

FAMILY PRACTICE ONCOLOGY NETWORK PRIMARY CARE NEEDS ASSESSMENT



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EXECUTIVE SUMMARY

Submitted by:

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INTRODUCTION

British Columbia (BC) has a population of 4.62 million people; over 200,000 of whom have been diagnosed with cancer at some point in their lifetime¹. The prevalence of cancer in BC is growing by approximately 3% per year and the survival rate for all cancers continues to increase. Approximately 65% of adults and 80% of children diagnosed with cancer are now expected to live at least five years post-diagnosis¹. With this marked improvement in survival, there is a need to leverage the expertise of primary care providers in the province to ensure the increasing need for cancer care in BC is met. As we build a better understanding of the diverse and sometimes complex needs of patients after a cancer diagnosis, it is clear that to achieve sustainability and support primary care providers, a more robust primary care program at BC Cancer is needed.

To respond to the increasing demand on the cancer care system, BC Cancer is expanding the Family Practice Oncology Network (FPON) to become the Provincial Primary Care Program. Through this work, BC Cancer aims to strengthen relationships with primary care providers across BC, expand its successful educational offerings, and provide ongoing support and resources to primary care providers caring for patients with cancer, all to build capacity for cancer care within primary care. To support this expansion, FPON, in partnership with the University of British Columbia, Faculty of Medicine's Division of Continuing Professional Development (UBC CPD), conducted a province-wide primary care oncology needs assessment. The project was implemented in 2017, led by an inter-professional Working Group and completed in the summer of 2018

Key Objectives

FPON engaged UBC CPD to conduct a province wide needs assessment to:

- Understand the current and ongoing unmet needs of family physicians (FPs) providing care for patients throughout the continuum of cancer care; and
- Establish a sustainable mechanism through which the BC Cancer Provincial Primary Care Program
 can engage FPs throughout the province in ongoing, two-way communication to improve their
 ability to meet their needs and advocate on their behalf.

METHODS

The FPON Primary Care Needs Assessment was implemented in three phases. The first phase consisted of nine key informant interviews with subject matter experts from across the continuum of cancer care. The second phase consisted of a comprehensive online survey disseminated to approximately 5000 FPs and other PCPs across BC. The final phase consisted of focus groups with new to practice FPs, rural FPs, urban FPs and oncologists. Detailed descriptions of each phase are included below.



Each phase of the needs assessment was designed to collect important information pertaining to the core issues surrounding the current and future landscape of cancer care and the role that the FPs and other PCPs can play in supporting their patients living with cancer. The key informant interviews, survey and focus group protocols were designed to capture different perspectives and to learn more about respondents' experiences with, and recommendations related to, clinical knowledge and comfort, current processes and procedures, roles and responsibilities, and education needs for FPs and other PCPs in BC.

RECRUITMENT

Key informants were identified through the professional networks of Working Group members and are subject matter experts in primary care or stakeholders from affiliated or partner organizations. Nine interviews were conducted with one rural FP, two urban FPs, one general practitioner in oncology (GPO), one oncologist, three physician administrators at BC Cancer and one faculty member of UBC Department of Family Medicine.

Following the key informant interviews, a 15-minute online survey was developed for FPs and nurse practitioners (NPs) in BC as well as general practitioners in oncology (GPOs) and oncologists. The survey was distributed online via various marketing channels.

Focus group participants were recruited through the online survey from respondents who expressed interest in participating further, provided their contact information and self-reported their practice demographic information (nine new-to-practice, four rural FP, nine urban FP, seven oncologists).

DATA COLLECTION

The key informant interview protocols were designed by iterative development to capture different perspectives on a number of oncology-related topics. Questions explored key areas including FP knowledge along the continuum of cancer care, BC Cancer's role in supporting FPs, and how the Provincial Primary Care Program should operate. All key informant interviews were conducted via teleconference to minimize barriers to participation. A total of nine, 30-minute key informant interviews were conducted.

The online survey was designed by the Working Group over a four-month period (October 2017 to January 2018) through iterative development and received external review by subject matter experts and external stakeholders.

A total of 866 responses were collected (757 complete and 109 partial) after removing responses from ineligible respondents (i.e. non-PCP respondents or blank responses) resulting in a response rate of 18% (with 4852 considered to be the denominator).

