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 Appendices

December 2015
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APPENDIX A: Materials

Item 1: Request for Nomination
Note: Highlighted sections were tailored with the appropriate contact information for whom the nomination request was being sent.

Date
Name
Title
Organization
Address
City, Province   Postal Code
Email

RE:    Participation in the CanIMPACT Casebook Project

Dear <Salutation>, <Name>,

I am writing to you with an invitation to participate in CanIMPACT, a research study funded by the Canadian Institutes of Health Research. We are approaching leaders in Canada to assist us in profiling examples of initiatives that improve or support continuity and coordination of patient care between primary care providers and oncology specialists in Canada.

Community-based primary health care (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 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. The intent of the Casebook is to profile existing or new models of coordinated care that have been implemented by individuals, groups, or organizations across Canada in order to overcome system challenges and ameliorate patient experiences and outcomes.

Initiatives profiled in the Casebook will be used to identify care gaps and inform the development of an interdisciplinary and multijurisdictional shared-care framework aimed at enhancing the capacity of CBPHC to provide care to cancer patients and improving the linkages between primary and specialty care along the cancer continuum; it will cover diagnosis, treatment, survivorship and personalized medicine with a primary focus on patients with breast and colorectal cancers. The final framework along with supporting tools and resources will be evaluated in a randomized study.

Examples of a Casebook submission could include the following:
- A re-organization of care to improve the patient experience during transitions from one phase of care to the next (e.g., active treatment to follow-up care);
- The development of a tool to facilitate, for patients or providers, the delineation of roles and responsibilities among providers at different points in the cancer journey;
- The implementation of educational training and resources in order to improve knowledge and skills in providing cancer care in the community; or
- The development of a communication strategy or system to improve coordination of shared-care between specialist and primary care.
We are seeking nominations from you and other leaders across the country. Nominations must involve Canadian content or contributions, be from groups or individuals belonging to a recognized Canadian organization or institution and be seen to improve some aspect of cancer care coordination, delivery, organization, or patient care. In addition, we have outlined a list of inclusion criteria to facilitate your nominations and in turn, our selections of nominated cases. All criteria must be met for consideration. The criteria include:

- A specific challenge or issue, occurring within any phase of inquiry (that is, diagnosis, treatment, survivorship or personalized medicine), was identified and involved communication or coordination (at any level) with CBPHC;
- The solution to the challenge or issue involved a role for CBPHC;
- An organized and deliberate effort (big or small) was developed and implemented to address the identified challenge/issue.

You are free to nominate activities from your own or others’ organizations or jurisdictions. From these nominations we will be gathering more data and information to complete the initiative profile.

Enclosed you will find a nomination sheet that identifies the minimum information we require for the nomination. We would ask that you please complete the form and return it to our office or you may wish to send an email that includes this information.

Please forward your nominations to research assistant’s name, Research Assistant for the Casebook project, via email at research assistant’s email address by date. If you have any questions regarding the Casebook or the CanIMPACT research project, please contact research assistant’s name or myself at mbrouwer@mcmaster.ca.

We look forward to hearing from you and thank you in advance for your time and consideration.

Sincerely,

Melissa Brouwers, PhD
Knowledge Translation Lead, CanIMPACT
Associate Professor and Lead of Health Services Research, Department of Oncology, McMaster University
Associate Member, Department of Clinical Epidemiology and Biostatistics, McMaster University

CanIMPACT is funded by the Canadian Institutes of Health Research
CASEBOOK NOMINATION SUBMISSION FORM

Please complete the following nomination form. If you are submitting more than one nomination, please complete separate forms for each initiative. You may also send an email with the information below. Please forward your nominations to name of research assistant @ research assistant’s email address. Thank you for your time and support of this important project.

I. NOMINATOR DETAILS
Name: ___________________________ Phone: ___________________________
Organization: ___________________________ Email: ___________________________
Address: ___________________________
Assistant Name: ___________________________ Email: ___________________________

II. DETAILS OF NOMINEE

a) Name of initiative
If no formal name exists, a label that might best describe it

b) Short description of initiative
Please provide an overview of the initiative and how it generally meets the criteria for inclusion

c) Reports and Documents
Please list (and provide via email) any reports or supporting documentation about the initiative

d) Contact information for the initiative
Please provide the contact information for the initiative staff who is (are) the best point person(s) to communicate with regarding the initiative

i) Primary Contact
Name: ___________________________
Title or Position: ___________________________
Address: ___________________________
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*ii) Secondary Contact (if available)*

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CanIMPACT is funded by the Canadian Institutes of Health Research
Item 2: Request for Participation

Note: Highlighted sections were tailored with the appropriate contact information for whom the participation request was being sent.

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RE: Participation in the CanIMPACT Casebook Project for initiative name

Dear <Salutation>, <Name>,

I am writing to you with an invitation to participate in CanIMPACT, a research study funded by the Canadian Institutes of Health Research. We are approaching leaders in Canada to assist us in profiling examples of initiatives that improve or support continuity and coordination of patient care between primary care providers and oncology specialists in Canada.

Community-based primary health care (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 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. The intent of the Casebook is to profile existing or new models of coordinated care that have been implemented by individuals, groups, or organizations across Canada in order to overcome system challenges and ameliorate patient experiences and outcomes.

Initiatives profiled in the Casebook will be used to identify care gaps and inform the development of an interdisciplinary and multijurisdictional shared-care framework aimed at enhancing the capacity of CBPHC to provide care to cancer patients and improving the linkages between primary and specialty care along the cancer continuum; it will cover diagnosis, treatment, survivorship and personalized medicine with a primary focus on patients with breast and colorectal cancers. The final framework along with supporting tools and resources will be evaluated in a randomized study.

CONGRATULATIONS! The project initiative name has been nominated to be included in the Casebook. Nominator name suggested that we contact you to gather more data and information to complete the initiative profile. We invite you to be interviewed over the telephone by Research assistant’s name, Research Assistant for the Casebook project, between now and February 2015. The interview will take between 45-60 minutes to complete and will be scheduled at your convenience. If you are interested in assisting us with completing the profile about initiative name, please contact us with a list of dates and times that you would be available for an interview between now and February 2015 at casebookcanimpact@gmail.com. Research assistant’s name will be in touch with you to schedule an appointment. If you can recommend another contact to speak about initiative name, please forward their contact information along to us at your convenience. If you have any questions regarding the Casebook or the CanIMPACT research project, please contact research assistant’s name at research assistant’s email or myself at mbrouwer@mcmaster.ca.
We look forward to hearing from you and thank you in advance for your time and consideration.

Sincerely,

Melissa Brouwers, PhD

Knowledge Translation Lead, CanIMPACT
Associate Professor and Lead of Health Services Research, Department of Oncology, McMaster University
Associate Member, Department of Clinical Epidemiology and Biostatistics, McMaster University

CanIMPACT is funded by the Canadian Institutes of Health Research
Item 3: Telephone Interview Profile Form

Note: Highlighted sections were tailored with the appropriate contact information for whom the telephone interview form was being sent.

Date

Dear Name,

Thank you for participating in the CanIMPACT Casebook project. Please find enclosed your completed Initiative Profile Form. We have completed your Profile Form as best and as complete as possible based on the information we obtained through the nomination and interview processes. We kindly ask that you review the form and confirm or correct the content, and provide additional information where it is either lacking or incomplete.

Please submit your completed form via email (casebookcanimpact@gmail.com) no later than date.

Thank you again for your participation in this important project.

The CanIMPACT Team
Initiative Profile Form

CONTACT INFORMATION

PRIMARY CONTACT
Name: [Name]
Title: [Title]
Organization: [Organization]
Department: [Department]
Address: [Address]
City: [City]
Postal Code: [Postal Code]
Telephone: [Telephone]
Email: [Email]

SECONDARY CONTACT:
Name: [Name]
Title: [Title]
Organization: [Organization]
Department: [Department]
Address: [Address]
City: [City]
Postal Code: [Postal Code]
Telephone: [Telephone]
Email: [Email]

GENERAL INFORMATION ABOUT THE INITIATIVE
Please provide a written response in the boxes below.

Title of the Initiative
Provide the official title of the initiative.

Start Date of the Initiative
Provide the date the initiative was first implemented.

Implementation Level
Indicate the level at which the initiative is implemented; it may be locally within the organization, provincially/territorially or nationally.
**Cancer Diagnosis**  
Provide the specific diagnosis (or diagnoses) that was (were) targeted (e.g., breast, colorectal). If the initiative was not specific to one cancer diagnosis, please indicate as such.

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**Cancer Care Continuum**  
Provide the stage of the cancer continuum that the initiative targets: diagnosis, active treatment, survivorship (for the purposes of this form, we define survivorship as the time active treatment concludes onward) or personalized medicine. If the initiative is applicable to multiple stages, please indicate as such.

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**Initiative Focus**  
Identify the focus of the initiative with respect to the aspects of patient care that it addresses. For example:

- Accurate and timely diagnosis
- Management of cancer treatment, non-cancer physical health needs, psychosocial needs, acute cancer related symptoms, or chronic late stage symptoms
- Post-treatment surveillance
- Patient self-care and/or self-management

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<th>Initiative Focus</th>
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**Patient Care Setting**  
Patient care can take place in various settings. Indicate the setting(s) where your initiative takes place. For example:

- Cancer Centre
- Other Health Care Institution/Hospital
- Primary Care Provider Office or Cancer Centre
- Community (e.g., Wellness Centre)

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**Models of Coordinated/Shared Care**
Models of care can be categorized based on the provider leading the coordination of care versus those providers supporting the initiative. Indicate the overall model of care that best describes your initiative. For example:

- Primary Care Led/Specialist Supported
- Specialist Led/Primary Care Supported
- Co-led Primary Care and Specialist

**Rationale for Initiative**
What was the challenge or issue that prompted the initiative? Consider noting the type of patients involved, the quality issue or gap identified, and the specific indicators that signaled an issue.

**Detailed Information about the Initiative**
Please provide a written response to the questions in the boxes below.

*Describe your initiative with respect to the following:*

What is the specific goal or objective of the initiative? For example:

- To change clinician attitudes, knowledge, or behavior
- To change patients/family attitudes, knowledge, or behavior
- To change the organization, structure, or delivery of health care
Who led the development of the initiative?

Who leads/is responsible for the daily operations of the initiative?

Which types of providers deliver care within the initiative? Consider clinicians from primary care (e.g., family physicians, nurse practitioners, family practice nurses, allied health professionals) and specialist care (e.g., medical and radiation oncologists, general practitioners in oncology, surgeons, advanced practice nurses).

How does the initiative address the identified issue or challenge?
What are the responsibilities of involved providers? Distinguish between those leading the initiative (e.g., authority, governance, accountability) and providers carrying out the initiative (e.g., coordination and communication between care providers, and between providers and patients).

What were the barriers and facilitators to implementing the initiative? For example: Barriers associated with patients (e.g., language, motivation), providers (e.g., collaboration problems, skills, trust), organizations (e.g., lack of support by leaders), health systems (e.g., resources, insufficient funds) and the initiative itself (e.g., requires complex actions to implement, perceived as adding questionable benefit). Facilitators or supports that helped with implementation.

Were any other lessons learned during the implementation of the initiative? Consider what you would do differently and what you would do the same. Future directions of the initiative can also be included here.
How does the initiative improve the coordination and advance the quality of cancer care? Consider the impact of the initiative and how it might serve as a model of shared care.

Has an evaluation of the initiative been done? Please provide details regarding any evaluation, formal (e.g., program evaluation) or informal (e.g., short survey, anecdotes). Consider: Process outcomes (e.g., time to diagnosis after abnormal test result, compliance with clinical practice guidelines, wait time to treatment) Patient centered outcomes (e.g. patient participation in treatment decisions, patient satisfaction with physician share care communication) Clinical (including surrogate) outcomes (e.g., reduction in unnecessary tests or procedures, quality of life) Overall implementation of the initiative

What were the results of the evaluation? If results are not yet available or if an evaluation is in progress, please indicate as such.
What are the resource and cost implications (if any) of the initiative? Consider the different inputs needed such as money investment, professional resources (e.g., number of persons, their profession, training, full- or part-time), technology, and time.

**ADDITIONAL INFORMATION SOURCES**

Please list any additional sources of information about the initiative.

4.1 Related Materials (e.g., tools):

4.2 For more information visit (e.g., website):

4.3 This project is cited at:

4.4 Related publications:

**NOTES OR ADDITIONAL INFORMATION ABOUT THE INITIATIVE:**

**FOR THE NEXT PHASE OF THIS PROJECT WE WOULD LIKE TO SURVEY COMMUNITY PRIMARY HEALTH CARE PROVIDERS ABOUT THEIR EXPERIENCES WITH THE CANCER SYSTEM. CAN YOU PROVIDE THE NAMES OF SOME FRONT LINE PRIMARY CARE PROVIDERS THAT WE CAN APPROACH WITH THIS REQUEST?**
APPENDIX B: Profiles

1. **Clinical Breast Health Program**

**Interviewee and contact information:** Alanna Dukes, Nurse Navigator for the Clinical Breast Health Program, Alberta Health Services ([Alanna.Dukes@albertahealthservices.ca](mailto:Alanna.Dukes@albertahealthservices.ca))

**Date of interview:** January 26, 2015

**Implementation level:** Regional

**Implementation site:** Central Zone of Alberta Health Services, Alberta, Canada

**Implementation date:** 2007

**Targeted stage of cancer care continuum:** Diagnosis and treatment

**Targeted cancer diagnosis:** Breast

**Creation and development of materials:** N/A

**Delivery of initiative/program**

- Specialists (primarily nurse navigators)

**Initiative/program users:** Patients

**Overview**

The Clinical Breast Health Program (CBHP) was implemented in 2007 at a regional level, in the Central Zone of Alberta Health Services (AHS). The CBHP uses a nurse-led model of care to target newly diagnosed breast cancer patients who are transitioning from diagnosis to surgical treatment. At this transitional stage, nurse navigators work to provide patients with diagnosis-specific education and emotional support, as well as to help coordinate care by ensuring that patients are receiving appropriate tests or procedures in a safe and timely manner.

**Rationale**

For the majority of breast cancer patients, surgery is the first form of treatment that they receive. In the Central Zone of AHS, in 2007, wait times for breast cancer surgery required improvement. Furthermore, there was a need to provide patients with diagnosis-related education as well as emotional support, before their initial surgery consultations. Patients also required support and guidance post-surgery, before they were referred and introduced to the resources available within a cancer centre. All of these factors prompted the implementation of the CBHP.

Various health professionals working within CancerControl Alberta, as well as nurses and consultants, led the development of the program. The CBHP is managed by Gail Ganton, Manager of Ambulatory Care Community Oncology, AHS.

The current goal of the program is to decrease wait times for surgery and to provide care and support to patients prior to their surgery, as well as immediately post.

**Description**

The CBHP is available to recently diagnosed breast cancer patients living within the Central Zone of AHS. The program targets patients during the surgical phase of their treatment only. Family physicians refer the appropriate patients to the program. Nurse navigators and administrative assistants track and record patients’ wait times for surgery-related appointments and for referrals to cancer centres post-surgery.
All patient services are provided over the phone. Therefore, once referred, patients are able to call in to speak with a nurse navigator. A nurse navigator, located in the Red Deer Regional Hospital Centre, is responsible for answering patient phone calls; administrative support is provided. Nurse navigators address patients’ information and emotional support needs prior to their surgeries. They help to coordinate care by following up with patients to ensure that they have scheduled appointments for the correct dates and times. They also connect patients with community resources and services post-surgery, before they are transitioned to either a cancer centre, or back to their family physician, who remains fully informed about the status of their patient’s care. Nurse navigators occasionally meet with patients in person, when they come in for appointments at the hospital centre.

**Evaluation**

The CBHP initially received funding through the Wait Times Management Steering Committee as an 18-month pilot project. Permanent funding for the program was secured from the Committee after its members reviewed the CBHP evaluation report. The report was released in March 2009. Its purpose was to "demonstrate the effectiveness of the CBHP in providing an integrated, quality, multidisciplinary, patient-centred approach to breast cancer diagnosis and care within acceptable wait times". It focused on findings related to program activities, outputs and quality of care.

**Evaluation findings:**

- The participation of providers in the program (i.e. surgeons and family physicians) is continually increasing and they are satisfied with program processes and services.
- Staff provided efficient care to patients and acted on the recommendations for improvement that were made by patients and providers in the interim report.
- The majority of patients were satisfied with the timeliness of their care.
- The mean and median wait times from referral to CBHP to first surgery are longer than the established standard; however, patients with a positive breast biopsy have a shorter wait time from referral to surgery, compared to all patients.
- The mean and median wait times from surgery to initial treatment at a cancer centre have shown a slight increase.
- The program is aligned with the Vision 2012; the Future of Health Care in Alberta.
2. Comprehensive Breast Care Program

Interviewee and contact information: Dr. Kelly Dabbs, Medical Lead, Comprehensive Breast Care Program (cb.cp@albertahealthservices.ca)
Date of interview: December 16, 2014

Implementation level: Regional
Implementation site: Edmonton and Northern Alberta, Alberta, Canada
Implementation date: 2007
Targeted stage of cancer care continuum: Diagnosis
Targeted cancer diagnosis: Breast
Creation and development of materials: N/A
Delivery of initiative/program: Specialist providers (primarily nurse navigators)
Initiative/program users: Patients

Overview
The Comprehensive Breast Care program (CBCP) was first implemented in Edmonton in 2007 as part of a provincial initiative led by Alberta Health Services. The program quickly expanded from Edmonton to more northern areas of Alberta, and is now implemented on a regional scale. The CBCP uses a nurse-led model of care to target breast cancer patients who are at the diagnostic stage of care. The program focuses on accurate and timely diagnosis, coordination of diagnostic testing, as well as provision of patient education and support, prior to, and after, a patient’s appointment with a specialist.

