral to coordinated services
- There are regional differences in screen detection rates, diagnostic intervals, use of chemotherapy and use of ED for chemotherapy toxicity, particularly in rural areas.
- Policy implications of any intervention may include culturally sensitive information program about breast cancer screening targeted at recent immigrants; differential access / use of dedicated diagnostic assessment units across and within provinces and no formal process for ensuring access at the population level and remuneration strategies to encourage use of practice guidelines by primary care providers.

3.5 Personalized Medicine Project (Leads: June Carroll and Elizabeth Eisenhauer)

This stream was a qualitative exploration of primary care providers' experiences and perceptions of personalized medicine, especially in cancer, as well as their desired roles, in urban and rural inter-professional primary care team practices in Alberta and Ontario. (See Appendix 4 for slides).

Key findings:

- Primary care providers have infrequent experience with personalized medicine, and little awareness of triggers for genetic referrals.
- Providers are concerned over their lack of knowledge, and don't feel informed to have conversations with patients. Their lack of formal knowledge means that they draw more on personal experiences to influence their perceptions and attitudes, and are concerned that patients will make requests they are not equipped to answer.
- Providers have uncertainty about referrals, and are unsure about how to support patients in decision-making.
- Possible supports for primary care providers in the growing realm of personalized medicine include:
 - a buddy system with a genetic counselor,
 - resource within the clinic with expertise in genetics,
 - easy, accessible tools from a reliable source,

- web based resources,
- point of care tools,
- educational sessions from providers with expertise, and
- patient handouts.
- This stream supports the notion of a mechanism to link family physicians directly with genetic counsellors and/or patient navigator who could also be familiar with personalized medicine and who could increase capacity with at-risk patients, not just those diagnosed with cancer.

3.6 Access to Specialists through eConsult (Lead: Clare Liddy)

eConsult is a novel secure web based service for primary providers to access specialist care for their patients. The Champlain LHIN eConsult Service is a collaboration between The Champlain Local Health Integration Network (Ontario), The Ottawa Hospital, Bruyère Research Institute and Winchester District Memorial Hospital. This is an example of a possible intervention that could be studied and translated for use elsewhere. (See www.champlainbaseeconsult.com for more information).

Key Elements:

- eConsult provides direct non-urgent access to specialty care, with a one-week response time. Currently it does not include oncology consultations. Potential applications to oncology could be during diagnosis, follow up during active cancer treatment, and survivorship transitions.
- Goals include avoidance of referrals and increased confidence for cancer care within primary care settings; ultimate goals include a low-cost service delivery model that provides primary care providers with specialist advice within days instead of months, improved quality of care delivery and reduction of face-to-face referrals.^{6,7}
- eConsults utilize secure web-based technology to facilitate simple, effective and timely (not real-time) communication between primary and specialist care providers. Specialists may provide reply to the question, requests for additional information or referrals to specialists.
- This is a growing, low-cost service in Ontario, with good feedback from primary care providers.

3.7 Oncology Nurse Navigator in North Perth Family Health Team (Lead: Sarah Givens)

The North Perth Family Health team (based near London, Ontario) has pioneered the innovative role of an oncology nurse navigator as a primary care support for patients and families throughout the spectrum of care from pre-diagnosis through survivorship and palliative care.

Key Elements:

- A nurse provides a single point of contact for a caseload of patients with a confirmed cancer diagnosis. The navigator makes proactive contact with patients as soon as they are diagnosed. This is not time-limited – there is no official discharge from the program.
- Navigation is particularly critical in the transition between points of care, saving physicians' time and emergency department visits.
- Success factors include community buy-in, in-house expertise, clarity of roles, patients feeling supported, and improved work flow/load within the FHT.
- Current practice standards are based on physician feedback and timeliness of referral and preventive care screening compliance rates; the program has not been evaluated for long term patient outcomes.

3.8 Gigamap Development

Through the last stage of Phase 1, two “gigamaps” were developed. Gigamaps are a method of visually capturing the detailed elements of a system, context or environment across multiple layers, tracking and investigating relationships between all of the categories, including those that are connected in complex ways. The two gigamaps for CanIMPACT capture and integrate the processes, insights and relationships from the studies that describe the cancer experience from two perspectives:

1. Cancer Care in Canadian Healthcare System
2. Patient-Person Centred Cancer Journey

The gigamaps are provided in Appendix 6.