Focus groups protocols were designed to address gaps in the preliminary results from the key informant interviews and online survey. Protocols used a semi-structured framework which allowed feedback on the sequence of questions. Questions further explored the FP role in cancer care, how the Provincial Primary Care Program could support FPs, and key challenges to managing patients with cancer. Participants were





sent the protocols ahead of time. Focus groups were 90-minutes in duration conducted via WebEx and were moderated by the BC Cancer Provincial Primary Care Program Lead.

DATA ANALYSIS

Key informant interviews were audio recorded and transcribed. Data were tabulated, summarized, and analyzed for patterns or emergent themes. Qualitative survey data was analyzed on data collected from open-ended survey questions to identify key themes and further inform the quantitative data collected in each phase. Data summaries were reviewed by the Working Group for agreement and interpretation accuracy.

Further integrative analysis was performed for the purposes of report compilation and preparing recommendations. Similar thematic areas from the quantitative and qualitative analyses were grouped and reviewed holistically by the project team to draw out consistent themes and outcomes.

NEEDS ASSESSMENT FINDINGS

Roles and Responsibilities

Family physicians throughout the needs assessment saw their role as the main point of contact for their patients throughout their cancer journey as well as the main source of psychosocial support. This reflects the lifelong relationships that FPs build with their patients and the broad scope of family medicine practice.

Cancer screening and timely referrals to BC Cancer were highlighted as key parts of the FP role in cancer care along with co-morbidity management and ongoing monitoring and surveillance after treatment.

Findings revealed that FPs value two-way communication with the cancer care team and think it is important to be involved in treatment decisions. They value being informed of potential side-effects and necessary follow-up care both during cancer treatment and after cancer treatment has been completed. Family physicians noted that the more information they are given, the better they can support their patients to navigate the cancer care system successfully.

Clinical Knowledge and Care Delivery

The current state of FP cancer care knowledge is highly variable and related to a number of factors including the individual provider, the complexity of the patient and the point along the cancer care continuum. Findings supported the perception that cancer screening and referral are key parts of the FP role, with most respondents agreeing that FP knowledge is strongest in the early stages of the cancer journey, particularly for common cancers.

Knowledge gaps exist when patients are transitioning into active treatment and instructions received from specialist physicians are unclear regarding post-diagnosis work-up and next steps. This was confirmed by FPs as a point of stress when caring for their patients with cancer. Further gaps were identified around





follow-up after treatment, particularly with less common cancers and those without clear primary care guidelines. Only 50% of survey respondents agreed that they were confident managing post-treatment cancer follow-up and late-effects.

Shared care was identified as important and key for the sustainability of high quality patient care. Conversations around shared care were often focused on the importance of communication between members of the care team both around roles and responsibilities and regarding access to and sharing of patient information electronically through an electronic health record (EHR).

Challenges related to care delivery included geographic isolation or remoteness, small or limited care teams, limited resources, lack of time, patient characteristics (such as income status, frailty, and mental health), and treatment delays or long wait times.

Communication

The primary method of communication from BC Cancer identified by needs assessment respondents was the discharge letter or summary. Opinions varied regarding the effectiveness of this channel, with some finding the letters very useful and others citing their lack of detail as a challenge. This likely reflects individual provider and community differences.

Respondents indicated that immediately post-diagnosis, communication and knowing what they should do next can be difficult. Respondents agreed that specialists were easily accessible by phone if the appropriate contact information was available, but that finding the correct contact information often posed challenges. Respondents offered a number of suggestions and ideas for improving communication including:

- Access to the patient care pathway;
- Knowing the patient's appointments schedule;
- Clear information on who to contact during the day and after hours;
- Direct lines to their patients' oncology team; and
- Specific contacts for specific questions/issues

Education Needs and Barriers

Respondents made multiple references to complexity of cancer care and treatment. They indicated that there are many gaps in knowledge and barriers to learning. The two main barriers are the rapidly changing, complex field of oncology and a lack of access to high quality resources. The two main gaps in knowledge identified are advising on treatment options and treating side-effects or co-morbidities. Patients come to their FPs for advice on treatment options as well as when dealing with side-effects or other illnesses. Family physicians often do not feel equipped to provide advice on treatment options.

Respondents felt that BC Cancer should take a leadership role in establishing primary care guidelines as well as pioneering the implementation of novel strategies to maximize the effective use of practice data for practice improvement/quality improvement (PI/QI) purposes.





