SUPPORTIVE CARE FRAMEWORK REPORT

2016

CancerControl Alberta



Evidence based Optimized Quality of Life Person centered Social Integrated approach Practical Physical Informational Physical Spans the continuum of care

Message from the Council Co-Chairs

The need for a guiding document for CancerControl Alberta (CCA) Supportive Care was identified during the inaugural meeting of the Supportive Care Council in the spring of 2013. The idea for a comprehensive evidence-based document formed as the Council was tasked to advise CancerControl Alberta's Executive Leadership Committee (CCELC) on moving *Alberta's Cancer Plan* forward, prioritizing new initiatives and defining what constitutes core supportive care services. By the fall of 2014, it was abundantly clear that foundational work needed to be done to guide and direct the future growth and development of Supportive Care and a mandate to create the Supportive Care Framework, was received. Over the course of 18 months, a tremendous amount of work, engagement and collaboration was undertaken. It would not have been possible without the vision, passion and commitment of the core working group: Debora Allatt, Vivian Collacutt, Donna Rose, and Janice Yurick.

We would like to thank and recognize the many people from within CancerControl Alberta and those elsewhere in AHS, and externally, who contributed to this project. Without the tremendous support of Sarah Singh from AHS Knowledge Management Practice Support, this work would not have been possible. Jennifer Dotchin and her team from AHS Engagement and Patient Experience were instrumental in orchestrating and compiling much of the patient and clinician engagement work. A special thanks to Provincial Cancer Patient Education Specialists, Keira MacKinnon and Elysa Meek for editing and formatting. We would also like to thank the many managers, clinicians and community agency representatives that served as content experts on numerous working groups. It was a great joy to work collaboratively with you. Your knowledge and commitment to your profession and cancer care have greatly enriched this work. The collective spirit to "get it right" was inspiring.

We would like to acknowledge the tremendous contribution of the Supportive Care Council in the development of this framework. You recommended, criticized and affirmed every step of the way. Thank you for being the critical eye that served to make this framework strong. We are also grateful for the sage guidance of our Executive Sponsor, Brenda Hubley.

Finally, we would like to offer our sincere appreciation to the Albertan cancer patients and families that we serve. We value your partnership in this foundational work. You are the reason why this is important. We heard you and we hope we have accurately reflected your voices in this document. It is for you that we offer the Supportive Care Framework as a guide to ongoing development of supportive care services within CancerControl Alberta.

Sincerely,

Janice Yurick and Debora Allatt Supportive Care Council Co-Chairs

Executive Summary

Supportive Care describes all the health care services cancer patients and their families need beyond anticancer medical, surgical, and radiation interventions. It is defined as the provision of the necessary services for those living with or affected by cancer to meet all of their needs (physical, emotional, social, psychological, cultural, informational, spiritual and practical). (M. I. Fitch, 2008).

Changing our Future: Alberta's Cancer Plan to 2030 (Alberta Health, February 2013) outlines a strategy that acknowledges the role of the health care system in addressing the aforementioned supportive care needs of patients, families and caregivers. The strategy recognizes the importance of providing this care early and throughout the entire cancer trajectory. Meeting these needs is a responsibility of the health care system in collaboration, where appropriate, with community and volunteer organizations.

CancerControl Alberta's responsibility and role is as a primary provider, consultant, researcher and collaborator in the provision of supportive care services.

CancerControl Alberta's Supportive Care Council is tasked with providing advisement on the planning and development of comprehensive and integrated Supportive Care standards, programs, and services. It is the Council's vision to build – in partnership with patients, families and other stakeholders – a system with world-class, multidisciplinary, patient-focused supportive care services integrated provincially throughout the cancer journey for all Albertans with cancer. As an initial step, the Council has undertaken the creation of CancerControl Alberta's Supportive Care Framework to serve as a guiding and foundational document for the provision of supportive care for Alberta cancer patients. It identifies the functions and components of comprehensive cancer-related supportive care.

This report was developed using a foundation of guiding principles, an adapted model of care and application of rigorous methodology, as outlined below.