Rationale
The primary motivator for the development of the CBCP was the issue of wait times. Approximately 50% of women were experiencing a delay in diagnosis because many family physicians were uncertain of where to refer patients that were suspected of having breast cancer. Additionally, numerous cases of breast cancers were assumed to be benign, increasing wait times even further. Further motivators included the need to provide cancer education and supports for patients prior to their diagnoses, and to overall improve access and consistency of breast cancer care across Alberta.

Dr. Tony Fields, Department of Oncology, University of Alberta, led the development of the CBCP. The goal of the program was to diagnose patients in a timely manner and to ensure they receive high quality care.

Description
The CBCP is available in Edmonton and Northern Alberta. Patients are referred to the program by their family physicians and all program services are provided to patients over the phone. Nurse navigators provide education and support, and coordinate patient care, while unit-clerks schedule patients’ various diagnostic appointments. Family physicians remain fully informed about their patients’ progress the entire time that they are in the program.

Mammography sites and radiology groups across the region partner with the program to provide testing. Radiologists perform biopsies and pathologists review results and provide diagnoses. A patient with a positive result is sent to a surgeon, and patients with discordant results are seen by a non-surgical breast expert. All breast care surgeons in Edmonton participate in the program. If surgery is recommended, the program requires that the patient’s surgery be scheduled within three
weeks of the first surgical consultation; if that is not possible, the patient is sent to another surgeon who can make that guarantee. If a patient’s pathology result is benign, the patient’s family physician receives a recommendation from the program physician via the nurse navigator on how to best follow-up with their patient’s care. A social worker is also available to provide various forms of support to patients, ranging from the arrangement of transportation and financial support, to the provision of psychosocial support and counseling. The nurse navigators stop interacting with patients once they go into the cancer clinic post-surgery, or back to the care of their family physicians when surgery is not required.

The CBCP is managed by Gail Ganton, Manager of Ambulatory Care Community Oncology, Alberta Health Services. A program committee meets quarterly to discuss quality assurance, to review wait times and to identify and solve any flaws in the system.

Evaluation
The project team completed a formal evaluation shortly after the program’s implementation. Both patients and family physicians were satisfied with the program. Additionally, cancer clinics reported that newly diagnosed patients arrive well informed, and that this improves the outcomes of their first clinic consultation. Finally, the implementation of the program has resulted in decreased wait times and a decreased number of unnecessary breast investigations. Post-evaluation, the program team continues to receive satisfaction letters from both patients and family physicians.

Barriers and Facilitators
There were several barriers that the project team had to address and overcome during implementation.

- Radiology teams across the province tended to work very independently of each other, and for the program to be successful, they would have to communicate and work together. Fortunately, they welcomed collaboration in order to meet the goal of the CBCP.

- Cancer specialists were reluctant to have benign patients in the program. As many cancers are initially misdiagnosed clinically as benign, benign cases are included in the program until a diagnosis is confirmed.

- There was an initial lack of understanding by both family physicians and cancer specialists in regards to their program roles and responsibilities, as many thought that the CBCP was a screening program or a cancer follow-up program.

- The main facilitators of implementation were clinical champions; the specialists who believed in the overall vision of the CBCP and encouraged others to not only support the program, but to become involved. Furthermore, having a multidisciplinary team allowed the program members to develop a stronger understanding of each other's disciplines and to therefore to collaborate more effectively.

Lessons Learned
There were two primary lessons learned. The first was that the provision of educational materials to family physicians and patients decreased the number of additional referrals for clearly benign conditions, such as breast pain. The second was that having nonsurgical physicians treat nonsurgical problems can decrease wait times as a result of reducing the backlog in the surgeons’ offices.

Additional Notes
Additional information about the program can be accessed online: http://www.albertahealthservices.ca/services.asp?pid=service&rid=1022658
3. Diagnostic Assessment Programs

Interviewees and contact information: Melissa Kaan, Group Manager of Diagnostic Assessment Programs, Cancer Care Ontario (Melissa.Kaan@cancercare.on.ca) and Dr. Claire Holloway, Provincial Clinical Lead of Diagnostic Assessment Programs, Cancer Care Ontario (Claire.Holloway@cancercare.on.ca)

Date of interview: February 11, 2015

Implementation level: Regional
Implementation site: Ontario, Canada
Implementation date: 2007
Targeted stage of cancer care continuum: Diagnosis
Targeted cancer diagnosis: Lung, colorectal and prostate
Creation and development of materials: Government organization (i.e. Cancer Care Ontario)
Delivery of initiative/program: Specialists and primary care providers (primarily specialists and nurse navigators)
Initiative/program users: Patients

Overview
Diagnostic Assessment Programs (DAPs) are implemented by Regional Cancer Programs (RCPs) across Ontario. Cancer Care Ontario’s provincial oversight of DAPs began in 2007 and currently, there is provincial oversight for lung, colorectal and prostate cancer DAPs. Some RCPs may call their programs DAPs, while others choose different titles. DAPs provide accurate and timely diagnosis in a patient-centred environment, and coordinate the patient journey from referral for suspicion of cancer to a definitive diagnosis or rule-out. Cancer Care Ontario provides approximately $2.7 million of funding annually for DAPs. The RCPs are responsible for daily operations of their DAPs.

Rationale and Development
In 2007, a signature event held by Cancer Quality Council of Ontario raised numerous challenges that existed in the diagnostic phase of the cancer journey. This prompted Cancer Care Ontario to oversee and to continue to develop initiatives designed to address these identified challenges, under these four objectives:

- To improve quality and accessibility of care for patients;
- To advance a patient-centred approach in diagnostic care;
- To drive integrated-care delivery among services and providers; and
- To maximize the value of care being delivered.

Description
DAPs are a new entity in the province of Ontario, developed to improve the experience of patients with suspected cancer as they go through the diagnostic process. DAPs are made up of multidisciplinary teams that manage and coordinate the entire process of a patient’s diagnostic care, and can facilitate access to cancer treatment services for patients with a cancer diagnosis. This improves access to care and reduces distress for the patient.

Patients are referred to the program by their family physicians. Once referred, they are connected to a patient navigator. Many of the patient navigators are registered nurses trained in cancer patient navigation. Navigators are responsible for facilitating evidence-based diagnostic testing, by offering navigation support to patients, and arranging centralized access to services and access to a
multidisciplinary health care team. This intervention most often occurs in a hospital setting; however, patient navigators are also available to provide support over the phone and by email. Appropriate medical specialists advise on a patient’s course of diagnostic care and recommend a course of treatment when a definitive diagnosis is made.

**Evaluation**

An evaluation of the DAPs has not been conducted.

Cancer Care Ontario does collect the following information, when and where it is available:

- Patient access
- Patient experience
- Utilization
- Uptake across the province
- Type of diagnosis

DAPs are regionally-based, therefore Cancer Care Ontario has limited access to information which could be used to evaluate the DAP initiative, as a whole. A large-scale evaluation is not possible until Cancer Care Ontario has improved access to information for patients being assessed for cancer outside of DAPs across the province.

**Barriers and Facilitators**

There have been several challenges to implementing DAPs across the province. DAPs are a new model of care, which has necessitated a change in practice for family physicians and specialists. Evidence of facilitated access and improved patient experience encouraged primary care buy-in, while evidence of improved clinic efficiency encouraged specialist buy-in. Family physicians’ lack of awareness of the programs was a challenge which had to be overcome early on. To address this problem, administrators engaged with regional primary care leads appointed by Cancer Care Ontario, to inform physicians about the existence of DAPs and to encourage them to refer their patients to the programs. Other barriers included developing the role of the patient navigator and ensuring that work was appropriately resourced. Funding provided by Cancer Care Ontario helped to facilitate the implementation of DAPs, as this created accountability to Cancer Care Ontario through funding deliverables.

**Lessons Learned**

The key lessons learned were that 1) it is important to identify key measures of success prior to program implementation, and 2) that an overall structured approach to implementing DAPs that allows flexibility for regional needs may improve both clinical engagement and patient outcomes.

**Future Directions**

Under the new mandate of the provincial DAP program, Cancer Care Ontario plans for provincial oversight to extend to all disease sites. However, mechanisms for this oversight have yet to be implemented. Cancer Care Ontario is also focused on improving the standardization of DAPs across the province by implementing standardized referral and transfer of care criteria for lung, colorectal and prostate DAPs, introducing a consistent measurement approach and by monitoring impact on wait times. The improved standardization will provide Cancer Care Ontario with an opportunity to assess the DAP initiative and more specifically, to evaluate its effect on patient care.
4. eReferral

Initiative/Program: eReferral
Interviewee: Allison Bichel, Executive Director, Alberta Health Services
Contact information: Ms. Bichel’s role within Alberta Health Services has changed since the time of her interview. Ms. Jodi Glassford (Jodi.Glassford@albertahealthservices.ca) now leads the eReferral project.
Date of interview: December 5, 2014

Implementation level: Provincial
Implementation site: Alberta, Canada
Implementation date: 2014
Targeted stage of cancer care continuum: Referral, specific to diagnosis and treatment
Targeted cancer diagnosis: Breast and lung
Creation and development of materials: N/A
Delivery of initiative/program: Government organization (i.e. Alberta Health Services)
Initiative/program users: Specialists and primary care providers

Overview
EReferral for breast and lung cancers, and hip and knee arthroplasty, launched across the province of Alberta in July 2014. The initiative is implemented on a provincial scale, across all six cancer centres and 12 hip and knee sites in Alberta. Through a collaboration between specialty and primary care, eReferral targets diagnosis and treatment of breast and lung cancer by preparing patients for efficient triaging and self-care, and by ensuring that patients receive accurate and timely diagnoses.

Rationale and Development
In 2008, Dr. Charles Butts (CancerControl Alberta) and his team redesigned referral practice to improve access and coordination for patients across all of the province’s cancer centres. These actions laid a foundation for the automation of the referral process for CancerControl Alberta. Soon after, Alberta Health Services’ Provincial Access Team, Cancer Control Operations and the Cancer Strategic Clinical Network came together to develop eReferral. In 2011, the eReferral platform was built into Alberta Netcare (i.e. Alberta’s electronic medical records (EMRs)). CancerControl Alberta was chosen to be the first implementer of eReferral because the organization had focused on standardizing referrals across all six cancer centres in the province and had participated in clinical engagement by articulating referral guidelines. Having also improved upon clinical content standards, knee and hip arthroplasty was chosen as a second implementation group.

In January of 2012, cancer and hip and knee primary and specialty care providers worked together to design the referral process for various referrals (e.g. surgery, home care, psychosocial, etc., from specialty to primary care and vice versa) and to identify the roles and responsibilities of the involved providers. The goal of redesigning the referral system was to ensure that patients receive safe, efficient and timely transitions, which are standardized and automated.

Description
EReferral is best described as an electronic communication system or a request for service system. It is provided at no additional cost within Alberta Netcare and can be easily accessed through the Alberta Netcare Portal or through an EMR Parameter Launch Browser. Health care providers are
authorized by the Alberta Netcare team; if providers have access to Netcare, they automatically have access to eReferral.

Family physicians and specialists provide the referrals, as well as treatments and interventions. Triage clerks, triage nurses and nurse navigators coordinate patient care and ensure that patients experience safe and timely transitions in care. The Health Services Catalogue allows providers to search for information by zone, specialty, location, provider, or reason for referral. For example, when clerks and nurses search a reason for referral for a patient, the system displays the providers that are available to accept the referral and their approximate wait times. This allows the patient to choose where he or she would like to be referred.

Alberta Netcare’s eReferral accepts electronic referrals for confirmed breast cancer, confirmed lung cancer, and hip and knee arthroplasty. EReferral leverages existing information from Alberta Netcare by auto-populating demographic information. Labs and diagnostic imaging can also be easily attached to the referral and the system set-up allows users to create, send and track referrals as a team. Referrals can be saved as drafts for further completion by others and care providers have the option of sending a request for advice or consult. The system also offers standardized referral requirements that are used to check the referral for completeness before it is sent. Once the referral is sent, it is tracked in real-time; specifically, the time a referral is sent, received, and triaged and the time an appointment is made are all recorded. Received referrals can be processed by all authorized team members. Overall, this initiative provides patients with timely and appropriate access to services through the development and use of an automated, standardized and transparent referral system.

Evaluation
Evaluative data are currently being collected and analyzed. Measured outcomes include access, safety, acceptability, efficiency and effectiveness. The process evaluation is expected to be complete by the end of March 2015, and the outcome evaluation is expected to be complete by September 2015. Currently, there are over 500 referrals in the system and the following trends have been recorded since implementation in July 2014:

- Referrers tend to re-use the system
- More diverse referrers are using the system
- There has been an increase in number of referrals

Barriers and Facilitators
The main barriers to implementation were related to funding and budget, and program awareness within Alberta Health Services. Facilitators that contributed to the successful implementation of eReferral were high need for automated referrals, robust clinical design, high family physician and specialist engagement, and a strong project team.

Lessons Learned
The eReferral implementation team learned several lessons throughout the implementation process. Funding and program stability are often uncertain and unpredictable. Furthermore, the availability of a greater number of referral services is required on eReferral, in order to drive benefit in primary care. There is also a need for more research and development, as well as a need to strengthen clinical governance (i.e. to be stronger in working across silos, and to have a more rigorous process for adjudicating clinical content). Lastly, developers of similar programs must be aware of the technical complexity of an electronic referral system and the coinciding challenges.
**Future Directions**

In the future, integration across different web-based platforms will be necessary. This will prevent any duplication of work flow that results from the use of multiple EMRs across Alberta. The next stage of implementation will involve addressing other stages of the breast and lung (and most likely colorectal) cancer care pathways. The ultimate future goal for eReferral is to automate referrals for all tumour groups.

Note: This profile was not verified by the interviewee prior to Casebook publication.
5. **LEAN on cME**

**Interviewee and contact information:** Barbara Wasilewski, Executive Director, Manitoba Health (Barbara.Wasilewski@gov.mb.ca)

**Date of interview:** February 19, 2015

**Implementation level:** Provincial

**Implementation site:** Manitoba, Canada

**Implementation date:** 2012

**Targeted stage of cancer care continuum:** Education for primary care providers, regarding cancer diagnosis

**Targeted cancer diagnosis:** Not specific

**Creation and development of materials:** Primarily government organizations (Cancer Care Manitoba, Manitoba Health, Regional Health Authorities), health care providers (Diagnostic Services of Manitoba and Primary Care) and patients

**Delivery of initiative/program:** Primarily government organizations (Cancer Care Manitoba, Manitoba Health, Regional Health Authorities), health care providers (Diagnostic Services of Manitoba and Primary Care) and patients

**Initiative/program users:** Primary care providers (i.e. family physicians and their staff)

**Overview**

The In Sixty Initiative (also known as the Cancer Patient Journey Initiative) was launched by Manitoba’s provincial government in 2011 and has a mandate to reduce the time from the emergence of the clinical suspicion of cancer to the start of treatment to within sixty days. The initiative’s Primary Care Working Group (PCWG) was established soon after in 2012. Members of the working group represent Cancer Care Manitoba, Manitoba Health, Regional Health Authorities, Diagnostic Services of Manitoba, and Primary Care. Patient representatives also serve as working group members.

In Sixty’s PCWG has three goals:

- To develop and maintain diagnostic algorithms/pathways for common malignancies
- To improve communication between primary care clinicians, specialists and patients
- To help primary care providers get referrals “Out the Door in 24” (i.e. sending referrals of cancer suspicion within 24 hours)

This profile focuses on the first and third goals that are listed above.

**Rationale and Development**

Cancer Care Manitoba hired a LEAN Champion to conduct a pilot study to observe practices in regards to cancer suspicion at four primary care clinics. Study findings suggested that improving the referral process would result in more efficient and timely diagnostic testing for patients. This pilot study initiated the PCWG’s work to ensure that anyone with a high suspicion of cancer is referred for specialist consultation and/or diagnostic testing within 24 hours.

**Description**

The PCWG of the In Sixty Initiative assists primary care clinicians and their staff in streamlining work flow and getting crucial referrals “Out the Door in 24” through a program called LEAN on cME.
As part of the program, In Sixty’s Rapid Improvement Leads guide participating clinics (i.e. family physicians and their staff) through an internal audit of their clinic work flows, helping them to identify and correct work routines that are impeding on referral times. In addition, participants can attend LEAN on CME events, which combine the aforementioned review of work flows with case-based interactive modules (i.e. Early Cancer Diagnosis modules) that were developed by the PCWG. The Early Cancer Diagnosis modules aim to assist primary care providers in applying diagnostic pathways or algorithms for common malignancies in the clinical setting.

No additional costs or resources are needed for the PCWG, as it functions within existing In Sixty resources.

Evaluation
The PCWG is currently in the process of developing an evaluation framework for its programs.

Barriers and Facilitators
The main barriers to the implementation of LEAN on CME were the lack of awareness of the program and the assumption that all primary care providers want to receive information in the same manner. The primary facilitator was having the resource of a LEAN Champion to conduct the initial pilot study and subsequently help guide the development of the LEAN on CME program. Furthermore, having family physicians participate as members of the project team improved the program’s credibility.

Lessons Learned
To meet their goals, the PCWG initially planned to develop a communication plan for primary care providers; however, they quickly realized that shifting from the development of a communication plan to commencing a “change management” approach focused on provider engagement would be much more effective in supporting the PCWG’s goals.

Future Directions
The PCWG is currently distributing a self-assessment kit for family physicians that are unable to attend training sessions or workshops. The kit will guide them in collecting information about referrals and wait times, and in tracking improvements. The PCWG is also establishing the implications of using physicians’ electronic medical records to track referral patterns and patient wait times, which would allow them to receive immediate feedback on their referral process.