Other identified education needs of FPs included:

- Awareness of the education and resources are currently available to them;
- New education opportunities and resources on cancer treatments, new and emerging cancer care
 technologies, distinguishing cancer-related symptoms from treatment side-effects, and treating
 other general illnesses for patients with cancer;
- Communication support including physician-patient communication and community physician-BC Cancer communication; and
- Quality assurance of clinical skills

Another identified gap was a lack of resources for holistic care and allied health services. Mental health care and social workers were commonly mentioned as needed resources, and respondents did not always know how to find or connect patients with available resources.

Respondents highlighted that education needs to be flexible and dynamic to accommodate busy schedules and learning styles. The top three most preferred identified learning formats were in-person conferences, self-paced online modules and small group learning.

Provincial Primary Care Program

A wide range of issues and suggestions came from respondents with regards to role of the Provincial Primary Care Program. Discussions of stakeholders ranged from differences between urban and rural physicians and their practices, to raising the awareness of the program within the Ministry of Health, to advocating for compensation changes to better support specialist physicians and FPs who provide cancer treatment. The Divisions of Family Practice, the BC College of Family Physicians, the Doctors of BC, Health Authorities and UBC CPD were identified as key organizations to partner and collaborate with for the expansion of the Provincial Primary Care Program. Respondents thought that communication with FPs should be prioritized by BC Cancer both at the individual FP level as well as the FP community as a whole.

In terms of education and resources that the Provincial Primary Care Program should develop, respondents identified quick access to information and advice, rather than developing deeper knowledge of cancer care subjects as important. This supports the shift away from tumour focused education and indicates a shift to care pathway focused education. Family physicians want to know the best online sources used and recommended by oncologists. They also want information on alternative treatments for when patients ask questions or are undergoing these treatments.



KEY RECOMMENDATIONS SUMMARY

The three top priorities for the new Provincial Primary Care Program at BC Cancer, as identified by survey respondents, are:

- Advocate for improved access to appropriate clinical resources/services for patients (e.g. shorter wait times).
- Develop practice tools for supporting care for patients with cancer (e.g. treatment algorithms/pathways).
- Provide education and training for physicians.

Based on the needs analysis, there are four main areas in which to develop strategies for the Provincial Primary Care Program.

Given the scope of the recommendations, and the size of the team, it will be important to prioritize within and among the four categories of recommendations. For the strategies that are ultimately selected, setting up development and implementation patterns can assist in allocating workload and managing expectations. For instance, for a series of information resources or educational programs, establish topic/content-area priorities, then develop one resource or program at a time, establishing a consistent release schedule with the highest impact projects completed first.

1. INFORMATION RESOURCES

The needs assessment indicates that respondents have a strong preference for "just in time" resources. Guidelines for the most common cancers were well received and there were many suggestions for additional guidelines, tips, checklists, etc.

- 1.1 Continue to develop tumour-group guidelines and update existing guidelines as needed. Both the Cancer Care Outreach Program on Education (CCOPE) final report and the FPON needs assessment identified the tumour-group guidelines as a key resource and priority for ongoing development.
 - 1.1.1 Use the needs assessment results to prioritize the order for development of the remaining guidelines: blood/lymphoid, lung, and skin.
 - 1.1.2 Set a pattern for the development timeline (i.e. one new tumour-group per year) to both use Provincial Primary Care Program human resources effectively and to manage expectations.
- 1.2 Create infographics, checklists or guidelines for commonly requested areas of knowledge, such as:
 - 1.2.1 Resources for emergency room physicians regarding how treatments protocols are adjusted or differ for patients with cancer.
 - 1.2.2 Brief explanations of treatment options for physicians to use with patients.
 - 1.2.3 Tips for differentiating side-effects from symptoms.
 - 1.2.4 Overview of how to treat cancer patients with common illnesses or comorbidities.



- 1.2.5 Prioritize resource development by level of impact on patient care (either due to the critical nature of the information or the number of patients it will impact).
- 1.3 Expand the most effective existing information tools to include cancer care:
 - 1.3.1 Add oncologists to Pathways.
 - 1.3.2 Add oncologists to the specialists that are available via RACE line.
 - 1.3.3 Add BC Cancer to the EHR systems.
- 1.4 Bring the BC Cancer website up to a standard ensuring that FPs and cancer patients will not need to look beyond it for information.
 - 1.4.1 Improve user interface design.
 - 1.4.2 Add patient and professional portals.
 - 1.4.3 Improve content quality and implement a schedule for review and update.
 - 1.4.4 Create a searchable database of support contacts (from social workers, to mental health clinicians, to transportation support).
 - 1.4.5 Consider an app design for the BC Cancer website.
- 1.5 Explore ways to push updates to existing guidelines and other information resources to FPs. Use existing technologies and communication channels.