Some highlights from the gigamaps that inform the most meaningful intervention include:

- There is a huge amount of interaction between primary care physicians and patients at all stages of cancer care.
- Delays in diagnosis have a cyclic effect on a patient’s trust in their primary care provider.
- “Shifting the burden” shows how the stress builds starting from diagnosis.
- Patients experience stress while waiting for a diagnosis, and may blame their primary care provider for the delay, if it is unfair/inaccurate to do so.
- The need for improvements in cancer survivorship is increased by an increase in demand due to an aging population, early diagnosis, and improvements in survival.
- There is an increase in the number of cancer patients with other co-morbidities, driving demand for the health system to address more survivors over longer life and end-of-life care.
- There is an increase in overall health system demand considering general increase in demand due to growth and aging of the population as well as widespread multimorbidity.

4. DEVELOPMENT OF SCENARIOS FOR TESTABLE INTERVENTION

The afternoon of March 31 focused on small groups using initial draft scenarios to develop recommendations for the most meaningful and testable intervention for Phase 2 of CanIMPACT. The criteria and draft scenarios for intervention development were derived from the work of the streams in Phase 1 and the Navigation and eConsult “promising practices” shared with the group.

4.1 Development Criteria and Initial Scenarios

Development criteria included the following study parameters:

3 years; ~\$1 million; focus on breast cancer; covering the range of peri-diagnosis, treatment and survivorship

Elements:

- Does it have the potential to improve integration/ coordination?
- Is it patient-centred?
- Is it feasible to test (considering constraints)?
- Is it potentially scalable (considering different contexts and jurisdictions)?
- Is it potentially sustainable?
- Is it potentially applicable to cancer sites other than breast cancer?

Four initial scenarios were presented:

1. *Develop and pilot test an evaluation framework*

- An evaluation framework would allow for development of approaches tailored to the local circumstances, and would contribute to advancing the science from a measurement and quality indicator perspective.
- Possible approach: develop an evaluation framework for selected initiatives (e.g., navigation initiatives documented in the Casebook)
- Limitation: Does not directly implement and pilot test an innovative model of care.
- Key question: Would it be useful for jurisdictions/organizations aiming to establish initiatives?

2. *Conduct a pilot/feasibility trial of a navigation model based in primary care*

- Evidence from other diseases and from cancer screening and diagnosis show that navigation is effective. A navigator based in primary care could support all cancer patients in the team practice throughout the continuum of cancer care. In that sense, it is unique and innovative.
- Would provide the necessary data required to develop a full-scale trial.
- Key question: is this particular model of care generalizable / scalable / sustainable?

3. *Develop an on-line repository for cancer-specific guidelines and tools tailored for primary care, and develop and test a rigorous strategy to disseminate the tools.*

- This approach could be accessible across Canada and beyond, and could include resources such as clinical practice guidelines on survivorship care, tools for managing chemotherapy related toxicity, chemotherapy related late-effects and decision support for genetic testing.
- Limitations: would not directly address issues of integration/coordination of care.

4. Implement eConsult on its own or in combination with another scenario.

- This approach has been demonstrated as a practical, feasible tool to improve communication and continuity of care, but has not been used in oncology and there are currently a limited number of jurisdictions with access to the resource.

The group was also invited to create a hybrid of any of the above or to create a new scenario. Additional groups explored:

- Patient navigation with embedded patient activation
- Patient navigation with eConsult
- Patient navigation, online tools and eConsult
- Team activation with practice facilitation, goal setting and shared care
- Process for local innovation with common tools

The cases that follow were developed by the small groups; these are the detailed notes from their discussions.

4.2 Case #1: Evaluation Framework

There is currently no common evaluation framework that outlines common goals, outcomes or indicators for any intervention or initiative to improve coordination of cancer care across the system. One possible intervention is the development and testing of an evaluation framework that incorporates patient-centred, provider-driven and system outcomes.

The group that explored the evaluation framework identified several elements that need to be captured in a concerted evaluation effort:

- Inform access issue by identifying all players, their scope of practice, and if they are working to their extended scope of practice.
- Key principles of the framework are: context is key; mixed methods; program evaluation; logic model; should include people, places and processes; engage with decision-makers at the outset; cost.
- Define co-ordination in patient-centred terms, recognizing that different aspects of patient experience are differently weighted.
- Create shared language between primary care, generalists and specialists.
- Track vertical integration (how people move through the system), functional integration (information and communications systems), and clinical integration (what do individual providers actually do and how do they connect and intersect).
- Well-coordinated care is indicated by no complaints and no distress; how do we measure success in terms of the **absence** of indicators?
- Evaluation needs to recognize that coordination (how the parts work together) and navigation (how the parts are identified, located and moved through) are two different things.

4.3 Scenario #2: Patient Navigation in Primary Care

This intervention would test the value of a primary care-based professional navigator model for people with cancer, to support people across the journey.