Additional Notes
LEAN on CME is a reference to the combination of a Kaizen (an event that employs so-called “lean” methodology to improve systems) with Continuing Medical Education (CME).
6. **Ontario Breast Screening Program**

**Interviewees and contact information:** Meaghan Cunningham, Senior Policy Lead, Cancer Care Ontario (Meaghan.Cunningham@cancercare.on.ca) and Jessica Moffatt, Senior Policy Lead, Cancer Care Ontario (Jessica.Moffatt@cancercare.on.ca)

**Date:** February 10, 2015

**Implementation level:** Provincial
**Implementation site:** Ontario, Canada
**Implementation date:** 1990
**Targeted stage of cancer care continuum:** Screening and diagnosis
**Targeted cancer diagnosis:** Breast
**Creation and development of materials:** Not applicable

**Delivery of initiative/program:** Specialists (primarily patient navigators, medical radiation technologists and radiologists)

**Initiative/program users:** Patients

**Overview**
The Ontario Breast Screening Program (OBSP) was first implemented provincially in 1990. The program provides screening and accurate and timely diagnoses, offers support for transitioning from screening to diagnosis, and coordinates care post-screening. The OBSP is funded by the Ministry of Health and Long Term Care.

**Rationale and Development**
In 1989, the Ontario Cancer Treatment and Research Foundation, the antecedent organization to Cancer Care Ontario, developed a proposal for a province-wide breast screening program. The proposal cited seven international research studies, reporting that early detection of breast cancer, through screening, could prevent almost half of all breast cancer related deaths over the age of 50. The OBSP’s goals at the time were to reduce breast cancer mortality and morbidity, have a stronger role for individual women, emphasize community-based care, and create an overall provincial health strategy for breast cancer screening. The current objective of the program is to provide high quality breast cancer screening services for women at average risk for cancer, aged 50-74 years, and women at a high risk for breast cancer, aged 30-69.

**Description**
The OBSP is supported by a large team at Cancer Care Ontario. At the executive level, leadership is provided by the Vice President of Prevention and Cancer Control. Centrally, the program is led by the Radiologist in Chief, who heads the strategic clinic aspects of the program, and the Provincial Scientific Lead, who heads the research/evidence and evaluative components of the program.

At the site level, the program takes place in hospitals, independent health facilities and two mobile coaches, which promote screening in remote sites. The program empowers patients to take control of their care through the receipt of their screening results and reminders to return. Medical Radiation Technologists (MRTs), radiologists and patient navigators, along with administrative staff, ensure that women receive all of the services and benefits associated with the program. The radiologists and MRTs are responsible for the screening and diagnostic services. Patient navigators (some of which are registered nurses) contribute by helping individuals navigate through the diagnostic phase. Some patient navigators are specifically responsible for aiding the high-risk population, as referrals and screening services for this group are more complex. Various aspects of the program extend out from the screening and assessment sites; for example, program
correspondence is sent to women at their homes and results are shared with women and their family physicians. Therefore, the services offered by the OBSP reduce the workload for family physicians while ensuring that they are kept informed about the progress of their patients. Family physicians still play a crucial role in the OBSP by encouraging their patients to receive screening and by providing education and follow-up care to their patients, post-screening.

**Evaluation**

The OBSP undergoes extensive quality assurance, on an ongoing basis and formal evaluation occurs at various levels and at various frequencies. The OBSP adapted the Canadian Partnership Against Cancer's quality determinants framework. The evaluation framework groups indicators into the following domains: coverage; follow-up; quality of screening; detection; and disease extent at diagnosis. The OBSP outcome indicators were compared with Canadian indicator targets in the most recent OBSP report, published in 2013. The majority of the targets are either being met or exceeded.

The most recent program evaluation report is available online: https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=288834
7. Nova Scotia Breast Screening Program

**Interviewee information**: Ryan Duggan, Former Program Manager, Nova Scotia Breast Screening Program

**Contact information**: Theresa Foley, Acting Program Manager, Nova Scotia Breast Screening Program (Theresa.Foley@nshealth.ca)

**Interview form completed**: Mid-2014

**Implementation level**: Provincial

**Implementation site**: Nova Scotia, Canada

**Implementation date**: 1991

**Targeted stage of cancer care continuum**: Screening and Diagnosis

**Targeted cancer diagnosis**: Breast

**Creation and development of materials**: N/A

**Delivery of initiative/program**: Specialists

**Initiative/program users**: Patients

**Overview**

The Nova Scotia Breast Screening Program (NSBSP) was implemented provincially in 1991. The program is specialist-led with primary care support and targets breast cancer diagnosis.

**Rationale and Development**

The NSBSP was modeled after the first organized breast cancer screening program in Canada, established in British Columbia in 1988.

The NSBSP evolved by identifying the population of asymptomatic women over the age of 40 who were coming to hospital-run diagnostic centres for apparent screening. When a hospital diagnostic centre agreed to join the organized program, a management protocol was put in place to identify women who had been referred to the centre, but would meet the criteria for screening. These women would then be redirected into a screening pathway at the same centre (i.e., bilateral mammogram reviewed by radiologist at a later date). The team chose to start with the diagnostic sector, rather than launching screening with invitations to the general population, to ensure that women were being evaluated appropriately, while also reducing the benign surgery rate.

The introduction of screening also had significant implications for allocation of diagnostic breast imaging resources, as these resources can be used for both screening and diagnosis. A clinical pathway was therefore developed, so that once screening was launched, the established clinical pathway and associated resource utilization could be monitored. The objective of the program is to ensure high quality and equitable access to breast imaging care in Nova Scotia.

**Description**

The program is managed by a Program Manager, who is accountable to the Izaak Walton Killam Women’s Health Centre and the Nova Scotia Department of Health and Wellness. The NSBSP centrally books and navigates Nova Scotia residents across all breast imaging procedures in the province. This includes screening mammography for self-referred women over 40 (the majority of which report that they are encouraged to get screened by a family physician) and diagnostic mammography, ultrasound and Magnetic Resonance Imaging for men and women of all ages who have been referred to the program by their family physician. Accredited radiologists and
radiological technologists are involved in both screening and diagnostic breast imaging. All test results and follow-up information are shared with patients’ family physicians.

An information system (i.e. an electronic communication/information system) that supports client management, clinical reporting and patient navigation is used for real-time monitoring of individual patients throughout the clinical trajectory, as well as for monitoring wait times and managing breast imaging services. Booking clerks use standard triage protocols to ensure that clients receive appropriate breast imaging procedures. For patients that require follow-up exams, booking clerks forward the exam appointment information to the family physician, who then shares that information with his/her patient.

The program coordinates resource allocation across 11 fixed centres and one mobile unit. The core budget of the program is small and is primarily allocated to booking clerk compensation. The breast imaging care delivery is financially managed through the hospital centres (i.e. health authority).

**Evaluation**

Annual evaluation reports are published online. The reports provide an overview of the program’s initiatives and performance, in comparison to national performance indicators.

NSBSP annual reports can be accessed online: [https://breastscreening.nshealth.ca/annual-reports](https://breastscreening.nshealth.ca/annual-reports)

Additionally, there is regular reporting to District Health Authorities and clinical stakeholder communities on screening performance. Feedback is also provided to individual radiologists on their performance.

**Barriers and Facilitators**

There was some initial resistance to the program given that clinician’s performance would be measured; however, many clinicians did welcome feedback and viewed it as an opportunity to improve. Furthermore, the established information system was critical in supporting the implementation of the program. Lastly, the program benefitted from growing incrementally and being driven by opportunity; an initially large implementation would have been much more challenging.

**Lessons Learned**

The key lesson learned was that the establishment of an information system was critical as a foundation for both the clinical and business processes. A second lesson learned was that grassroots initiatives can be successful; however, implementers of these initiatives face a unique set of challenges.

**Future Directions**

The program is working to extend the formal navigation and pro-active booking approaches developed for the average risk screening population to other populations (e.g., high risk screening, breast cancer survivors).
8. **Survivorship Nurse Practitioner Program**

**Interviewees and contact information:** Karen Blain, Provincial Director, Provincial Survivorship and Primary Care Program, BC Cancer Agency ([Karen.blain@bccancer.bc.ca](mailto:Karen.blain@bccancer.bc.ca)) and Kristina Morrison, Survivorship Nurse Practitioner, Provincial Survivorship and Primary Care Program, BC Cancer Agency ([Kristina.morrison@bccancer.bc.ca](mailto:Kristina.morrison@bccancer.bc.ca))

**Date of interview:** February 27, 2015

**Implementation level:** Regional

**Implementation site:** Vancouver area and Fraser Valley, British Columbia, Canada

**Implementation date:** 2013

**Targeted stage of cancer care continuum:** Survivorship

**Targeted cancer diagnosis:** Not specific

**Creation and development of materials:** N/A

**Delivery of initiative/program:** Specialists (i.e. nurse practitioners)

**Initiative/program users:** Patients

**Overview**

The Survivorship Nurse Practitioner (NP) Program is one component of the British Columbia (BC) Cancer Agency’s Provincial Survivorship and Primary Care Program and is implemented on a regional level. Anyone that has received a cancer diagnosis, and does not have a family physician, is eligible for referral. The program’s key focus is to provide primary care, in its entirety, to unattached patients (i.e. patients who do not have a family physician). Another area of focus is the provision of survivorship/follow-up cancer care.

**Rationale and Development**

In 2012, the Provincial Survivorship Program at the BC Cancer Agency recognized a need to provide primary care to cancer patients/survivors who do not have family physicians. There were approximately 700 cancer survivors in the Vancouver area, and over 3000 cancer survivors in the Fraser Valley, who did not have a family physician. These individuals were not receiving primary care and support to ensure that their health needs (both cancer related and non-cancer related) were being met.

The development of the Survivorship NP position was led by Kristina Morrison, the first Survivorship NP. She was supported by the Provincial Survivorship and Primary Care Program, as well as The Nurse Practitioners for British Columbia (NP4BC) initiative.

The Survivorship NP Program has three goals:

- To ensure that survivors are attached in primary care and that their primary care needs are being met
- To address survivorship issues (e.g. long-term side effects, mental health, financial concerns)
- To build capacity across the continuum to support all cancer patients (i.e. to support the release of oncologists’ time, allowing for reduced wait times and increased capacity to care for complex patients undergoing active treatment)

**Description**

The Survivorship NP Program was implemented to directly provide primary care services to cancer patients and survivors who do not have a family physician. There are two, soon to be three,
Survivorship NPs in the program. The first Survivorship NP was implemented in Vancouver in February of 2013, the second in Fraser Valley in October of 2013, and the third is to be implemented by September 2015. Prior to assuming their roles, the Survivorship NPs participate in the General Practitioner in Oncology training program. Survivorship NPs are located in primary care settings and provide primary care and survivorship care to patients. In some cases, the NPs also provide care to their patients’ family members if they too do not have family physicians.

Karen Blain, the Provincial Director of the Provincial Survivorship and Primary Care Program, shares responsibility for the daily operations of the program with the Survivorship NPs, the Regional Health Authorities (RHAs) and the clinic administrators. Survivorship NPs are employed by, and accountable to, the BC Cancer Agency’s Provincial Survivorship and Primary Care Program, which partners with the NP4BC initiative, the RHAs and the primary care clinics where the NPs are located. The overhead required for the program, in terms of administrative support, supplies, and space, is facilitated through these partnerships. Furthermore, the BC Cancer Agency provides salaries for the NPs and funds their professional development.

Evaluation
An initial evaluation took place one year after implementation. Patient satisfaction with the Survivorship NP was measured. Respondents were asked about awareness, understanding of scope, benefits, opportunities for improvement and other comments; 61/97 of the patients who were surveyed responded.

The following is a list of measured outcomes, with the percentage of patients that identified as being satisfied with each:

- Accessibility: 97%
- Affective support: 97%
- Health information: 92%
- Decisional control: 89%
- Technical competency: 95%
- Overall satisfaction: 97%

The program team is currently developing an evaluation framework that will comprehensively study patient (health) and system outcomes, resulting from the implementation of the Survivorship NP role. Survivorship NPs are also required to report on a number of indicators to the Ministry of Health.

Barriers and Facilitators
There were several barriers to implementation of the Survivorship NP role. Both BC Cancer Agency staff and primary care staff were not aware that a Survivorship NP was being introduced into the primary care setting. Kristina Morrison was required to educate the public, and both primary and specialty care providers, about the Survivorship NP role; however, more communication should have been established prior to implementation. This would have prevented uncertainty and confusion surrounding the new position. Another barrier to implementation was deciding how the Survivorship NP would communicate with oncology staff. To address this, a standardized communication tool was created and implemented, and has been working well thus far. When implementation first started, primary and specialty care providers had low confidence in the ability of Survivorship NPs to provide primary care and support to cancer patients and survivors. The two current Survivorship NPs built and developed strong working relationships with these care providers, who now have an increased confidence in NPs’ abilities to provide high quality care.
An additional barrier was the lack of involvement from the RHA in the implementation of the second Survivorship NP. This resulted in significant pushback and barriers from RHA staff and physicians. As a result, the RHA has taken a leadership role in the implementation of the third Survivorship NP and will act as the operational leader, instead of the BC Cancer Agency.

It was difficult for the Survivorship NPs to be recognized as being the Most Responsible Provider for their patients in the primary care setting, in many of the electronic medical record systems utilized throughout British Columbia. NPs also initially experienced difficulty with attaining authority to access various services to be able to view patient diagnostic investigations, consult notes, medication lists, etc. These barriers were overcome over time as it became clear that Survivorship NPs can, and do, provide effective comprehensive care to complex patients because of their specialized knowledge in oncology and their ability to effectively assess patients in a systematic way.

**Lessons Learned**

Each Survivorship NP works in a different primary care setting; therefore, the set of barriers she/he encounters is unique. The work setting impacts job satisfaction and success of the role. An ideal practice setting is one where a NP has physician support and has other NPs to partner with as well. An environment such as this allows for collaboration, mentoring and consultation between physicians and Survivorship NPs.

**Future Directions**

Future directions for the Survivorship NP Program are to produce ongoing strategies to promote and raise awareness of the role of the Survivorship NP, to expand the network of Survivorship NPs across BC, and to continue to evaluate the program for continuous improvement for both patients and providers.
9. Juravinski Cancer Centre Well Follow-Up Clinics

Interviewee and contact information: Dr. Jonathan Sussman, Director of the Program in Transitions in Care within the Applied Health Research Network of the Ontario Ministry of Health and Long-Term Care (Jonathan.Sussman@jcc.hhsc.ca); additional comments from Margaret Forbes, Advanced Practice Nurse, Well Follow-up Clinics

Date of interview: January 19, 2015

Implementation level: Local
Implementation site: Hamilton area, Ontario, Canada
Implementation date: 2012
Targeted stage of cancer care continuum: Survivorship
Targeted cancer diagnosis: Breast and colorectal
Creation and development of materials: Specialists (Nurse Practitioner)
Delivery of initiative/program: Specialists (Nurse Practitioner)
Initiative/program users: Patients

Overview
The Juravinski Cancer Centre Well Follow-Up Clinics were implemented locally in 2012. The purpose of the clinics is to facilitate the transition of appropriate breast and colorectal cancer survivors from specialty care to primary care. This transition is established through the encouragement of patient self-care/self-management and through the provision of post-treatment surveillance.

Rationale and Development
The implementation of the Well Follow-Up Clinics at the Juravinski Cancer Centre was initiated through Cancer Care Ontario’s Models of Care for Cancer Survivorship Initiative. Cancer Care Ontario had identified significant variations in care practices and recognized that standardization was required. It was also recognized that oncology resources for follow-up care were limited. Cancer Care Ontario practice guidelines report that for breast cancer, and most likely colorectal and prostate cancers, a primary-care led survivorship care model produces as good, or better outcomes, than one led by oncology care. Therefore, Cancer Care Ontario supported shifting the responsibility of survivorship care from specialists to family physicians and provided the 14 regional cancer centres across Ontario with one-time catalyst funding of $100 000 to implement new models of well follow-up care for breast cancer patients in March of 2012. The same was done for colorectal cancer in April of 2013; however, the provided funding was $75 000.

By supporting the Juravinski Cancer Centre Well Follow-Up Clinics, as well as other similar initiatives across the province, Cancer Care Ontario was hoping to stimulate a sustainable evidence-based model, through which appropriate low-risk patients (i.e. patients who do not have any significant ongoing issues with their cancer or its treatment) could be transitioned back to primary care.

The development of the Well Follow-Up Clinics at the Juravinski Cancer Centre was led by: Dr. Jonathan Sussman; Margaret Forbes, Nurse Practitioner; Anne Snider, Director, Department of Oncology, McMaster University; Cathy Bennett, Manager, Oncology Patient Education; and a team of nurses.
Description
The Well Follow-Up Clinics are located at the Juravinski Cancer Centre in Hamilton, Ontario. Oncologists are responsible for identifying and referring patients, who are eligible to transition, to the Well Follow-Up Clinics. The clinics are managed by Ms. Forbes. A primary nurse works alongside Ms. Forbes to safely transition patients who have completed their active cancer treatment and have no ongoing cancer-related issues. Educational materials are provided to the transitioning patients. Patients visit a transition clinic one to three times and meet with a nurse practitioner to complete a survivorship care plan and to identify any ongoing needs. Patient needs are either addressed immediately or are documented so that they can be connected to community services. Patients receive a transition letter and their survivorship care plan before transitioning to primary care. Family physicians receive copies of their patients’ survivorship care plans and transition letters, via fax.

The clinics function within existing resources and the primary costs required for the clinics are nursing-related.

Evaluation
At the Juravinski Cancer Centre Well Follow-Up Clinics, various types of data were collected. The number of patients being transitioned through the clinic was tracked. Satisfaction questionnaires were completed by oncologists and interviews were conducted with patients and family physicians to learn about their level of satisfaction with the clinics. The aforementioned data was submitted to Cancer Care Ontario, who conducted an evaluation of all of the 14 regional cancer centres’ survivorship programs for breast and colorectal patients/survivors.