2. EDUCATIONAL PROGRAMMING

Emphasize practical application and care delivery over theoretical knowledge in all education programming. Prioritize topics that will impact the most patients and/or FPs. Vary delivery methods. Track all results to inform program planning annually.

- 2.1 Create new programming to meet the highest identified needs along the cancer care continuum, particularly at transition points. The needs assessment found that FPs have variable levels of knowledge along the cancer care continuum, find the transition points particularly problematic and stressful, and find it difficult to keep up with changing technologies, treatments and guidelines. The top four priorities for new educational programming should be:
 - 2.1.1 Post-acute treatment and long-term follow-up.
 - 2.1.2 Managing initial work-up and making a diagnosis.
 - 2.1.3 Cancer prevention.
 - 2.1.4 Managing pain during active treatment.
- 2.2 Coordinate release of new guidelines and other information resources with more in-depth education opportunities. For instance:
 - 2.2.1 Release an information resource and offer a webinar for review and discussion.
 - 2.2.2 Pair an information resource with a 5-10 minute presentation for Division of Family Practice members.





- 2.3 Transition in-person workshops to self-paced online modules after two years.
 - 2.3.1 Though more respondents identified a preference for in-person learning over online self-paced modules or webinars, attendance at workshops over the four-year CCOPE program was around 800 participants from a potential 5000-6000 FPs. A participation rate of under 20% leaves room for the learning resources to reach a much larger audience. In a two-year period, especially if that time limit is known/advertised, those who prefer in-person learning will have sufficient time to participate. The time limit may actually increase participation rates among those with this learning preference.
 - 2.3.2 The existing four tumour-group workshops could be transitioned in order of either age or popularity. As new workshops are developed (tumour-groups or other topics), plan to offer them throughout the province for about two years prior to transitioning them to self-paced online modules. To retain some of the facilitator-led and peer-to-peer aspects of workshop learning, the follow-up component could be done as a webinar, with the option to attend live for questions and discussion or view later as a recording.
 - 2.3.3 This strategy will address the learning preferences of a larger audience and also allow for the initial round of development and engagement to benefit from the more immediate feedback and iteration possible with in-person teaching and learning.
- 2.4 Review the CCOPE workshop participation data and analyse for month and location participation rates.
 - 2.4.1 Determine highest participation months and cluster workshops in those months. This strategy will enable marketing to focus on normalizing certain months or dates, so they become part of the expected rhythm of the year, enabling participants to plan ahead, partially addressing the primary barriers identified and potentially increasing attendance.
 - 2.4.2 Set a location pattern for the workshops that encourages regional participation and does not split enrolment between locations. For instance, rather than offer a workshop in Port Alberni one day and Parksville the next, offer at one location in spring and one in fall. This still gives the choice of attending in your home location or the option of attending earlier in the same region. Track participation rates and refine locations over time.
- 2.5 Target education and resources at the transition points (such as diagnosis to treatment and graduation to follow-up) and to specific roles (emergency room physicians, nurse navigators, locums).
 - 2.5.1 Create learning resources and education opportunities that equip FPs to better support patients at these points, thus reducing their own stress as well.
 - 2.5.2 Create quick reference information resources for emergency room physicians on identified issues such as protocol variations for cancer patients being treated for other illnesses or conditions.
 - 2.5.3 Develop training to prepare nurses for the navigator role.
 - 2.5.4 Develop soft skills education for locums giving diagnoses to patients they have just met, along with tips for connecting these patients to supports.



- 2.6 Track program metrics by delivery method (workshop, conference, webinar, self-paced online module) and use the data to inform annual programming decisions. For instance:
 - 2.6.1 Total number of each program offered, number run, number cancelled, cancellation rate (i.e. 20 workshops offered, 15 run, 5 cancelled, 25% cancellation rate).
 - 2.6.2 Average participation rates per program (i.e. 20 webinars offered, 400 participants in total, average participation per webinar = 20).
- 2.7 Track program metrics by topic, such as:
 - 2.7.1 Within the webinar program, track participation by live attendance and recording viewed for every topic. Determine which webinar topics are no longer needed (low attendance and viewings), which topics do not need to be done live (much higher viewing, with correspondingly high satisfaction rates), and which topics need to be live (higher attendance, lower satisfaction when recording viewed).
 - 2.7.2 Watch for workshop attendance to drop off by tracking cancellation rates and average participants per course. Discontinue or transition those topics to a webinar format.
- 2.8 As part of the development process and when updating any course or program, address non-technical aspects of cancer care:
 - 2.8.1 Review the language and cultural indicators to ensure that cancer is identified as a chronic disease.
 - 2.8.2 Identify and provide guidance for dealing with social barriers.
- 2.9 As conferences are more popular than workshops, awareness of CME Day is higher than workshops, respondents would like more education near them, and it is difficult for physicians to set aside time for frequent educational programming: make CME Day a regional event, replacing some of the current workshop opportunities with a full-day program on a standard annual schedule.
 - 2.9.1 Prioritize the following education formats: in-person conferences, followed by self-paced online modules, followed by small group learning.