Principles

The following principles have been applied throughout the development of the Supportive Care Framework:

- ✓ Care will be person-centered.
- ✓ Care will be evidence-informed.
- ✓ Access to Supportive Care will be enhanced.
- ✓ Care will respect diversity.
- ✓ Care will be integrated and interdisciplinary.
- ✓ Care will be provided through collaborative practice with other providers, primary care providers, and community providers.
- ✓ Clinical research and knowledge development will be fostered in Supportive Care disciplines and programs.
- ✓ Supportive Care disciplines at the tertiary level in oncology have specialized expertise.

Models of Care

This framework identifies two key models of care by which equitable and coordinated access to Supportive Care services may be achieved and sustained. The tiered model of Supportive Care, developed by Margaret Fitch describes a way of identifying patient and family services and correlating different levels of need to the level of health care expertise required (M. I. Fitch, 2008). The strength of this approach lies in improving system capacity.

The Hub and Spoke model of care delivery (Demaerschalk et al., 2009) would allow CCA to intentionally plan the full scope of services in any discipline or specialty program that will be available at its tertiary, regional and community sites. The highest level of expertise along with the largest range of services would be in "hubs" located at the tertiary sites. As expertise grows within regional centres, they too, would also serve as "hubs" for surrounding communities. Care provided and supported within smaller community cancer centres and other community facilities represents the "spokes." Careful attention to the education and empowerment of the "spokes" is vital. The Hub and Spoke approach can improve access bringing comprehensive cancer care closer to home in a way that supports both patients and health care providers.

Methodology

The Supportive Care Framework was developed by using rigorous and objective evidence-based methodology and extensive stakeholder engagement and consultation. The framework was informed in equal part by scholarly evidence (research-based), clinical expertise, and patient values, needs and preferences. The review of literature used standardized methodology seeking the highest level of evidence available in the areas of supportive care research to inform the understanding as to where the greatest and best effects from supportive care may be realized. Honoring the wisdom of practice that experience and expertise yields, widespread consultations with local, national and international health, cancer and cancer supportive care experts were conducted. Within the province, 75 clinicians, physicians and administrators, representing 27 different clinical areas, completed a survey.

To understand current state, a rapid environmental scan was conducted by AHS Engagement and Patient Experience, looking at cancer programs throughout Canada as well as selected programs in the USA, UK, and New Zealand. This was followed by 24 Canadian and 14 international key informant interviews with recognized experts. Consultations were also held with the CCA Radiation Medicine and Systemic Therapy Councils, AHS Primary Health Care, Cancer Strategic Clinical Network, AHS Community and Clinical Engagement.

Extensive patient engagement was undertaken to broaden the understanding of their needs, preferences and experiences. This included: surveying patients and families from around the province and engaging in focused discussions with patient groups, including the Calgary Patient and Family Advisory Council, Supportive Care Council patient advisors, and Provincial Patient Education Committee advisors. Additional information was incorporated utilizing the results of the Joint ACF/CCA Patient Partner Day and the Ambulatory Oncology Patient Satisfaction Survey from 2014. Stakeholder meetings with community agencies included representatives from Canadian Cancer Society, Wellspring Edmonton, and Wellspring Calgary. Seven discipline-specific working groups, whose selection was based on common practice provincially, nationally, and internationally, were organized to synthesize the collection of evidence and formulate recommendations. Each group worked on definition, role, application of the model, identification of partnerships, and evidence review and subsequently established recommendations collaboratively. Working with specialty program areas, the Council established criteria to be used for growth and development of future and emerging specialty program areas. Community agencies were engaged to help shape types of partnerships as well as outline a transparent and standardized process by which partnerships may be established.

Identified Gaps

The Framework revealed some significant gaps in the supports and health care services that are currently offered:

- Awareness and knowledge of the scope and availability of supportive care services is limited;
- Variability exists in service availability and accessibility, even within comparable sites;
- Patients and families are not consistently informed about or referred to supportive care services;
- Identification of complex needs does not consistently prompt referral to specialized supportive care services;
- Incorporation of Supportive Care Services into clinical care pathways and guidelines is sparse and inconsistent;
- Current care models are not satisfactorily supporting the needs of those living with cancer as a chronic disease;
- Supportive care needs of patients at points of transition in care are not optimally considered or managed across the system;
- Strategies and training to accommodate for Alberta's diverse and vulnerable populations is lacking;
- Clinical research opportunities within the specialty areas of supportive care are limited in scope, support and structure;
- Symptom management processes and outcomes are inconsistent across the province.