The report which summarizes the combined results is available online: https://cancercare.on.ca/common/pages/UserFile.aspx?fileId=258056

Barriers and Facilitators
The program team encountered initial barriers to implementation. One of the challenges was the reallocation of nursing resources. Another barrier was the reluctance of oncologists to transfer their follow-up patients to primary care. Clinic staff was required to give lectures about the Well Follow-Up Clinics to raise awareness and increase understanding of the program. The lectures also provided program staff with a venue to address any public concerns. A major facilitator to the implementation of the clinics was Cancer Care Ontario’s grants of $100,000 for the implementation of the Breast Cancer Well Follow-Up Clinic and of $75,000 for the implementation of the Colorectal Cancer Well Follow-Up Clinic.

Lessons Learned
The implementation team learned that the Well Follow-Up Clinics require strong collaboration with family physicians to ensure success.

Future Directions
The team hopes to develop better knowledge translation strategies to facilitate communication between family physicians and oncologists. They also plan to train oncologists and nurses to transition patients in the primary care setting, as opposed to only in the transition clinic setting.

Additional Notes
Additional information about the program can be accessed online: http://www.cancerview.ca/idc/groups/public/documents/webcontent/hhr_repo_well_followup.pdf
10. **Optimizing a Cancer Survivorship Model for Northeast Ontario**

**Interviewees and contact information:** Mark Hartman, Regional Vice President, North East Regional Cancer Program (mhartman@hsnsudbury.ca); Dr. Amanda Hey, Regional Clinical Lead, North East Regional Cancer Program (ahey@hsnsudbury.ca); and Dr. Carole Mayer, Director of Research and Regional Psychosocial Clinical Lead for the Supportive Care Oncology Program, Northeast Cancer Centre (cmayer@hsnsudbury.ca)

**Date of interview:** December 9, 2014

**Implementation level:** Regional
**Implementation site:** North East Ontario, Ontario, Canada
**Implementation date:** 2012
**Targeted stage of cancer care continuum:** Survivorship
**Targeted cancer diagnosis:** Breast and colorectal
**Creation and development of materials:** Government organization (i.e. Cancer Care Ontario), Health Science North’s Northeast Cancer Centre (NECC) staff, North East Ontario specialists and primary care providers, patients

**Delivery of initiative/program:** NECC Specialists and inter-professional team

**Initiative/program users:** Patients and community-based family physicians

**Overview**

Optimizing a Cancer Survivorship Care Model for Northeast Ontario was first implemented as a 14-month Canadian Foundation for Healthcare Improvement EXTRA project, which lasted from May 2012 to August 2013. The project is implemented on a regional level and takes place in both cancer centres and family physicians’ offices across Northeastern Ontario. The program targets breast cancer patients, with ongoing work that includes colorectal cancer patients. The focus of the project is to transition cancer survivors from specialist to primary-led care, and provide both cancer survivors and community-based family physicians with ongoing survivorship support.

**Rationale and Development**

The issue that prompted the initiative was the local, regional and provincial shortage of medical oncologists, coupled with the expectation of an increase in cancer prevalence within the population. Furthermore, there was a need to provide high-quality transitions in care for cancer patients and survivors. While working on this EXTRA project, the project team was also working with Cancer Care Ontario, who was requesting that all regional cancer centres develop and test models of follow-up care for transitioning breast (and later colorectal) cancer patients, from specialty to primary care.

The initiative had two goals. The first was to study if clinicians are accepting of and adapting Cancer Care Ontario’s practice guidelines regarding patient transitions in care. The second was to create a high-quality breast cancer pathway for transitioning patients.

Mark Hartman, Dr. Carole Mayer and Dr. Amanda Hey led the development of the initiative and worked alongside a steering committee and two working committees. The steering committee consisted of various stakeholders, administrators, oncologists and family physicians. The steering committee had two working committees. One working committee was responsible for developing clinical pathways, as well as educational materials for patients. The other was responsible for the optimization of electronic transfer of patient medical records and well follow-up recommendations to community-based family physicians. A third group of clinicians (i.e. specialists, primary care and
allied health care providers) contributed to the development of continuing professional development materials, more specifically, a clinical guide for breast cancer well follow-up care that was intended for use by community-based family physicians in North East Ontario. The guide was distributed in hard copy and electronic format, via the cancer centre’s website. The resources that were developed by the working committees were presented to the steering committee for review and approval. Patient representatives were a part of all three committees.

To ensure a high-quality transitional process, transitions in care pathways (i.e. algorithms for transitioning patients from specialty to primary care) were designed by the project team. The design of these pathways was based on findings relating to patient barriers, which came from in-person consultations with patients across Northeastern Ontario, patient survey results and a review of the literature. Results from focus groups, individual interviews and surveys with oncologists, nurses, radiation therapists, allied health care professionals and community-based family physicians were considered in the design process as well.

**Description**
In order to address the shortage of oncologists in the region, the initiative shifted care from oncologists to family physicians and a project framework was built to ensure that appropriate transitions to and from the cancer centre would occur in a safe and timely fashion.

The project is housed at Health Sciences North, an academic health science centre in Sudbury, Ontario. Managers and frontline providers, including physicians, specialists, social workers and nurses, are responsible for the daily operations within the cancer centre, and for ensuring that appropriate transitions are initiated. After patients complete active treatment, they receive a follow-up care package and are asked to attend a transition class, led by a nurse and a social worker. After the class is complete, the participants are sent a needs assessment, which allows them to identify any unresolved needs or concerns. Needs assessments are sent back to the social worker and supportive care team, who then intervene for psychosocial and other non-medical issues, and triage based on patient needs. Eventually, the patients go to transition care clinics, where they interact with family physicians who have an interest in working with breast cancer patients. These physicians help to transition the patients to family physicians in their community. As the patients are transitioned, individualized discharge notes and appended standardized well follow-up surveillance guidelines are sent to their family physicians. Patients’ medical records are also shared with the family physicians.

The project also delivers education to family physicians through the production of cancer well follow-up care clinical guides. Furthermore, workshops for health care providers will be held at the November 2015 Regional Conference. Additional workshops are being planned for specific communities in the region in 2015 and 2016.

Various resources, including human resources, financial resources, and time, are required to support the initiative. Ongoing implementation costs include both material and human resources for producing and reviewing survivorship care plans at visits, arranging and holding transition classes, ongoing costs of technical upgrades for electronic solutions, and production and maintenance of clinical guides for community-based family physicians.

**Evaluation**
A formal evaluation of the initiative has not been completed. Currently, transition class content is being evaluated. In addition, registration, attendance, percentage of needs assessments returned by discharged patients, and the number of referrals made is being recorded.
**Barriers and Facilitators**
There were no identified barriers to implementation. Meanwhile, the collaboration of the steering committee and the working committees was a positive way of managing the project and facilitating its implementation.

**Lessons Learned**
There were three key lessons learned during the implementation of the project. Having a centralized advisory committee in place at Cancer Care Ontario would have been helpful to the implementation of the initiative. For example, an advisory committee could have overseen the development of Cancer Care Ontario-endorsed continuing professional development content on cancer well follow-up care for family physicians, or could have developed centralized call-back systems for various surveillance tests. More specifically to patient care, the team learned that non-medical aspects of follow-up (e.g. psychosocial factors) contribute to health and well-being and should be addressed in practice guidelines and in follow-up models of care. Lastly, also in relation to patient care, the team observed that patients of the same disease type are not homogeneous; therefore survivorship management should always be considerate of risk and need stratification.

**Future Directions**
Since the initiation of the project, further cancer system developments have led to a modification of the NECC transition pathway algorithm for breast and colorectal cancer patients in well follow-up, which are expected to lead to earlier transition to the community-based family physician. To this end, revision of the clinical pathway, relevant process supports and educational materials for patients and providers is underway. These revisions to process and educational content are available upon request.

**Additional Notes**
The project team has also been working on a Cancer Care Ontario funded project involving both North East and North West Ontario cancer centres, which focuses on using electronic medical records to transfer discharge notes and surveillance guidelines to family physicians. For this project, the following measures will be evaluated: effectiveness of content; acceptability of format; and impact on improving readiness of family physicians to care for follow-up patients. To support this electronic medical record project and to evaluate the transition process as a whole, internal Information Technology/Information Management work is being done to create tracking mechanisms of transition and discharge visits. Family physicians, representing use of the common electronic medical records, have provided feedback on electronically transmitted documents.
11. **Wellness Beyond Cancer Program**

**Interviewee and contact information:** Robin Morash, Advanced Practice Nurse, The Ottawa Hospital ([rmorash@toh.on.ca](mailto:rmorash@toh.on.ca))  
**Date of interview:** December 23, 2014

**Implementation level:** Regional  
**Implementation site:** Champlain Local Health Integrated Network, Ontario, Canada  
**Implementation date:** 2012  
**Targeted stage of cancer care continuum:** Survivorship  
**Targeted cancer diagnosis:** Breast and colorectal  
**Creation and development of materials:** Specialists (with patient input)  
**Delivery of initiative/program:** Specialists (primarily registered nurses)  
**Initiative/program users:** Patients

**Overview**

The Wellness Beyond Cancer Program (WBCP) is a regional program of the Champlain Local Health Integrated Network (LHIN) implemented in March of 2012 for colorectal cancer patients, and in February of 2013 for breast cancer patients. The program focuses on transitions in care and survivorship by providing two possible discharge streams of follow-up care for patients who have completed their active cancer treatment.

**Rationale and Development**

The model of transitioning patients from active treatment to survivorship care in place prior to the WBCP was considered to be unsustainable. The program team saw the development of the WBCP as an opportunity to ensure that: patients were discharged from their oncologists’ care in a coordinated, safe and timely manner; had access to comprehensive care through a shared care approach; were involved in ongoing cancer surveillance; and received screening for other malignancies as per recommended guidelines.

Development of the program first started in 2010 following a cancer survivorship retreat, held concurrently with a call for proposals from Cancer Care Ontario. Stakeholders identified key priorities in cancer survivorship. A steering committee and working groups assembled to work on planning, developing and implementing the priorities. The goal of the program became to ensure that all people, at the end of cancer treatment, have access to appropriate follow-up care and the resources required to best meet individual needs.

The program has four key objectives:

- To improve the cancer system efficiently and to enhance transition and coordination of care
- To empower patients to participate in the management of their care and well-being
- To provide survivors and family physicians with a care summary and follow-up plan
- To improve knowledge of family physicians, regarding survivorship needs, assessment and management

**Description**

The WBCP is available within the Champlain LHIN in Ontario, Canada and all program services are offered within the cancer centre. Breast and colorectal cancer patients are referred to one of two discharge streams during a discharge appointment with their oncologist. Once referred, they
receive an information package and complete a needs assessment. A registered nurse uses the needs assessment to create personalized patient care plans.

In the first stream, the patient is discharged back to their family physician. This stream is chosen if the patient has minimal outstanding treatment side effects, issues or concerns. The patient has a WBCP discharge appointment with the program’s registered nurse during which the patient’s personalized care plan is reviewed and any identified unmet needs are addressed. A copy of the care plan, and discharge letter, is sent to the patient’s family physician.

The second discharge stream is ongoing shared care between the WBCP’s nurse practitioner, every 4-6 months, and the patient’s family physician. This stream is selected for patients who have a high risk of recurrence, have unresolved acute effects of treatment, and/or do not have a family physician. Additionally, all patients are invited to attend a disease-specific survivorship class, co-taught by the program’s nurse practitioner and registered nurse. The purpose of the class is to empower patients towards self-care and management of late and long-term side effects. Within both streams of care, a reassessment appointment is coordinated in the future for any breast cancer patients who require a hormone review. A rapid reentry process through the WBCP is in place to address any cancer recurrences and new cancer diagnoses.

The introduction of the program required a new process management tool to be implemented. The tool allows for tracking of patients from referral, needs assessment completion, care plan completion, care plan approval and final appointment to transfer patients to primary care. The implementation of this tool was required to manage the volume of referrals safely.

Program members provide education and support to both patients and family physicians, as needed. Family physicians are provided with a telephone number to call if they have questions or need advice regarding patient care. When the WBCP was first implemented, educational sessions were provided to family physicians throughout the region (both one-on-one sessions and educational events). The program team is planning to provide educational updates through the same methodology, and to create and distribute regional primary care newsletters. Finally, the WBCP also provides a venue for research, in conjunction with colleagues in psychosocial oncology.

The greatest cost implication for the program is staff. The following staff is currently a part of the WBCP:

- 1 full-time and 1 part-time Nurse Practitioner
- 1 full-time and 1 part-time Registered Nurse
- 1 full-time and 1 part-time Clerk

Physical requirements for the program include clinic space, and meeting space for the survivorship classes.

**Evaluation**

Program evaluations have been completed with disease site cohorts. Satisfaction surveys were distributed to both patients and family physicians, one year post-discharge from the program. Patients were asked to evaluate the overall support/care received, the quality of information provided, and their ability to recognize and report symptoms. Physicians were asked to evaluate if they knew who to contact with patient-specific questions, if they found the patient’s care plan helpful for delivering care, if they felt comfortable with ordering follow-up tests, and if they found the WBCP discharge process clear. Overall survey results for both patients and physicians were very positive.
Evaluation surveys are also distributed to patients after every survivorship class. Survey responses continue to be extremely positive, with the majority of participants reporting to be either satisfied or very satisfied with care coordination, follow-up testing, resource availability and management of late and long term effects.

**Barriers and Facilitators**
There were several challenges encountered during WBCP implementation. There was a general lack of understanding of the role and responsibilities of the nurse practitioner (a new position within the cancer centre). Also, many oncologists experienced a reluctance to discharge their patients and refer them to the program. They feared that if patients were no longer in their care, local recurrences that may be amenable to curative therapy, late complications of treatment, and timely and appropriate surveillance tests, would be missed. A related challenge was family physicians’ lack of: cancer care knowledge; ongoing surveillance for cancer survivors; and ways of providing support to patients undergoing follow-up cancer care. As awareness and understanding of the program improves, the aforementioned barriers are gradually being overcome.

There were also several facilitators that supported implementation. Cancer Care Ontario submitted a call for proposals for breast and colorectal cancer survivorship programs at the same time as initial ideas were circulating. In addition, the vision of the Program Manager, as well as the ongoing support of the Vice President of the Regional Cancer Program, the Patient and Family Advisory Committee and patient advisors who were on the steering committee, encouraged support for the WBCP from others.

**Lessons Learned**
Project members agree that the following are integral components of the success of the WBCP:
- Communication amongst primary care, specialty care and the WBCP team
- Patient empowerment
- Provision of education and support to patients and their family physicians
- Patient and family involvement in the development of program resources and materials
- Clear re-entry mechanism

The following components were also necessary to ensure that the program was successful and constantly improving:
- Developing processes to address variations in program uptake by oncologists
- Overcoming challenges that arise from the implementation of a new process management tool/electronic communication system designed to manage patient flow
- Streamlining the referral options from three to two
- Responding to patient feedback by reviewing and revising program structures

**Future Directions**
The program is moving ahead with a vision to determine opportunities for expansion to other disease sites and patient populations.
12. **Transition Care Clinic**

**Interviewees and contact information:** Dr. Matthew Cheung, Associate Scientist, Sunnybrook Health Sciences Centre ([matthew.cheung@sunnybrook.ca](mailto:matthew.cheung@sunnybrook.ca)) and Dr. Simron Singh, Medical Oncologist, Sunnybrook Health Sciences Centre ([simron.singh@sunnybrook.ca](mailto:simron.singh@sunnybrook.ca))

**Date of interview:** January 21, 2015

**Implementation level:** Regional

**Implementation site:** Greater Toronto Area, Ontario, Canada

**Implementation date:** 2012

**Targeted stage of cancer care continuum:** Survivorship

**Targeted cancer diagnosis:** Colorectal cancer and hematological malignancies

**Creation and development of materials:** Specialists (oncologists)

**Delivery of initiative/program:** Specialists (primarily nurse practitioner, with oncologist support)

**Initiative/program users:** Patients

**Overview**

The Transition Care Clinic (TCC) was implemented in 2012 on a regional level (i.e. Greater Toronto Area). Recently, the clinic team has been expanding their reach by collaborating with various sites outside of the Greater Toronto Area. The team targets colorectal cancer and hematological malignancy patients who have completed active treatment and are transitioning to the survivorship stage of their care. They focus on providing evidence-based survivorship care, including long-term surveillance.

**Rationale and Development**

Within a cancer centre, patients who are undergoing active treatment are prioritized over those who have completed their treatment. As a result, survivors are often overlooked and do not receive optimal care. Furthermore, research evidence has indicated that the responsibility of follow-up care can be safely and effectively shifted from specialists to family physicians, recognizing that family physicians require the right tools and education to be able to successfully care for survivors. The aforementioned evidence led Dr. Matthew Cheung and Dr. Simron Singh to develop the TCC. They are responsible for the daily operations of the clinic, along with Nurse Practitioner, Ruby Sangha.

The overall goals of the TCC are to support patients who have successfully completed cancer treatment in their transition from the cancer centre back to their family physician, and to provide these patients with optimal and evidence-based survivorship care.

**Description**

The TCC takes place at the Odette Cancer Centre at Sunnybrook Health Sciences Centre in Toronto, Ontario. At the TCC, patients receive comprehensive survivorship care from the clinic’s nurse practitioner, Ruby Sangha. Ms. Sangha interacts with patients on a daily basis and develops survivorship care plans for them through an automated process that draws information from existing electronic databases within the hospital. The care plans provide a medical history, along with long-term recommendations for future survivorship care. An accompanying web resource allows patients to connect to the Odette Cancer Centre and access survivorship-related information and resources post-discharge. Patients’ electronic care summaries can be accessed by their family physicians. Furthermore, family physicians receive education from specialists, focusing on best survivorship care practices. Dr. Cheung and Dr. Singh are responsible for the development of the
educational component of the program, as well as the clinical oversight of the TCC. A research team works also within the TCC to gather information regarding patient outcomes. Overall, the TCC provides a patient-centred, evidence-based approach to transitioning patients from active treatment to follow-up care.