3. COMMUNICATION PRACTICES

The needs assessment identified areas where communication practices and channels can be improved to facilitate better care delivery and reduce stress for FPs and oncologists. Communication can also provide a channel for physicians to give input to BC Cancer and the Provincial Primary Care Program, as well as for raising awareness of programs and resources.

- 3.1 Reduce the number of communication channels/tools and the number of steps to get to advice or information.
 - 3.1.1 Identify the most accessible and effective communication types and develop strategies to use them, limiting duplications.
 - 3.1.2 Electronic medical record utilization is 91%.



- 3.1.3 Email and websites are still the most preferred methods of communication for both clinical and non-clinical communications.
- 3.1.4 Ensure that clear and accurate contact information is included with every communication or documentation.
- 3.1.5 Discontinue and replace or reroute dated communication techniques such as letters and faxes.
- 3.1.6 Modify the discharge letter to address feedback regarding its limitations, creating a template and conducting training as needed.
- 3.2 Focus on two types of communication:
 - 3.2.1 Urgent: real-time consults such as secure text messaging, direct phone.
 - 3.2.2 Non-urgent: asynchronous such as email or electronic medical record.
- 3.3 BC Cancer should prioritize communication with FPs:
 - 3.3.1 Accessibility to individual FPs.
 - 3.3.2 Communicating to the broader FP community.
- 3.4 Host a monthly poll on the BC Cancer website, particularly if/when a professional portal is added, to do straw votes on topics for information resources and education programs. Ask questions such as:
 - 3.4.1 What are the most common questions you get from patients that you are not certain how to answer?
 - 3.4.2 What are your top three CME needs this year?
 - 3.4.3 What is the best resource you have found in the past month?
- 3.5 Use existing and preferred communication channels to increase awareness of FPON/Provincial Primary Care Program programs (email, websites, and Divisions of Family Practice meetings).

4. RELATIONSHIP BUILDING

It is important that relationship building be undertaken not as an additional drain on time or increase in complexity of communication, but to make real improvements in care delivery with reduction of stress for health care providers.

- 4.1 Use Quality Improvement projects as a key method for relationship building among FPs, specialist physicians, nurses, and allied health professionals.
 - 4.1.1 Identify areas where improvements in care delivery are needed and bring together volunteer teams to create and test guidelines and strategies.
 - 4.1.2 Ensure teams are representative of all groups that would be involved in implementation, which may vary project by project.
 - 4.1.3 Provide teams with the best available practice data.
 - 4.1.4 Gives a practical and immediate focus to building relationships with visible achievements.





- 4.2 Further develop shared care and inter-professional team approaches.
 - 4.2.1 Include FPs in inter-professional teams, even if virtually or asynchronously.
 - 4.2.2 Develop one team member, likely a nurse, to take on the Navigator role, with additional duties, training and time allocated to providing navigation services to patients and FPs.
 - 4.2.3 Have one point of contact for patients and for primary care providers, with that contact reaching out to other resources as needed.
- 4.3 Use existing methodologies, procedures, and technologies from other specialties.
 - 4.3.1 Learn from how other specialists interact with FPs and adapt what works well.
 - 4.3.2 Adapt specific processes such as the gastrointestinal first access referral sheets.
 - 4.3.3 Use the electronic medical record system to expand shared care for cancer patients, by connecting BC Cancer to other systems and by normalizing use for team communications.
- 4.4 Partner with key stakeholders and organizations to ensure alignment of priorities and to maximize communication channels.
 - 4.4.1 Involve the Divisions of Family Practice, the BC College of Family Physicians, Doctors of BC and UBC CPD in the expansion of the Provincial Primary Care Program.