Navigation is defined as a “proactive, intentional process of collaborating with a person and his or her family to provide guidance as they negotiate the maze of treatments, services, and potential barriers through the cancer journey”.⁸

Proposed navigator role:

- Health professional with oncology expertise; this could be oncology nurses or oncology social workers depending on the particular needs of the community or population they support.
- Accountability is to collaborate with community resources, acute care services, clinical staff, social workers and other allied health providers to ensure patients and families receive individualized supports as required during their transition into the cancer system, on their journey through it, and beyond.

Key effectiveness factors:

- Relational care and continuity over time
- Resource tailored to specific population and needs
- How engaged the primary care and cancer program are in the development of this role
- Openness of the two systems to “integration and improved care coordination”
- Clarity around primary/secondary outcomes
- Clarity around trajectory focus and population focus
- Role development support (competency development to do the role/orientation)
- Role implementation support (community, primary care and cancer engagement)
- Support to measure impact of the navigator role

Desired Outcomes:

Primary outcomes: Improving the patient/family/provider experience

- Improved patient/family decision making capacity (supported to understand disease and treatment options)
- Understand next steps in care
- Understand who to call with problems/questions
- Increased awareness of supportive care services
- Decreased levels of distress for patients and healthcare providers
- Advanced care planning

Secondary outcome: System outcomes such as:

- Decreased interval times from suspicion to diagnosis, from diagnosis to treatment, from symptom presentation to symptom management.
- Improved care coordination between primary care and cancer services.
- Cost effective – lower cost Health Care Professional to provide proactive intervention which decreases downstream health system utilization (GP visits, ER visits, admissions to hospital)
- Decreased physician workload
- Increased compliance with treatment and screening/surveillance recommendations
- Understand the value of investment in this role based on different populations/size and type of practice

Proposed Pilot Study:

Test the impact of three approaches to defining and developing the role and articulating “improved integration” in different, comparable sites:

1. Introduce a new navigator role with extensive change management and integration support; provide the community with support to identify gaps, resources, orientation, focus and patient engagement.
2. Provide funding for a navigator position with similar skills but without formal programmatic and change leadership support.

3. Study a clinical environment with no navigation intervention to articulate the potential value of a navigator role/the impact of not having one.

4.4 Scenario #3: Online Guidelines and Tools

This intervention would be the creation of a comprehensive national resource base aimed at Canadian physicians and patients with two key elements:

- Well-organized extensive collection of resources that is graphically attractive and easy to use, including guidelines, checklists, practice tools, videos, free online courses, useful to both providers and patients.
- Interactive space for primary care providers to post questions that specialist advisors respond in a timely way and a patient portal for similar questions.

Potential value:

- Create integration at the highest level through a collective of primary care providers and specialists so patients are confident their providers have the best information.
- Ensure specialist expertise is sharable across the country; possible source of CME learning for providers.
- Creation of searchable database of responses to questions.

Detailed elements:

- National bilingual resource hosted with a variety of collaborators and partners (CAPCA, CIPAC, CMAO), hosted by CFPC.
- Evaluation of the resource would include uptake, downloads, preferred info source, implementation in different parts of the country, provider insights about how this is changing practice and whether patients feel like they are getting more answers.
- Roll out could be province by province supported by the hospital EMR system.
- Implementation would include organization integration with discussions around shared cancer care.

4.5 Scenario #4 eConsult

This intervention focuses on the eConsult model as a managed approach to alternate use of healthcare resources, connecting primary care providers and specialists through online portals.

The focus for the pilot study has several lenses (following a quadruple aim model):

- Does eConsult translate into good healthcare?
- What is a viable funding and cost model that contributes to healthcare sustainability?
- How does this approach support integration, coordination and scalability?
- How can this be available to providers who have differing technology and funding?
- How is this appealing and useful to primary care practitioners, specialists, the health system and patients?
- How could this approach support social determinants of health and cancer prevention?
- How does this support relationships between care providers and the system itself?

Considerations for a study:

- Identify desired end points and indicators that would demonstrate them
- Define scope of eConsult – risk factors, diagnostic period, tests done between referral and consultation, treatment approaches, survivorship, co-morbidities.
- Determine how to ask non-urgent and follow up questions.

- Study design would include randomization, stratification, rural and urban settings, applicability of electronic resource. Identify who would assign cases.
- Explore alternative funding approaches and how to increase utilization (e.g., CME)
- Explore how to scale this across provinces, and the advantages of eConsult vs. telephone consult

4.6 Scenario #5 Navigation and Patient Activation

This intervention combines patient navigation processes embedded in primary care with focused patient activation, the development of the patient’s knowledge, skills, and confidence to manage specific problems and implement self-management behaviors to improve health recovery, optimize health and survival.