The program functions under existing resources and is self-sustaining. Minimal financial resources were initially required in order to create the electronic care plans, as well as to have a nurse practitioner join the TCC.

**Evaluation**

An 8-month pilot project was conducted after the TCC was first implemented (2012-2013). There were 66 visits and 28 discharges within this time (53% of visits and 93% of discharges were for gastrointestinal patients, and 47% and 7%, respectively, for hematology).

Results:
- 28 discharges resulted in resource utilization savings of 122 Odette Cancer Centre visits and 118 hospital CT scans
- Symptom screening results (across the domains of anxiety, depression, pain and tiredness) were on par with other cancer patients, dispelling concern that TCC patients experience different/more symptoms after treatment and during transition
- Patient feedback indicated that those who found it difficult to attend Odette Cancer Centre appointments appreciated knowing that guidelines were available, and were comfortable with family physician follow-up, while others, whose family physician missed initial presenting symptoms, preferred cancer centre “specialists” and did not feel comfortable

Based on the review of the pilot study, the following changes were made to the TCC:
- Switching from a family practitioner to a nurse practitioner to transition patients
- Creating electronic survivorship care plans

A second evaluation, which focuses on the patient point of view, is currently underway. The research team (i.e. research students, along with an independent qualitative evaluator) is collecting data from patients who have been transitioned from the TCC. More specifically, the team is collecting qualitative data to identify which health outcomes are most valued by patients during a time of transition.

**Barriers and Facilitators**

The primary barrier to the implementation of the TCC was the reluctance of some oncologists to transition their patients to other care providers. These oncologists preferred to follow their cancer patients into long-term survivorship care. The TCC gained support as Dr. Singh and Dr. Cheung spoke publicly about the initiative prior to its implementation. This helped to increase awareness of the program and provided a venue for the doctors to address public concerns. Additional facilitators to implementation were funding that was received through Sunnybrook Hospital’s Innovation Grant and the strong administrative support received by the TCC.

**Lessons Learned**

The main lesson learned was that the creation of a successful patient-centred program requires patient engagement.

**Future Directions**

Currently, the TCC team is working on creating an educational video for patients, which will describe the transitional process. They are also planning to further develop their web resource, to
ensure that patients feel involved and engaged in their own care. The research component of the program will also continue to be developed, as more patient data are collected. In regards to the program as a whole, the team plans to incorporate other tumour site groups, including prostate and breast cancer in 2015. Lastly, as a result of their success, Dr. Cheung and Dr. Singh are developing a business model to highlight the system benefits of the TCC.

**Additional Information**
Additional information about the program can be accessed online: [http://sunnybrook.ca/content/?page=cancer-transition-care-clinic](http://sunnybrook.ca/content/?page=cancer-transition-care-clinic)
13. Well Follow-Up Care for Colorectal Cancer Survivors and their Circles of Care

Contact information: Hugh Langley, Senior Medical Advisor, Ministry of Health and Long-Term Care (hugh.langley@ontario.ca) and Candice Christmas, Doctoral Candidate, Health Policy & Equity, York University (cchristmas@horizonkmb.ca)

Interview form completed: October 2015

Implementation level: Regional
Implementation site: South East Local Health Integration Network (LHIN 10), Ontario, Canada
Implementation date: 2014
Targeted stage of cancer care continuum: Survivorship
Targeted cancer diagnosis: Colorectal
Creation and development of materials: Government organization (Cancer Care Ontario) and specialists (oncologists and advanced practice nurses), general practitioners in oncology, family physicians
Delivery of initiative/program: Specialists (medical and radiation oncologists, advanced practice nurses, general practitioners in oncology, surgeons), nurse practitioners and family physicians
Initiative/program users: Patients

Overview
The Well Follow-Up Care for Colorectal Cancer (CRC) Survivors and their Circles of Care program was implemented on a regional level in 2014. Its implementation was led by the South East Regional Cancer Program (SERCP) at Kingston General Hospital, the South East Local Health Integration Network (LHIN 10)’s tertiary care hospital and Queen’s University academic health sciences centre. The SERCP, in partnership with regional primary care, aims to ensure post-treatment surveillance to CRC survivors and to enable their self-care and management.

Rationale and Development
In 2010, Ontario’s Provincial Cancer Agency, Cancer Care Ontario, had reported extensive wait times for patients seeking active treatment and therefore mandated that new models of CRC well follow-up care be established in all of the province’s regional cancer centres. SERCP staff conducted the following research in order to guide the development of their CRC well follow-up model:

- Literature review and inventory of best practices and professional development programs related to cancer well follow-up care
- Literature review on tools available to measure specialists’ attitudes towards CRC follow-up care
- Identification of existing knowledge translation tools around continuity of care for cancer survivors
- Mapping of objectives from each of the three Cancer Care Ontario pilot projects (i.e. North York, Champlain and North West) in search of commonalities and unique features
- Focus group sessions in the three pilot project sites to determine program strengths, weaknesses, lessons learned and opportunities for knowledge transfer and exchange
- Pilot survey for family physicians in LHIN 10 regarding attitudes around CRC follow-up care, their roles, awareness of evidence-based follow-up guidelines and preferences around knowledge exchange

The results from this research directed the development of a “discharge to primary care provider” model for CRC patients in LHIN 10. Meetings with LHIN 10 family physicians (to consult and inform them) were also conducted in preparation for this change in practice, and to ensure that all care providers have the resources they need and the policies in place to make an effective transition.

The primary goals of the program are to:

- Reduce the amount of follow-up care by medical oncologists and surgeons;
- Increase the capacity of oncologists to provide active treatment;
- Improve coordination and communication between specialists and primary care providers to improve cancer system efficiency and enhance the transition and coordination of care for cancer survivors;
- Improve access for patients and ensure CRC survivors have adequate access to high-quality care and follow-up services post-treatment;
- Improve patient satisfaction by empowering patients to participate in the management of their care and overall well-being post-treatment; and
- Improve provider satisfaction by finding ways of improving communication and transfer of knowledge among several health care providers.

**Description**

Before being discharged to primary care, CRC patients have one well follow-up appointment at the South East Regional Cancer Centre (SERCC). During this appointment, they meet with their oncologist or a General Practitioner in Oncology (GPO) to determine if they meet all criteria to be discharged. If they do, a discharge letter is prepared for the patients’ primary care providers (i.e. family physicians or nurse practitioners). Patients also meet with an oncology nurse during their well follow-up appointments, to review patient education material on follow-up care and to receive a patient satisfaction survey. Transitioning patients’ primary care providers receive a discharge package, which includes the following:

- “Dear Primary Care Provider” Letter, with information about the program and directions for care
- Receipt of Information Sheet (RIS), to confirm that the discharge letter and follow-up care package has been received and that the primary care provider assumes on-going well follow-up care for the patient; this must be signed by the provider and faxed back to the cancer centre
- Detailed discharge letter dictated by the specialist (generally the medical oncologist) or GPO
- Tool Kit: Summary of colorectal well follow-up care, surveillance protocol and secondary prevention measures; Carcinoembryonic Antigen Test form for Life Labs; Copy of Colorectal Well Follow-up Patient Binder Insert; Colorectal Well Follow-up Care Primary Care Provider Survey (from Cancer Care Ontario)
Furthermore, by coordinating with primary care providers, the Project Lead ensures that patients meet with them for ongoing well follow-up care six months post-discharge.

Program resources include one Project Lead (available one day per week), office space and access to a computer and fax machine.

**Evaluation**

The Quality Assessment Program to Enable Compliance with Well Follow-Up Care for Colorectal Cancer Survivors and their Circles of Care was established to ensure continuity of care for colorectal patients transitioning from the SERCP to primary care. This program involves an audit process to ensure that a discharge letter is completed by the specialist, a follow-up appointment with the specialist is scheduled, that the family physician sends a RIS to the SERCC within one month post-discharge, and that a six month post-discharge appointment with the patient’s family physician is scheduled.

The following are findings from the evaluation report, "Report on Quality Assessment for Colorectal Cancer Well Follow-up Care", conducted from June 2014 – August 2015. A total of 80 patients were discharged during this time frame; however, only 31/80 (39%) RISs were received by the SERCC. Since September 5, 2015, 70/80 (87.5%) RISs had been received. Efforts continue to encourage the non-responding family physicians to send in their sheets, including sending the information by fax rather than Canada Post (which is typically how the family physicians receive information from the hospital).

Two surveys were administered as part of the evaluation. One was a patient survey, for those being discharged from the cancer centre to their family physician for CRC well follow-up care. As of August 28 2015, 22/77 (29%) of patients had responded to the survey. Generally, patients strongly agreed that they were provided with a clear plan for their care, were satisfied with the emotional support and the information that was provided to them, and felt prepared for transitioning to primary care. The second survey was intended for family physicians taking on the well follow-up care of CRC patients. As of August 25 2015, 14/66 (21%) of family physicians had responded to the survey. Generally, the respondents somewhat agreed/strongly agreed that they were well informed by the cancer centre in regards to providing follow-up care, understood their role and were confident in their ability to provide follow-up care. Family physicians did not feel that they had enough information about the community resources that were available to them and their patients; therefore, these resources are now included in the family physicians’ Tool Kits.

**Barriers and Facilitators**

Key barriers to program implementation were the region’s varied ways of chronicling and storing patient data and a lack of integration between Electronic Medical Record (EMR) systems. Although some family physicians have remote access to Kingston General Hospital’s EMR (Patient Care System), “view only” access does not allow them to update files (which can be important if the patient is admitted to emergency or needs to be re-admitted to the cancer centre because of suspicion of recurrence). Therefore, physicians cannot update a CRC survivor’s medical information
(e.g. lab results, scans, medication changes). Furthermore, the hospital is unable to create flags and reminders about required surveillance tests and imaging for family physicians. Another barrier can be oncologists’ reluctance to release follow-up care to family physicians, as some oncologists would prefer to continue providing follow-up care to their patients.

In regards to facilitators, the interdisciplinary nature of the project team and the members’ dedication to engaging meaningfully with primary care providers was the project’s key strength. Primary care providers were able to actively participate in the design of the follow-up care model and their concerns were addressed. Having a dedicated Project Lead who is well connected to the family medicine community has been advantageous to the program. Additionally, having a dedicated staff member oversee the transition has been an imperative, particularly until quality assessment and continuity of care elements can be automated.

Lessons Learned
Three key lessons were learned by means of program evaluation. The first was that the significance of the discharge visit must be emphasized to cancer centre staff. The second was that the receipt of the RIS is critical for ensuring that a patient receives continuity of care and for guaranteeing that the hospital is legally protected. The final lesson was that the use of EMRs to generate auto-reminders to family physicians would facilitate the process of providing well follow-up CRC care and would also conserve costs.

Future Directions
The SERCP is incorporating the findings of the cancer well follow-up care quality assessment project into the next round of strategic planning under the theme “integrating primary care with cancer care”. Better integration would ensure continuity of care, patient satisfaction, and equity across disease groups, demographic groups and geographies. Process standardization is being explored for: patient entry into the cancer care system from primary care (e.g., Diagnostic Assessment Programs); quality assessment for all patients discharged back to primary care to ensure continuity of care (e.g., RIS process for all appropriate diseases/sites); and monitoring of patient and family satisfaction. Additionally, The SERCC and the Kingston General Hospital will soon be piloting a similar evaluation model (i.e. Quality Assessment Program) for palliative care.
14. **Embedding Disease Pathway Management Published Pathways into Process of Care: Focus on Transition from Active Treatment to Community-Based Follow-up Care for Colorectal Patients in Northern Ontario**

**Interviewee and contact information:** Jana Belanger, Project Manager, Northeast Cancer Centre ([janbelanger@hsnsudbury.ca](mailto:janbelanger@hsnsudbury.ca))

**Date of interview:** January 6, 2015

**Implementation level:** Regional

**Implementation site:** Northern Ontario, Canada

**Implementation date:** 2015 (planned)

**Targeted stage of cancer care continuum:** Survivorship

**Targeted cancer diagnosis:** Colorectal

**Creation and development of materials:** Government organization (i.e. Cancer Care Ontario), Northern Ontario cancer centres’ staff and clinicians

**Delivery of initiative/program:** Northern Ontario cancer centres’ staff and clinicians

**Initiative/program users:** Patients and community-based primary care providers

**Overview**

The “Embedding Disease Pathways Managements (DPMs) Published Pathways into Process of Care: Focus on Transition from Active Treatment to Community-Based Follow-up Care for Colorectal Patients in Northern Ontario” project began in March 2014 and is currently in its development and testing phase. The project team plans to implement the program on a regional scale in March 2015 at two different sites. The program is being funded through Cancer Care Ontario. Once implemented, it will target colorectal cancer patients and their community-based family physicians to provide them with survivorship care that adheres to CancerCare Ontario’s Disease Pathway Management Colorectal Cancer follow-up guidelines.

**Rationale and Development**

The development of the program was initiated out of a need to find more efficient ways (i.e. electronic processes and pathways) to share patient information with family physicians within the community and to ensure that family physicians are supported in providing care to transitioning patients.

The development of this project was led by a steering committee, along with Ms. Jana Belanger, Project Manager. Two sites in Northern Ontario will implement the initiative. A site manager at each location will be responsible for overseeing the daily operations. Site managers will report to Ms. Belanger, who will then report to the steering committee, as well as Cancer Care Ontario, on the progress of the two sites.

The goals of this project are 1) to increase family physician and patient adherence to the Disease Pathway Management Colorectal Cancer Follow-up Care Pathway evidence-based surveillance guidelines, and 2) to embed and optimize electronic processes and capabilities of issuing survivorship care plans and recall prompts to patients and family physicians.
Description
This project will be implemented across Northern Ontario, Canada at two sites. There will be one implementation site in the Northeast: Health Sciences North (HSN). The implementation in the Northeast will be delivered by an HSN oncologist, and supported in the community by family physicians. There will be one additional implementation site in the Northwest: Thunder Bay Regional Health Sciences Centre. The implementation at this site will be Nurse Practitioner-led with primary care support.

This project involves building an electronic solution to be able to send survivorship care plans directly to a family physician’s electronic medical records. The project also addresses the adherence to the Colorectal Disease Pathway Management Follow-up Guidelines by sending out reminder letters (using electronic solutions where possible) to family physicians and patients as a prompt for follow-up care.

The processes differ slightly for the Northeast and Northwest sites. In the Northwest (i.e. Thunder Bay Regional Health Sciences Centre), registered nurses will work with a Nurse Practitioner to develop an assessment containing the components of a survivorship care plan, while at the Northeast site (i.e. Health Sciences North) the attending oncologist will dictate an individualized discharge note for the patients containing the individualized components of a survivorship care plan and an imported addendum containing standardized surveillance recommendations. For both sites, the survivorship care plan will be sent directly to family physicians through Physician Office Integration (POI) (i.e. directly to the family physicians’ electronic medical records), auto-fax, or if the physician is not subscribed to an electronic distribution method, by mail. The reminder letters are automatically generated according to the Disease Pathway Management Follow-up Guideline timeline, and are triggered upon patient discharge to be sent to the family physicians using electronic solutions (POI or auto-fax) or via mail. Patients will receive their survivorship care plans in the clinic, at their time of discharge, and will receive all of their reminder letters via mail.

The two sites are governed by a steering committee, which is led by the Regional Vice President of the Northeast Cancer Centre. The committee meets monthly and has representation from both implementation sites, as well as Cancer Care Ontario. There are also interdisciplinary working groups, which meet monthly, at each implementation site. They are responsible for conducting research, and developing and reviewing content for the survivorship care plan, and developing the electronic solutions.

Overall, the initiative is expected to improve coordination and advance the quality of cancer care by providing follow-up care information to family physicians, by way of survivorship care plans, and supporting adherence to the Colorectal Cancer Follow-up Guidelines, by way of the reminder letters.

Evaluation
A formal evaluation of the program is in progress. A pre-implementation survey was disseminated to the staff who would be involved in the distribution of the survivorship care plans and reminder letters to measure satisfaction with the implementation process, electronic solutions and impact on their workload. A post-implementation survey will be disseminated after implementation is complete.
Barriers and Facilitators
The key barrier to implementation has been the technical aspect of the project (i.e. the alignment of electronic interfaces required for the project). The development team would have negotiated more time for development and testing if they had foreseen the technical issues they would encounter.

Lessons Learned
There were two key lessons learned. It is important to gather the appropriate stakeholders from the beginning of the project to suitably plan the phases and activities of the project and their associated timelines. Furthermore, the development of a technical solution may result in unexpected outcomes. While the technical limitations are significant, they are not always known until the testing phase. Equally, it is not always known how systems will interact with each other, or when a system will experience a “crash” or downtime. Therefore, building a reliable and sustainable electronic solution requires thorough testing and extensive communication among stakeholders.

Future Directions
The family physician survivorship care plan and reminder letter solutions developed in both the Northeast and the Northwest are easily expandable to other disease sites. The solutions were developed using a systematic approach that does not limit the number of disease sites that may use the electronic pathways. Further consultations with internal and external stakeholders would be required, and would contribute to the evolution of these pathways, while ensuring they are used in the most efficient manner.
15. **Provincial Integrated Cancer Survivorship Program**

**Interviewee and contact information:** Shelley Currie, Provincial Project Manager, PICSP, Alberta Health Services (shelleym.currie@albertahealthservices.ca)

**Date of interview:** December 12, 2014

**Implementation level:** Provincial  
**Implementation site:** Alberta, Canada  
**Implementation date:** 2014  
**Targeted stage of cancer care continuum:** Survivorship (post-treatment transitions through to well-follow-up)  
**Targeted cancer diagnosis:** Not specific  
**Creation and development of materials:** Government organization (i.e. Alberta Health Services), specialist, primary care providers, patient and family representatives, community-based organizations  
**Delivery of initiative/program:** Government organization (i.e. Alberta Health Services), specialists, primary care providers, patient and family representatives  
**Initiative/program users:** Government organization (i.e. Alberta Health Services), specialists, primary care providers, patients and family, public

**Overview**

The Provincial Integrated Cancer Survivorship Program (PICSP) is a provincial program of Alberta Health Services’ CancerControl Alberta. The PICSP business plan was accepted in July 2014 and program work started in September 2014. The program focuses on the survivorship phase of the cancer care continuum and emphasizes improving transitions in care, supporting patients’ capacity for self-management, providing interventions to support optimal living and improving decision support for family physicians. The PICSP includes disease-specific and general cancer resource development and health system change management.

**Rationale and Development**

There was a need to effectively transition appropriate cancer patients to primary care in order to ensure that cancer centres had the capacity to treat newly diagnosed and complex care patients. Furthermore, as the number of cancer survivors continued to grow, more knowledge became available regarding survivors’ needs, their preferences and their resilience. Therefore, it became necessary to combine all of the emerging survivor-related knowledge and research into an integrated model within the health services delivery system in Alberta.

The development of the business plan was co-led by Dr. Janine Geise-Davis and Dr. Linda Watson, and the grant for the program was held by the Senior Medical Director and the Executive Director of CancerControl Alberta, Dr. Paul Grundy. The overall goal of the PICSP became to improve transitions, and post-treatment experiences and outcomes, for cancer patients in Alberta and their healthcare providers.

**Description**

The PICSP team is based within the Person-Centred Care Integration Team (Strategic Lead – Linda Watson) of Alberta Health Services’ CancerControl Alberta and is under the leadership of the Director of Community Oncology and Provincial Practices, Brenda Hubley. It is implemented through Alberta’s cancer care centres: Tom Baker Cancer Centre in Calgary; Cross Cancer Institute in Edmonton; and Community Oncology, which is a program responsible for four regional cancer
centres and 11 community cancer centres across the rest of Alberta. The Provincial Project Manager of PICSP, Shelley Currie, is responsible for the daily operations of the implementation Project Team. The PICSP is not a clinical program; rather, it is a change management initiative. The project team works with operations leaders, clinical leaders and multi-disciplinary clinicians across the province who are responsible for the delivery of care within cancer centres, primary care and chronic disease management teams.

PICSP resources include:
- Full-time Provincial Manager, PICSP
- Full-time Provincial Education Specialist
- Part-time Provincial Education Consultant
- Full-time Survivorship Transitions Analyst
- A small resources budget for materials and travel

Otherwise, the program functions within existing Alberta Health Services resources.

The PICSP consists of three streams of work:

Patient Survivor Education and Empowerment
The purpose of this stream of work is to improve Albertans’ access to the most current information on survivorship/transitions in care. This will help patients and survivors self-navigate to resources or services that they themselves, or their family members, may need. Strategies include maximizing the potential of Alberta Health Services’ online presence (i.e. MyHealthAlberta.ca) as a trusted source of cancer/survivorship health information. Transition education and outreach education events will be integrated into the Provincial Patient Education Program of CancerControl Alberta. A Provincial Education Specialist is responsible for the design and delivery of educational interventions and resources intended to support people transitioning from post-treatment, as well as those who may be required to return to a cancer centre. A Provincial Education Consultant works alongside the Education Specialist.

Transitions of Care Infrastructure
The purpose of this stream of work is to embed knowledge and best practices related to effective transitions in cancer care into the healthcare delivery system. The PICSP team includes a Survivorship Transitions Analyst who is working with Provincial Tumour Teams on a current state analysis of transitions of care tools and resources, as well as Information Technology and data management processes within CancerControl Alberta and their interfaces with primary healthcare settings. The work of the Transitions Analyst includes partnering with the Tumour Teams and Site-Specific Groups to develop a base template in the CancerControl Alberta electronic medical records (EMRs) for transitions of care, as well as to maximize interfaces with the provincial EMRs. This work will involve designing and testing mechanisms to embed follow-up guidelines into the EMR system to ultimately generate electronic follow-up/transition plans for patients and their family physicians.

Models of Care
The purpose of this stream of work is to develop, pilot and evaluate models that aim to embed best practices into the entire cancer system for all cancer patients. The team is currently drawing from best practices that show promise for scalability in a provincial delivery system.

Evaluation
An evaluation framework is being developed for each component of the project.
Barriers and Facilitators
The primary challenge with completing this project lies in translating the results of high-quality short-term, tumour-and/or healthcare delivery specific research studies into sustainable health services delivery for the entire population. To address this challenge, the project team must balance the research findings with feasibility for provincial implementation and sustainability. They must ensure that any changes that are being instituted in health services delivery result in the most beneficial outcomes for the greatest number of people, and also have the least possible negative impacts on frontline care providers.

Lessons Learned
Thus far, working through the various aspects of the project has taught the team three key lessons. The first lesson is that working within the provincial framework ensures that the processes, tools and resources that are being developed, tested and implemented, align with the larger organization’s business model, policies and regulations. The second lesson is when a team has been mandated to develop, test and implement health system change that is provincial in scope, it is important to have the proper supports in place, at the provincial level, to guide and support that team. CancerControl Alberta has recently developed a Provincial Practices Portfolio that is combining work related to provincial standards of care, education for survivors and healthcare providers, and provincial standards for the collection and effective use of information and data to support quality improvement. This is a positive development for the PICSP project team and has necessitated some revisions to the original business plan. The third lesson is the importance of patient engagement as a key component of the initiative. In addition, engagement with cancer community groups and agencies is important in ensuring that the roles of those who support cancer patients throughout their cancer journey are sustained and enhanced.

Future Directions
The PICSP Project Team will continue to engage with each Provincial Tumour Team in CancerControl Alberta as provincial follow-up guidelines are developed for specific sub-populations of patients completing cancer treatment. The Team will work with key stakeholders to create tumour-specific patient and healthcare provider information resources and tools based on these guidelines. The Team will also support current state analysis and care pathway mapping to ensure alignment of cancer follow-up care with other patient care pathways (e.g. clinical pathways, chronic disease management pathways). The goal of this work is to improve and expand dissemination, uptake and efficacy of cancer follow-up guidelines and practices across the province.

Additional Notes
The team is closely partnered with another provincial project team called Building Cancer Prevention and Collaborative Initiatives to Empower Survivors (Building CAPACITIES). The Building CAPACITIES project was implemented in Alberta in 2014 and targets breast and prostate cancer patients in the survivorship phase of care. Building CAPACITIES is developing and testing an intervention to improve decision support, self-management and transition coordination in five primary care sites. The Building CAPACITIES team engages with the pilot sites to explore and understand the promotion of wellness in the survivor population, the provision of cancer prevention information and surveillance to identify recurrences and prevent second cancers, and the provision of care coordination and comprehensive decision support in relation to medical follow-up requirements. The collected data will help the PICSP to develop an overall survivorship care model for the province.
16. **Moving Forward After Cancer Treatment**

**Interviewee and contact information:** Donna Bell, Program Manager, CancerCare Manitoba (donna.bell@cancercare.mb.ca)  
**Date of interview:** March 13, 2015

**Implementation level:** Provincial  
**Implementation site:** Manitoba, Canada  
**Implementation date:** 2009  
**Targeted stage of cancer care continuum:** Survivorship  
**Targeted cancer diagnosis:** Breast and colorectal  
**Creation and development of materials:** Government organization (i.e. CancerCare Manitoba), physicians and nurses  
**Delivery of initiative/program:** Specialists (i.e. cancer clinic staff)  
**Initiative/program users:** Patients

**Overview**
Moving Forward after Cancer Treatment is a provincial survivorship program. It was first established in 2009 and is funded by CancerCare Manitoba (CCMB). The program specifically targets individuals with breast cancer and colorectal cancer (CRC) who are transitioning from active treatment into survivorship/follow-up care. Within the next six months, the program will also target patients with ovarian cancers, lymphomas and advanced or palliative cancers.

**Rationale and Development**
CCMB had recognized that a standardized approach was needed to:

- Decide what types of patients can be transitioned to follow-up in the primary care setting;  
- Communicate with family physicians and patients at the time of transition from active treatment into follow-up care; and  
- Clarify the roles and responsibilities of various providers in the shared care of cancer survivors.

To address the issue of standardization, CCMB developed a pilot project and applied for a grant from the Canadian Partnership against Cancer (CPAC). Moving Forward after Cancer Treatment was first implemented in 2009 as a 14-month "survivorship initiative” pilot project.

The development of the program was led by Ms. Donna Bell, Project Manager, and two project leads: Dr. Jeffrey Sisler and Jill Taylor Brown. The overall goal of the initiative became to ensure that disease sites groups (DSGs) transition patients to primary care using materials and processes that have been established through the program.

**Description**
An advisory committee, made up of clinical and administrative members of different departments at CCMB, decides how the project will proceed. Working groups, which typically consist of physicians, nurses and members of the CCMB administrative team, develop materials and resources and advise on integrating standardized materials into the clinical setting. Currently, two working groups have formalized and standardized a transition process for breast and CRC patients. With every new DSG that the project team implements, a working group specific to that disease site will be created.
The standardized transition process for breast and CRC patients is as follows. At the conclusion of active treatment and start of follow-up care, clinic staff meets with the patient for a transition appointment. The clinical team that is most involved in the patient's care is the team that is responsible for transitioning the patient. This appointment informs the patient of their transition and of how they will be proceeding with their care. During the appointment, the patient's needs are identified and referrals for specialists are provided. A follow-up care plan, consisting of three distinct sections, is given to the patient. The first section is patient-specific and includes a treatment summary along with follow-up recommendations. The second section is specific to the DSG and the final section provides general healthy lifestyle information and a list of available resources for cancer patients living in Manitoba. Family physicians and specialists receive the first section of their patient’s care plan.

A full-time transitions manager is responsible for managing the program. CCMB provides administrative support, and existing staff within cancer clinics carry out the transitions appointments. Operational costs are run through CancerCare Manitoba’s Community Oncology Program. To date, the initiative has received $20 000/year for research and the development of materials.

**Evaluation**

A formal evaluation of the program has not yet been conducted. The project team has, however, conducted a research study for the CRC-specific implementation. Baseline surveys with questions regarding transitions from active treatment to follow-up care were disseminated to CRC patients one year before the implementation of the program. This baseline data have been published. A similar survey was distributed post-implementation to patients who were transitioned through the program; however, the data are still being collected. A proposal for a similar research study for the breast cancer-specific implementation has been made. Baseline surveys have been disseminated and data are being collected.

**Barriers and Facilitators**

The main barrier to implementation was the reluctance of oncologists to provide their patients with transition appointments. There were several facilitators to implementation. The Advisory Committee met monthly during the first year of implementation to ensure program success. Clinic champions or leaders also encouraged oncologists and clinic staff to provide their patients with transition appointments. Furthermore, a portion of the initial CPAC grant allowed for the team to pay for technical support, which was required for integrating reports into electronic medical records.

**Lessons Learned**

Clinic champions were crucial to the successful implementation of the program. Champions were oncologists, family physicians in oncology, nurses and clerks who emphasized the benefits of the program to oncologists who were initially reluctant to conduct transition appointments with their patients.

**Additional Notes**

Additional information about the program can be accessed online: http://www.cancercare.mb.ca/resource/File/CCPN/Presentations_2011/Moving_Forward_after_Colorectal_Cancer_2011_Sisler.pdf

Note: This profile was not verified by the interviewee prior to Casebook publication.
17. Transition Volunteer Navigator Program

Interviewee information: Shaun Lorhan, Program Leader, Survivorship and Primary Care, British Columbia Cancer Agency (slorhan@bccancer.bc.ca)

Contact information: Karen Blain, Provincial Director, Survivorship and Primary Care, BC Cancer Agency (Karen.Blain@bccancer.bc.ca) and Jennifer Law, CPAC Project Manager, Survivorship and Primary Care, BC Cancer Agency (Jennifer.Law2@bccancer.bc.ca)

Date of interview: February 24, 2015

Implementation level: Multi-Provincial

Implementation site: British Columbia and Nova Scotia, Canada

Implementation date: 2015 (planned)

Targeted stage of cancer care continuum: Survivorship

Targeted cancer diagnosis: Breast and colorectal

Creation and development of materials: Government organization (i.e. British Columbia Cancer Agency)

Delivery of initiative/program: Government organization and transition navigators

Initiative/program users: Patients

Overview

The Transition Volunteer Navigator Program is one component of a larger initiative called “Leveraging a Suite of Existing Tools to Support Patients and Health Care Professionals in the Cancer Post-treatment Transition Period”. This larger initiative was established to support health care professionals and cancer patients in post-treatment transitions. It is being funded by the Canadian Partnership Against Cancer for a period of three years: January 2014-January 2017, and is led by British Columbia (BC) Cancer Agency’s Survivorship and Primary Care Program. The initiative consists of four projects, which are specific to breast and colorectal cancer diagnoses.

The following projects/programs make up the initiative (implementation date):

- BC Guidelines Evaluation Survey (currently underway)
- Assessment of breast cancer patient needs, with respect to patient care summaries (April 2015)
- Transition Volunteer Navigator Program (July 2015)
- Development of a web-based portal for patients (July 2015)

This profile will focus primarily on the Transition Volunteer Navigator Program, with mention of the web-based portal project. These two components target the supportive care needs of patients, post-active treatment, and provide them with tools for self-management.

Rationale and Development

A growing number of cancer survivors in BC have expressed the need to be supported in living healthfully post-active treatment. The Survivorship and Primary Care Program has developed the “Leveraging a Suite of Existing Tools to Support Patients and Health Care Professionals in the Cancer Post-treatment Transition Period” initiative to leverage existing tools for both patients and care providers, to help optimize patients’ transitions in care, as well as their overall survivorship experience.
This larger initiative has three goals:

- Effectively support patients transitioning from oncology care to primary care
- Understand patient information needs
- Equip family physicians with the information needed to support patients in transition

**Description**

The “Leveraging a Suite of Existing Tools to Support Patients and Health Care Professionals in the Cancer Post-treatment Transition Period” initiative is overseen by BC Cancer Agency’s Provincial Survivorship and Primary Care Program. For this initiative, the BC Cancer Agency has partnered with the Canadian Cancer Society BC/Yukon and Nova Scotia Divisions, as well as Cancer Care Nova Scotia.

To support the implementation of the Transition Volunteer Navigator Program, the project team developed a competency framework which will be used to recruit, screen and train applicants. Transition Volunteer Navigators will be recruited by the Canadian Cancer Society, in both BC/Yukon and Nova Scotia. Volunteers will provide navigation services via phone to patients within Nova Scotia, as well as the Canadian Cancer Society through the Canadian Cancer Society’s Cancer Connection Program. The Transition Volunteer Navigator will be responsible for connecting the patient with the web-based portal resources, which will allow patients to self-manage their transition. The web-based portal provides information about overall healthy living and offers tools that allow patients to set and track personal health goals.

The larger initiative has focused on leveraging existing resources to implement the four projects. Therefore, the main resource required for ongoing implementation of the initiative is staff.

**Evaluation**

An evaluation plan has been developed for the components of the initiative, but has not yet been implemented.

**Note:** The barriers and facilitators, lessons learned and future directions are specific to the larger initiative, rather than the Transition Volunteer Navigator Program. This is because at the time of the interview, the transition program (and the web-based portal) had not yet been implemented.

**Barriers and Facilitators**

By combining four separate projects into one initiative, significant effort has been required to ensure that the support and resources are in place to enable the uptake of recommendations and the implementation of services. As well, organizational changes within the BC Cancer Agency have reduced the readiness for implementation within the agency. These have been the only challenges encountered by the implementation team.

The consistency of information received from patients and providers regarding gaps in care, has facilitated the progress of the various projects. In addition, the fact that existing resources were used to create sustainable programs and projects within the BC Cancer Agency has been a major facilitator to implementation. Lastly, the organizational partnerships initiated through this initiative have allowed each partnering organization the opportunity to gain from the wisdom and experience of project partners.
Lessons Learned
The project team has learned that consensus and investment in consultation at developmental stages will be integral to the success of this initiative, as they ensure stakeholder support and ensure that the initiative maintains momentum.

Future Directions
The results of this initiative will be used to inform future activities within Survivorship and Primary Care at the BC Cancer Agency and partner institutions - Canadian Cancer Society (BC/Yukon and Nova Scotia Divisions) and Cancer Care Nova Scotia.
18. Victorian Cancer Survivorship Program

Interviewee and contact information: Dr. Bruce Mann, Director of Breast Care Services for the Royal Melbourne and Royal Women’s Hospitals (bruce.mann@mh.org.au)

Interview form received: April 12, 2015

Implementation level: Regional
Implementation site: Victoria, Australia
Implementation date: 2012
Targeted stage of cancer care continuum: Survivorship
Targeted cancer diagnosis: Breast
Creation and development of materials: Specialists (i.e. breast care nurses)
Delivery of initiative/program: Specialists (i.e. breast care nurses)
Initiative/program users: Patients

Overview
The Victorian Cancer Survivorship Program was first implemented as a pilot project in Victoria, Australia in January of 2012. The program targets breast cancer patients, specifically those with Ductal Carcinoma in Situ (DCIS) and early invasive (Stages 1-3) breast cancer (ESBC). The focus lies in the survivorship stage of care, more specifically, post-treatment surveillance, endocrine treatment adherence, side effect management and psychosocial needs management.

Rationale and Development
There were three ongoing issues which prompted the development of the Cancer Survivorship Program. The first was an insufficient capacity in the acute care facility, which resulted from an increased demand and volume of patients undergoing long-term surveillance there. Poor communication between specialists and family physicians added to the challenge, as did a lack of survivorship care planning.