Key Elements:

- Creation of a process that supports patient and family navigation (a set of tasks and access to different people and resources across care, some electronic) that account for multi-morbidities and the complexity of cancer care. This process includes coaching and activation support for the families of patients, which each person can access and use in different ways.
- In this context, navigation is not a role or person but a process with defined components: holistic assessment; evidence-based care pathways; existing toolkits made available electronically; virtual navigation and interaction with providers.
- This may include case management where appropriate.
- Common training and skills development for providers.

Study design:

- 1) Work with the community to develop toolkit that focuses on patient activation in four sites: two urban and two rural settings. Design process would build in components that would focus on individualized care. Integrate into social networks that enable patient behavior (e.g., spouse).
- 2) Provide toolkits to trial, based on care-based plans tailored to each patient.

Considerations:

- Patients who “don’t want to be activated” or don’t have family/friend resources.

4.7 Scenario #6: Navigation and eConsult

This intervention combines implementation of critical components of both the navigation process and eConsult approach with a concerted change management process.

Key elements:

- Implement critical components of the navigation process tailored to local needs, focusing on core issues of patients and providers, and assess communication, relationships, role clarity, and outcomes
- Conduct participatory community research to determine which sites are ready and most appropriate for this intervention and which populations could most benefit (e.g., vulnerable populations with breast cancer)
- Provide navigation sites with change management resources and support (readiness assessment, change management piece, facilitation, evaluation framework)
- Conduct evaluation across communities, including funders
- Provide access to eConsult to patient navigators, with on-call component to provide urgent responses when they’re working in emergency rooms, etc.
- Support patient navigators with particular expertise for transitions back to primary care after treatment.

4.8 Scenario #7 Shared Care Model

Develop, implement and conduct a rigorous evaluation of a collaborative care and team-based delivery model, co-designed with primary care providers, specialists and patients/family.

Potential Intervention:

- Implement a model in 2 or 3 jurisdictions, including the cancer clinic and aligned family practice, adaptable to the local context. Build on best practice collaborative work and team-building strategies adapted to the cancer environment.
- Focus on high risk breast cancer population and high risk metastatic disease.
- Identify patient group open to participating as part of a team model.
- Create a trial with improvement cycles that follows the same patient through the research.
- Create tool kits and resources to facilitate collaborative, team-based care, with intentional goal-setting structured communication, and focused access to community supports. (This fits the interprofessional, team-based education of incoming practitioners).

Outcomes to explore:

- How will this focus on collaborative care and team-based work reduce the burden of disease, especially the burden of care coordination on patients and families?
- How does this improve timeliness and access to care?
- How can this improve communications and relational continuity of care?
- How can this contribute to research on effective team based models?
- How can this contribute to shared decision-making with patients?
- Possible indicators include patient experience, availability, satisfaction of care, and team effectiveness.

4.9 Scenario #8: Local Innovation with Common Evaluation Framework and Access to Tools

Argument: Since there is no single solution that will work across Canada and no clear evidence for any specific intervention, this group argued that the most effective approach is a **process** that provides the tools, knowledge translation strategy and resources to support users to create their own solutions.

The overarching research framework for this approach would be to identify the evaluation strategy and metrics to evaluate: (a) the fidelity of the operationalization of these factors; (b) the process impact of these factors; and (c) the clinical and system impact of these factors, resulting in an overarching, tested set of factors/principles/components of a high quality integrated cancer strategy.

5.0 Conclusions

As each of the scenarios was presented by the small groups, participants used i-clicker technology to rate their support for each possible Phase 2 intervention based on five key criteria:

1. Does this scenario have the potential to improve integration/coordination of care between primary care and cancer specialists?
2. Is the scenario feasible to test within the constraints of CanIMPACT?
3. Is the scenario patient-centred?
4. Is the scenario generalizable/adaptable across settings?
5. Is the scenario scalable and sustainable?

The participants rated their overall support for each scenario as it was presented, then rated their support over the entire set. Voting numbers are captured in Appendix 7.

In the assessment of the entire set of eight scenarios, no one emerged as generating overwhelming support: no scenario received a majority of votes for the highest rating, and no scenario received a majority of votes for the lowest rating. This assessment prompted a discussion, during which a refined set of scenarios was presented, with all of the patient navigation scenarios combined into one set as they were very similar. In this round, the patient navigation scenarios and eConsult model with other potential IT support emerged as the leaders. A final round of discussion was held in which it became clear that the overtly patient-centred approaches (i.e. navigation) were more easily understood and recognized by some players (especially patients), while it was also clear that lack of communication between primary care and oncology providers is a key problem. Thus, studying a modified form of eConsult, in settings with and without existing navigation programs, received the majority of votes as being the most feasible, generalizable, adaptable, scalable and sustainable.

6.0 References

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