The identification of these issues led a team of experts, including the Director of The Breast Service, the Lead Breast Care Nurse, the Hospital General Practitioner Liaison Officer and the Chief Executive Officer of BreaCan, a community-based peer support service, to successfully apply to be a site for the Victorian Cancer Survivorship Program. The overall goal of the program was to develop and implement a new model of post-definitive treatment care for patients with DCIS and ESBC.

Description
The Cancer Survivorship Program was based at the Breast Service of Royal Melbourne and Royal Women’s Hospitals. It focuses on implementing a new model of survivorship care, which shifts the provision of care from the cancer care specialist to the family physician. Patients who are 6-12 months post-definitive treatment meet with a breast care nurse to receive a treatment summary and to identify any unmet needs they may have. After the appointment, the nurse may initiate various referrals and develops a follow-up care plan, which is approved by a consultation surgeon and medical oncologist before being sent to the patient’s family physician. The patient then meets with her family physician to review the plan and to consent to its implementation. This new model of care ensures that breast cancer patients’ follow-up care is initiated in a shared-care manner. Therefore, family physicians are involved in holistic patient care and routine demand is reduced in the hospital.
The Breast Service is responsible for the overall governance of the program and is accountable for it as well. In regards to resource and cost implications, extra nursing time and administrative assistance is required, but modelling suggests that the extra costs are more than balanced by an expanded capacity for the Breast Service to accommodate more new referrals within the existing medical workforce.

**Evaluation**
The pilot project was evaluated in 2013 and was shown to be very successful. Qualitative survey and telephone interview data from breast cancer patients (i.e. program users), family physicians and breast care nurses were collected. The implemented model of care has had a positive impact on the patients who receive the services as well as the breast care nurses who deliver the program. The breast care nurses felt more satisfied with their jobs and they, along with family physicians, felt that the overall quality of service being delivered had improved. Overall, patients, family physicians and nurses found the implementation of the new model of care to be a useful and effective process change for the provision of follow-up care. As a result of the program, Breast Care Services have been able to manage an increased number of referrals without an increase in wait times and within existing senior medical staff capacity.

**Barriers and Facilitators**
The existing system was complex and had been in place for many years, therefore the majority of individuals embedded in the system did not recognize a need for change. Additionally, while the majority of family physicians were happy to participate, a proportion of them did not see what was being proposed as being a part of their job description. A barrier to continuing the initiative beyond the project phase was that it required extra time for breast care nurse employment; however, the additional time was justified, as the program allowed a greater number of patients to be seen and to be managed without increasing the medical workforce of the Breast Service.

**Lessons Learned**
In order to implement a sustainable and effective program, data regarding the various impacts of change must be continuously collected and evaluated.

**Future Directions**
The new model of care will be reviewed and updated as needed, but is now considered a standard part of the management of patients with DCIS and ESBC. Other sites in the state of Victoria are now developing and implementing their own version of the model, using the experience and documentation of this project as a template. The senior staff from the Royal Melbourne/Royal Women’s Breast service plays a facilitative and mentoring role in this expansion. Additionally, consideration is being given to adopting this model for use in other tumor sites.
19. **Oncology Navigation Program**

**Interviewees and contact information**: Dr. Rob Annis, Family Physician (robannis@mac.com); Lindsay McGee, Quality Manager; and Sarah Givens, Oncology Nurse Navigator (sgivens@npfht.ca) (North Perth Family Health Team)

**Date of interview**: January 15, 2015

**Implementation level**: Local  
**Implementation site**: North Perth, Ontario, Canada  
**Implementation date**: 2007  
**Targeted stage of cancer care continuum**: All stages (nurse/patient navigation)  
**Targeted cancer diagnosis**: Not specific  
**Creation and development of materials**: Primary care providers  
**Delivery of initiative/program**: Primary care providers (specifically, a Registered Nurse)  
**Initiative/program users**: Patients

**Overview**
The Oncology Navigation Program was first implemented on a local level in 2007, and is targeted towards all cancer patients in North Perth. The program ensures that patients are educated and properly cared for throughout their entire cancer journey, including their transitions in care.

**Rationale and Development**
Registered nurse and North Perth Family Health Team (NPFHT) member, Sarah Givens, gained a great deal of insight into the thoughts and concerns of cancer patients through her experience working at cancer centres. Many patients expressed their concern about being discharged from the cancer centre and transitioned to primary care. Therefore, when Ms. Givens came to work with the NPFHT, she shared those patient concerns with her team, who then collaborated with her to develop the Oncology Navigation Program.

The Oncology Navigation Program successfully fulfills patient needs by being based out of primary care, as patients with questions about their treatment or care are mostly likely to contact their family physicians' offices for answers. The goal of the program is to educate patients and provide them with safe and timely care, throughout their entire cancer journey.

**Description**
The Oncology Navigation Program is managed through the NPFHT, located in North Perth, Ontario. The program supports patients in their navigation through the complex health system by ensuring they are provided with accurate, timely care, as well as safe and timely transitions in care. The program also ensures that patients' family physicians communicate with one another and remain informed about their patients.

Ms. Sarah Givens (RN) manages the Oncology Navigation Program and is the program's sole nurse navigator. She is responsible for helping patients and their families navigate through the health care system. Her current caseload is approximately 235 patients. There are 10 family physicians working within the NPFHT; approximately half send all of their patients to Ms. Givens while the other half send most. Primary care nurses work alongside the physicians and interact with patients who may need additional supports or specialized services.
Ms. Givens’ role is funded through the NPFHT as she is paid as a 1.0 FTE Registered Nurse. Additional resources required are minimal; they include access to an office space or exam room, a telephone and a computer.

**Evaluation**
A formal evaluation of the program is currently in progress. The NPFHT’s Quality Assurance Committee has established an evaluation framework that will measure the following outcomes: turnaround rates; screening rates; and time spent with patients. The team also receives informal feedback from physicians.

**Barriers and Facilitators**
A barrier to implementation was communicating the feasibility of the program to NPFHT members. The program’s simplicity and practicality, along with encouragement from a few key physicians within the team, convinced initially doubtful team members to support the program. An additional barrier was the fact that the creation of Ms. Givens’ role resulted in the reallocation of nursing resources.

**Lessons Learned**
The program team learned several important lessons during the development and implementation of the Oncology Navigation Program. One of these lessons was that when developing a program, the unique skills as well as the time limitations of the involved healthcare providers must be taken into account. Furthermore, knowledge of available resources and how to effectively utilize those resources, strong communication between healthcare providers, and the establishment of measurable outcomes are all critical to program success. In addition, the main focus of a patient-centred program should always be to fulfill the needs of the targeted patient group. The final lesson learned was that there is an overall important need for navigation in the healthcare system.

**Additional Notes**
The success of the Oncology Navigation Program has inspired both the Vascular Health Team and the North Huron Family Health Team to develop navigation programs for their patients. Both teams are using the NPFHT’s Oncology Navigation Program as a guiding example.

Note: This profile was not verified by the interviewees prior to Casebook publication.
20. Alberta Cancer Foundation Cancer Patient Navigation

**Interviewee and contact Information:** Linda Watson, Lead, Person-Centred Care Integration, Alberta Health Services ([Linda.Watson@albertahealthservices.ca](mailto:Linda.Watson@albertahealthservices.ca))

**Date of interview:** February 3, 2015

**Implementation level:** Provincial

**Implementation site:** Alberta, Canada

**Implementation date:** 2012

**Targeted stage of cancer care continuum:** All stages (nurse/patient navigation)

**Targeted cancer diagnosis:** Not specific

**Creation and development of materials:** N/A

**Delivery of initiative/program:** Specialists (i.e. registered nurses with oncology experience)

**Initiative/program users:** Patients

**Overview**

The Cancer Patient Navigation program was implemented provincially in 2012, through the support of the Alberta Cancer Foundation (ACF). The program is available to all cancer patients and all stages of care are targeted. The program is led by patient navigators (i.e. registered nurses) and focuses on access to relevant and timely information for decision support, improved access to supportive care services and the provision of care close to home.

**Rationale and Development**

The program is targeted towards cancer patients living in rural areas. The experience of these individuals is more complex than that of urban cancer patients due to their limited access to supportive care services and their ongoing need to travel in order to access cancer resources. There is also a need to provide more support for rural Albertan patients both before, and after, their treatment is complete.

The primary goal of Cancer Patient Navigation is to improve the cancer patient experience of Albertans living in rural areas.

**Description**

Cancer Patient Navigation program implementation involved a staged hiring of patient navigators in all of Alberta’s 15 Community Oncology sites, more specifically, 11 community cancer clinics and four regional cancer centres in small urban isolated communities.

Family physicians refer their patients to the program. The patient navigators who deliver the initiative are registered nurses, often with oncology experience. Their role is to connect with patients, explain treatment choices and test results, assist with physical, emotional and practical challenges and coordinate patient care. They also enhance access to supports and services by recognizing the needs of patients early on and making appropriate referrals. Overall, patient navigators seek to improve the patient experience by providing support and care coordination to both patients and their families. Through their collaboration with other health care services, they are able to improve the continuity and coordination of care with other health care professionals and improve overall system efficiencies.

A program coordinator is responsible for delivering an orientation to the patient navigators and discussing concerns, ongoing competency development, and provincially standardized elements of
the program with them. Local managers work with patient navigators to ensure that they have the proper resources, space, time and clinical integration in the communities in which they are situated.

Evaluation
The project team initially received two years of funding from the Alberta Cancer Foundation, lasting from April 2012 – March 2014. As part of the project, the team was required to complete an evaluation. Sources of evaluative data included surveys, focus groups, workload measures as well as utilization data.

The measured outcomes and key results were as follows:

- **Program implementation**
  *This measure was evaluated by the ability to establish navigator positions in each of the 15 community sites and to develop structures and implement strategies to ensure the success of the navigators. The program was successful in these areas and made significant achievement within only two years.*

- **Program impact on patient and family experience**
  *Patients agreed that navigators improved their experience through better continuity of care, better access to information, meaningful support and provision of person-centred care. They suggested that increased awareness and a simpler referral system would improve the program.*

- **Navigator role**
  *Navigators identified similar areas of impact as the patients. They felt that they enhance care continuity, improve access to information, and provide person-centred care. They believed that program supports facilitate their ability to be effective as navigators; however, important areas for program improvement included role clarity, increased program awareness and more mentorship.*

- **Teamwork and engagement**
  *Only baseline data have been collected and analyzed from patients, navigators, family physicians and other stakeholders. The following navigator outcomes were perceived to have a positive impact on patients and their families: provider well-being; supportive care; continuity of care; care coordination; and system effectiveness.*

- **Health system impact**
  *Establishing the return on investment for the program requires quantifying the impact that the navigator role has on health system utilization over time. Only baseline data were available at the time of the evaluation. These data will be compared to provincial utilization data once they become available.*

**Barriers and Facilitators**
There were several barriers to program implementation. A key barrier was the lack of both patient and family physician awareness about the program in targeted communities. Another barrier was the geographic dispersal of navigators, which limited the ability of the program coordinator to support navigators’ questions. Furthermore, there was no provincial standardization regarding how to deliver navigation orientation across the sites and at the beginning of implementation, there were no experienced navigators available to mentor the newly hired patient navigators.

A facilitator to implementation was the delivery of community stakeholder meetings to introduce and explain the navigator role. At these meetings, community agencies were asked to formally partner with the program to enhance patients’ access to resources. To address geographical barriers between navigators, web-based communication strategies were developed. These
strategies allowed navigators in different catchment areas to communicate and share information. Finally, experienced navigators have begun to train and mentor new patient navigators.

**Future Directions**
The program team plans to collaborate with the Alberta Medical Association and patient education teams to ensure that patients and physicians are aware of the program. They also plan to work on role optimization to identify which components of the role should be provincially standardized and which components can be locally contextualized. In relation to this, patient navigators will be cross-trained to ensure that they are able to work in various catchment/geographic areas. Additional time and resources will be allocated to learning the best methods of connecting with patients as early in their cancer journey as possible, and learning how to optimize the practice with the clinical staff at each implementation site.

Note: This profile was not verified by the interviewee prior to Casebook publication.
21. *Establishing Oncology Pivot Nurses in Québec*

**Contact information:** Charles Boily, Cancer Management Coordinator, Ministry of Health and Social Services, (Charles.Boily@msss.gouv.qc.ca)

**Interview form completed:** Early 2015

**Implementation level:** Provincial  
**Implementation site:** Québec, Canada  
**Implementation date:** 2004  
**Targeted stage of cancer care continuum:** All stages (nurse/patient navigation)  
**Targeted cancer diagnosis:** Not specific  
**Creation and development of materials:** Advisory committees (Committee of the Evolving Oncology Pivot Nurse, and the Consulting Committee of Oncology Nurses)  
**Delivery of initiative/program:** Oncology pivot nurses  
**Initiative/program users:** Patients and their families

**Overview**

In 2000, the Establishing Oncology Pivot Nurses (OPNs) in Québec program was first piloted by the Ministry of Health and Social Services (MHSS) in the Montérégie region of Québec. In 2004-2005, departmental funding was provided for the implementation of OPNs on a provincial scale. Nurses work as part of supra-regional, regional or local oncology teams. Regional-level OPNs tend to work within specialized teams that receive patients of a specific tumour site, while local OPNs work within all tumour sites. The majority of OPNs serve patients from the diagnostic stage of care through to survivorship; however, restricted resources in some regions of the province allow for OPN assistance only during the treatment stage.

**Rationale and Development**

Research evidence indicated that cancer patients require assistance when navigating the cancer system. Therefore, OPNs were established to assist patients and their relatives by acting as easily accessible and readily available navigators of care, as well as sources of information and support.

The Cancer Research Branch of Québec (CRBQ), of the MHSS, provided essential OPN training during the program implementation. The CRBQ also provided a portion of the required funding for the OPN positions; local institutions, such as hospital and community centres, provided the remainder of the funding.

The ultimate goal of the program was to ease the cancer experience of patients by supporting them and helping them navigate the health care system, and by ultimately improving the overall continuity and coordination of personalized care.

**Description**

Every oncology centre within the province of Québec has one or more OPNs, each of which are assigned to a certain number of patients, who are all at different stages of care. The majority of OPNs work within hospitals that offer oncology services. Although many local community centres do not offer specialized oncology services, OPNs are still able to provide services and care through these venues.

The primary duties of the OPNs are to:

- conduct a physical, psychological and social needs assessments on patients;
• educate and inform patients;
• coordinate patient care; and
• support patients and their families throughout their entire cancer journey.

OPNs first meet with patients to comprehensively assess their needs. They then develop individualized intervention plans for the patients and introduce them to cancer-related resources that will best address the identified needs. They also help patients connect with other cancer care specialists and update family physicians who inquire about their patients.

The daily management of the program is fairly decentralized. The CRBQ and the department heads of the OPN sites are responsible for supplying the nurses with resources. Counselors in specialized care organize OPN meetings at the local, regional and provincial levels, during which OPNs discuss their experiences, share opinions and exchange clinical tools. Counselors in specialized care also play an important role in training and providing clinical support for the OPNs.

Two advisory committees (i.e. the Committee of the Evolving Oncology Pivot Nurse and the Consulting Committee of Oncology Nurses) work together to: better define the OPN role; develop new online tools for training OPNs; develop new program tools; and refine ministry tools that are currently in use.

Financial resources are primarily required for OPN salaries, training and scheduling.

Evaluation
A formal evaluation of the program has not yet been conducted on a provincial level. Some program outcomes were evaluated through the dissemination of an “OPN and patient experience” survey, which aimed to distinguish if the assignment of an OPN is correlated with a better patient care experience. The report summarizing the results of the survey concluded that patients who were assigned an OPN were more likely to give an excellent evaluation of the quality care and services they received. The positive correlation between the assignment of an OPN and care experience is stronger for certain subgroups of patients, specifically those who identify as low-income and those who identify as immigrants. The survey results support the hypothesis that the implementation of OPNs within interdisciplinary healthcare teams can improve the overall cancer patient experience.

Barriers and Facilitators
Barriers to program implementation included healthcare professionals’ misunderstanding of the OPN role, the opinion of some that the introduction of the role would solve all existing problems within the cancer care system, lack of inter-professional collaboration and the lack of managerial support (in some cases).

On the other hand, there were also several facilitators, which encouraged or supported program implementation. Facilitators included implementation of the OPNs in all oncology centres in Québec by the MHSS, strong administrative support, the hiring of credible and experienced nurses as OPNs, the availability of initial and ongoing training for the OPNs and the development of tools and resources to aid OPNs in their daily work with patients.

Lessons Learned
In order for the implementation of a new OPN role, within an already established healthcare team, to be successful, the following is required:
• Proper preparation for a change in team dynamics
• Active supporters of program implementation
- Interprofessional collaboration
- Strong managerial and administrative support

Future Directions
The OPN program will stay in place as a permanent component of cancer care. As the program has been implemented in the whole province, its responsibility relies on the new integrated centers of health and social services created in each region on April 1st, 2015.

Additional Notes
Information about the program can be accessed online:


Related Publications

Dubé-Linteau, A., (2014) Enquête Québécoise sur la qualité des services de lutte contre le cancer 2013 : L’infirmière pivot en oncologie et l’expérience patient, Québec, Institut de la statistique du QuÉBEC, 60P.


Ministère de la santé et des services sociaux (MSSS), 2008, Rôle de l’infirmière pivot en oncologie, Comité consultatif des infirmières en oncologie, Québec, 16p.


22. **Community-Based Cancer Patient Navigation**

**Contact information:** Meg McCallum, Manager, Education and Patient Navigation, Cancer Care Nova Scotia ([meg.mccallum@ccns.nshealth.ca](mailto:meg.mccallum@ccns.nshealth.ca))

**Interview form completed:** October 2015

**Implementation level:** Provincial  
**Implementation site:** Nova Scotia, Canada  
**Implementation date:** 2002  
**Targeted stage of cancer care continuum:** All stages (nurse/patient navigation)  
**Targeted cancer diagnosis:** Not specific  
**Creation and development of materials:** Government organization (Cancer Care Nova Scotia)  
**Delivery of initiative/program:** Specialized oncology nurses  
**Initiative/program users:** Patients and their families

**Overview**
Community-Based Cancer Patient Navigation was first launched in 2002 by Cancer Care Nova Scotia (CCNS), in collaboration with three district health authorities. It has since expanded across the province. Navigators are available to patients with all forms of cancer, who are at any stage of care, as well as their families. They ensure accurate and timely diagnosis and treatment, coordinate patient care, help to manage symptoms, educate patients about their diagnoses and encourage patient self-care and management.

**Rationale and Development**
In 2000, CCNS conducted focus groups with cancer patients, survivors and their family members to identify the challenges Nova Scotians experience with the cancer care system. Several focus groups were specifically held in First Nations and African Nova Scotian communities. Interviews were also conducted with health professionals. The focus groups revealed major challenges for patients and their families including: limited information about diagnosis and treatment; lack of support for the emotional distress experienced during diagnosis and treatment; difficulties with transportation to the cancer centres; fragmented care; and the financial burden of cancer. The interviews also revealed that family physicians felt disconnected from the cancer system.

In an effort to address some of the challenges identified, in 2002, CCNS, in collaboration with three district health authorities (i.e. South West Health Authority, Pictou County Health Authority and Guysborough Antigonish Strait Health), led the development of the Community-Based Cancer Patient Navigation program. A 2004 evaluation of the program led to its subsequent expansion across the province. The goals of the program are to:
- Enhance coordination of care
- Reduce patient and family distress
- Enhance patient education
- Empower patients and their families

**Description**
Community-Based Cancer Patient navigators are specialized oncology nurses (Certified in Oncology Nursing) who are employed and managed by the Nova Scotia Health Authority. Nine navigators provide services to adult and pediatric cancer patients in all health zones in the province (with the exception of the Central Zone). Navigators are available to patients at regional hospitals and the Cape Breton Cancer Centre over the telephone, and they can also visit patients at their homes. The
navigators coordinate patient care, which often involves facilitating communication between oncologists and primary care providers. For example, if a patient is experiencing health concerns or problems with the health care system, the navigator works with the patient’s oncology team, physician/nurse practitioner and community-based services to resolve the issue(s). Conversely, the oncology team and family physicians/nurse practitioners readily engage the navigator to coordinate patient care. Navigators also provide patient education, physical and psychosocial symptom management (including patient assessments, interventions and referrals) and they provide or refer patients to practical supports and resources.

CCNS hosts a network for the navigators. The network is intended to ensure consistent practice, enable identification of cancer care system issues, allow for the sharing of innovative ideas and resources, and to provide navigators with continuing education opportunities. CCNS also financially supports the navigators’ participation in conferences and courses.

CCNS maintains the cancer patient navigation database. Cancer patient navigators manually record every encounter with a cancer patient/family member on a navigation log. The log includes patient identifiers, diagnoses, phase (i.e. pre-diagnosis, newly diagnosed, recurrence, living with cancer), referee position, issues identified (e.g. information, coordination of care, practical/financial needs, symptom management and system issue), any referrals made on behalf of the patient/family member and a space for charting other pertinent information. The logs are part of the patients’ health records and copies of these logs are mailed to CCNS on a monthly basis. The logs are entered into the database after the patient identifiers and diagnosis are verified by the Cancer Registry. This information allows CCNS to analyze navigation activity and to identify trends and systems issues.

The following resources are required for the program:

- Navigator salaries
- Office space and equipment
- Database infrastructure, and associated data entry and analysis capacity
- Manager, to support network development and maintenance

**Evaluation**

A formal evaluation of the program was completed in 2004. The complete evaluation report is available online at [http://www.cancercare.ns.ca/site-cc/media/cancercare/PtNavEvaluationSummaryReport(1).pdf](http://www.cancercare.ns.ca/site-cc/media/cancercare/PtNavEvaluationSummaryReport(1).pdf)

Evaluation results revealed that the program has aided patients and their families, by helping them to manage emotional distress and by acknowledging and addressing their information needs and logistical challenges associated with having cancer. The program has contributed to:

- More efficient use of clinical time for physicians
- More appropriate use of community-based health professionals’ time
- Addressing problems related to integration, coordination and continuity of cancer care

**Barriers and Facilitators**

The primary barriers to implementation were limited funding, lack of understanding of the Community-Based Cancer Patient Navigator role by other health professionals and lack of a single province wide electronic health record system (which would make coordination of care and navigation more efficient).
The key facilitator to program development was the expressed need of patients, families and health professionals for cancer navigation support.

**Lessons Learned**
Throughout program implementation, CCNS learned the importance of properly establishing the database and the data definitions, efficiently reporting navigation activity and systems issues to stakeholders, and broadly promoting the navigator role to the public and health professionals.

**Future Directions**
Currently, CCNS is exploring how various navigation functions can be shared by multiple disciplines to expand the program to serve residents of the Central Zone of the Nova Scotia Health Authority.

**Additional Notes**
More information about CCNS and Community-Based Cancer Patient Navigation is available at [www.cancercare.ns.ca](http://www.cancercare.ns.ca)

In addition to the community-based cancer patient navigators, there are four disease specific nursing roles within the Central Zone, which provide navigation for adult head and neck oncology patients, adult brain tumour patients and women having cancer related breast surgery. There are also eight nurses, within the tertiary pediatric hospital, who serve as navigators for pediatric cancer patients. These roles are *not* part of the community-based cancer patient navigation network coordinated by CCNS.

**Related Publications**


23. **Uniting Primary Care and Oncology**

**Interviewee and contact information:** Dr. Mark Kristjanson, Medical Lead of Primary Care, CancerCare Manitoba (mark.kristjanson@cancercare.mb.ca)

**Date of interview:** February 13, 2015

**Implementation level:** Provincial

**Implementation site:** Manitoba

**Implementation date:** 2006 (provincially implemented)

**Targeted stage of cancer care continuum:** Education for primary care clinicians, associated with the entire cancer care continuum

**Targeted cancer diagnosis:** Not specific

**Creation and development of materials:** Government organization (i.e. CancerCare Manitoba)

**Delivery of initiative/program:** Government organization (i.e. CancerCare Manitoba)

**Initiative/program users:** Specialists and primary care providers

**Overview**

Uniting Primary Care and Oncology (UPCON) was implemented on a provincial level in 2006 in the province of Manitoba. The program supports the shared care of cancer patients through collaboration with their network of primary care clinics. The UPCON Program provides support to family physicians through educational/training opportunities and events, provincial newsletters, a provincial cancer helpline, and the encouragement of collaboration between primary care and CancerCare Manitoba (CCMB). The program is funded by CCMB.

**Rationale and Development**

Prior to the implementation of UPCON, there was a need to improve the communication and collaboration between cancer care and primary care in Manitoba. This included improving the quality of referral information sent to CCMB by Primary Care and improving CCMB’s communication back to primary care, regarding patient status, treatment history and follow-up recommendations.

The UPCON program was officially launched in 2004. Led by Dr. Jeff Sisler and supported by funding from the federal Primary Health Care transition fund, UPCON began as a partnership between 12 family practice clinics/primary health care centres in Winnipeg. In 2006, CCMB supported a proposal to expand UPCON beyond initial city boundaries, becoming a provincial initiative.

The overarching goal of the provincial program is to improve the quality of care provided to Manitobans touched by cancer, by supporting their family physicians with programs and services that educate, build collaborative relationships and provide clinical support. In 2012, UPCON and the Community Cancer Program Network joined forces to become the Community Oncology Program at CCMB.

**Description**

Currently, there are over 50 primary care clinics in the UPCON network, located in all regions of the province.
UPCON provides primary care clinicians with cancer care education, familiarizes family physicians with the resources available at CCMB, and establishes personal connections between family physicians and oncologists.

UPCON's educational curricula are based on the identified educational needs of family physicians. CCMB develops educational programs and events for UPCON, and partners with the Community Oncology Program's Family Physicians in Oncology to maintain a strong role for them in the shared care of patients.

The resource and cost implications of the initiative are as follows:

- 1 full-time Program Manager
- 1 full-time Administrative Assistant
- 0.5 part-time Education Coordinator
- 2, 0.4 full-time equivalent family physicians (one focused on oncology, and the other focused on primary care)
- 1 full-time Transitions Manager

The UPCON annual budget is $35,000 - $40,000, the greatest portion of which is utilized for education and communication. Staff salaries are covered by CCMB.

**Evaluation**

A formal evaluation of UPCON has not yet been conducted. The UPCON team solicits feedback on an ongoing basis from clinicians who participate in UPCON educational events. Being Continuing Medical Education accredited, every educational program and event requires an evaluative component.

**Barriers and Facilitators**

There were no identified barriers to implementation. A facilitator to the uptake of UPCON is access to CCMB's electronic health record system. Also, UPCON's educational programs and events can be accessed by members of UPCON-affiliated clinics, free of charge, whereas clinics which are not affiliated with UPCON must pay a fee to be able to access some UPCON events.

**Lessons Learned**

The UPCON Program has created a platform for ongoing interaction between primary care and cancer care that has supported primary care cancer education and served as a focal point within the cancer agency for primary care engagement. One indirect indicator of this engagement is a recent survey of family physicians sponsored by the International Cancer Benchmarking Project, where the response rate by Manitoba family physicians was dramatically higher in Manitoba than in any other jurisdiction.

**Future Directions**

UPCON will continue to assist, as it has done since June 2011, in the planning and implementation of health care system changes effected through Manitoba's Cancer Patient Journey Initiative, also known as In Sixty. The In Sixty Initiative, funded by the provincial government, has a mandate to reduce the time from the emergence of the clinical suspicion of cancer to the start of treatment to within sixty days. UPCON provides representation to In Sixty on behalf of primary care clinicians and on behalf of Cancer Care Manitoba (UPCON's medical lead is the co-chair of In Sixty's Primary Care Working Group). UPCON also plays a key role in educating family physicians with respect to health care system changes effected through In Sixty and providing clinical support in this regard. UPCON will continue to develop continuing professional development programs and products.
relevant to In Sixty. An example is the series of Early Cancer Diagnosis modules, which are case-based interactive modules based on the diagnostic algorithms developed through In Sixty.

Additional Notes
A more detailed description of UPCON programs, events and newsletters can be accessed online: http://www.cancercare.mb.ca/home/health_care_professionals/information_for_health_care_professionals/upcon/
24. **British Columbia Family Practice Oncology Network**

**Contact information:** Karen Blain, co-Chair of the British Columbia Family Practice Oncology Network and British Columbia Cancer Agency’s Provincial Director of Survivorship and Primary Care ([Karen.Blain@bccancer.bc.ca](mailto:Karen.Blain@bccancer.bc.ca)); Jennifer Wolfe, Education Coordinator, British Columbia Cancer Agency’s Family Practice Oncology Network ([jennifer.wolfe@bccancer.bc.ca](mailto:jennifer.wolfe@bccancer.bc.ca)); and Dr. Phil White, Medical Director and co-Chair of the British Columbia Family Practice Oncology Network ([drwhitemd@shaw.ca](mailto:drwhitemd@shaw.ca))

**Interview form completed:** October 2015

**Implementation level:** Provincial  
**Implementation site:** British Columbia, Canada  
**Implementation date:** 2003  
**Targeted stage of cancer care continuum:** All stages (education)  
**Targeted cancer diagnosis:** Not specific  
**Creation and development of materials:** Government organization (i.e. British Columbia Cancer Agency), oncologists, general practitioners in oncology and family physicians  
**Delivery of initiative/program:** Government organization (i.e. British Columbia Cancer Agency)  
**Initiative/program users:** Family physicians, nurse practitioners and general practitioners in oncology

**Overview**
The British Columbia Family Practice Oncology Network (BC FPON) was formed in 2003 and is implemented on a provincial scale. The Network provides education and training to family physicians and nurse practitioners, enabling them to provide community-based cancer care (including accurate and timely diagnosis, management of cancer treatment and patient needs, as well as post-treatment surveillance and follow-up care) to patients across the province.

**Rationale and Development**
A need to enable family physicians to provide care for cancer patients and their families resulted from an increase in cancer incidence in BC. The provision of oncology training to select family physicians eliminates the need for many patients to travel to major cancer centres to receive their treatment. This consequently reduces oncologists’ workloads.

The development of BC FPON was led by Dr. Simon Sutcliffe, former BC Cancer Agency President, in partnership with the original BC FPON Council, which consisted of family physicians, oncologists and medical educators. The goals of the Network are to strengthen family physicians’ abilities to care for cancer patients in their home communities and to improve the continuity and transition of care between the BC Cancer Agency and community-based physicians.
Description
BC FPON’s daily operations are led by Dr. Phil White, family physician in Kelowna, who serves as the Medical Director of the Network. Dr. White co-chairs the program with Ms. Karen Blain, the BC Cancer Agency’s Provincial Director of Survivorship and Primary Care. The BC FPON works with family physicians in their communities as well as both community-based and cancer centre-based General Practitioners in Oncology (GPOs). These primary care providers are often involved in the production of resources, and many individuals also serve on working groups that focus on different areas of cancer care.

The Network has implemented three strategies to support family physicians in their provision of cancer care, and to facilitate effective relationships and improved coordination of care.

1. **Continuing Medical Education (CME) and skill enhancement for family physicians**
The GPO Training Program is an 8-week program that was created to develop and support the oncology skills of rural family physicians. Through the training program, family physicians learn how to administer and supervise chemotherapy treatments, resulting in improved access to cancer care for patients living in rural communities. In addition to the GPO Training Program, Oncology CME Webcasts allow family physicians to learn from and engage with BC Cancer Agency oncologists. Furthermore, community workshops on breast, colorectal, prostate and advanced cancers are also available. Family physicians attend these workshops, which are facilitated by GPOs. Oncologists participate in the development of the workshop materials as well as in the post-workshop follow-up sessions. Finally, during an annual Family Practice Oncology CME Day held in Vancouver, oncologists present and provide workshops on the most current topics of cancer care. They also network with family physicians that are situated all across the province.

2. **Adaptation of cancer care guidelines, for use in the primary care setting**
Family physicians, oncologists and subject experts have collaborated to produce and publish customized guidelines on breast, colorectal and female genital tract cancers, as well as palliative care. All guidelines are comprehensive; they include flow charts and patient information sheets, and are available for download through www.bcguidelines.ca. Guidelines on upper gastrointestinal cancers will soon be published and work on HPV-related head and neck cancers, as well as prostate cancer, will begin in the near future.

3. **Journal of Family Practice Oncology**
Twice a year, the initiative produces the Journal of Family Practice Oncology. The Journal intends to establish a sense of cancer care community at the primary care level by featuring “practice-ready” information from oncologists and other subject experts.

The BC FPON budget is approximately $300,000, with additional funds from pharmaceutical sponsorships and education revenue which support expert consultation and program delivery. Total staffing for the program includes 2.83 Full Time Equivalents (i.e. 1.0 Education Coordinator, 0.5 Program Assistant, 0.1 Medical Lead, 0.9 Program Leader, and a 0.33 sessional position for medical leadership).
**Evaluation**

GPO Training graduates were surveyed in 2010 regarding their role in the community, their views on the effectiveness of the program and ways in which the training could be improved. All GPOs demonstrated strong support for the program. They expressed a need for ongoing CME as well as opportunities to maintain competency.

**Barriers and Facilitators**

The complex health care system in BC presents some challenges for FPON. As oncology is one of many conditions of focus for primary care providers, it is difficult to engage primary care providers before they've encountered a specific cancer-care case. Limited funding and staff resources are additional challenges. Addressing all of these issues has become a priority for the BC Cancer Agency.

FPON’s activities are facilitated by strong engagement of both specialists and primary care providers. Oncologists, GPOs and medical residents regularly contribute their time to teach in the GPO training program, lead oncology-focused webcasts and write articles for the Journal of Family Practice Oncology. Primary care providers who have an established relationship with FPON help to share oncology information with their colleagues in family practice. FPON’s work is also facilitated by a partnership with the University of British Columbia’s Faculty of Medicine Division of Continuing Professional Development (UBC CPD). UBC CPD organizes and delivers the Community Oncology workshops across BC and manages registration for FPON’s monthly webcasts. Lastly, maintaining a partnership with the BC Guidelines and Protocols Advisory Committee, a joint committee of Doctors of BC and the BC Ministry of Health, has been an essential component of FPON’s work in adapting and disseminating oncology clinical practice guidelines for the primary care setting.

**Lessons Learned**

The BC Cancer Agency learned to place an emphasis on program planning, and to ensure that the planning is headed by a strong succession-oriented team.

**Future Directions**

In order to meet the diverse and complex needs of cancer survivors and to support the health system in ensuring equitable high quality care, a comprehensive and sustainable strategy that leverages ‘top of license’ practice and optimizes existing resources is required. This will require a dramatic shift in both culture and current practice for both specialty and primary care.

The Network will continue to align its efforts as part of the BC Cancer Agency's Survivorship and Primary Care Program, including playing a key role in efforts to enhance oncologist/primary care communications with regard to effective patient transition. In addition, with the BC Ministry of Health strategy to facilitate effective shared care of patients, the Survivorship and Primary Care Program will lead the engagement of oncology and primary care providers in developing a primary care action plan to support quality care of cancer patients throughout the cancer care continuum.
There will also be an emphasis placed on sharing knowledge of the Network’s impact on a broader scale, both throughout Canada and internationally.

**Additional Notes**
Cancer Care Guidelines, Oncology CME Webcast recordings and the Journal of Family Practice Oncology can be accessed online via [www.fp.on.ca](http://www.fp.on.ca).