Priorities for Action

The Supportive Care Framework clearly outlines opportunities for addressing identified gaps. Priorities for action are as follows:

- Develop a model of leadership and provincial accountability that fosters and enables programmatic standards and practices within supportive care, including specialty program development, across CCA.
- Undertake a current state and gap analysis of CCA Supportive Care Services including disciplines and specialty programs. Identify priority areas for investment.
- Integrate Supportive Care services into site and provincial tumour teams, clinical guidelines, care pathways, care teams, staff orientations, performance standards, and patient and family orientation in a more intentional manner.

Summary

While the large majority of Albertan cancer patients tell us their cancer care was good, very good or excellent (2014 AOPSS survey), improvements can be made. Consistently the voice of patients, families and clinicians indicates there is opportunity to improve the cancer care experience, particularly within the realm of whole person care and supportive care. In the most recent Ambulatory Oncology Patient Satisfaction Survey analysis (2014), the top ten areas for provincial quality improvement related to Supportive Care.

I've learned that I can only rely on AHS to treat the tumours in my body. I would like to see the system treat ME and not just my cancer.

~Patient (Calgary)

The Supportive Care Council believes that the health system has a responsibility to provide care that does not just "treat the tumours" but also optimizes the health and well-being of patients and families. Fully realizing Alberta's Cancer Plan to 2030 will require embracing a transformational change from a health care system that treats cancer to a health care system that treats people who have or have had cancer. Success will see changes in how CancerControl Alberta chooses to structure, resource, collaborate, and partner with patients and families. There are examples of supportive care excellence that exist within CancerControl Alberta that can be leveraged to provide provincial leadership in the growth and development of supportive care clinical and practice services.

The strength of this report lies in the collaborative approach taken, which resulted in conversation and increased levels of cooperation, unprecedented within the realm of CancerControl Alberta Supportive Care. The discipline-specific recommendations are consensus recommendations. Supportive Care services are poised to work with teams in CCA, AHS, primary care, and community partners, using this work as the foundation. Comprehensive supportive care is irrefutably an essential component to improving both health-related outcomes and patient experience. It is hoped that this framework, starting with the identified priority actions, will be the launch of excellence in patient-focused comprehensive cancer care in Alberta.

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diagnosis of cancer often comes with fear, uncertainty, and physical, social and psychological distress. Yet cancer patients should be able to enjoy life to the fullest. This means participating in the experiences that make life meaningful: work, play, relationships and spiritual endeavours. To do so, those affected by cancer may need symptom relief, counselling, education and other supports.

Alberta Health 2013, p. 30

Introduction

In September 2014, executive leadership asked CancerControl Alberta's Supportive Care Council to describe what supports the system should provide patients and families who are dealing with cancer. Further, they inquired as to which supports and services specifically required oncology expertise and which might be delivered by providers within the greater jurisdiction of Alberta Health Services (AHS) or by community agencies and providers. This has proven to be a challenging endeavor, the answers to which are complex and will require further iterative development, a provincial vision and new partnerships. While there are pockets of excellence around the province in support services, many gaps still exist. This document, *CancerControl Alberta: Supportive Care Framework* will begin to identify the gaps and make recommendations on future directions. It is designed to be a living document that will guide decisions around: the provision, distribution and organization of services; the determination of research and education activities; and the scope of internal and external partnerships. It has been developed in consultation with patients and families and their voice is reflected in the autobiographical stories and direct quotations embedded throughout the document. As supportive care work in the province proceeds, the *Supportive Care Framework* will provide guidance and lay the foundation for the future.

What is Supportive Care?

Supportive Care is an overarching concept that describes all the services cancer patients and their families need beyond the anti-cancer medical, surgical, and radiation interventions. It is defined as the provision of the necessary services for those living with or affected by cancer to meet their physical, emotional, social, psychological, cultural, informational, spiritual and practical needs during the diagnostic, treatment, and follow-up phases, encompassing issues of survivorship, palliative care, and bereavement (M. I. Fitch, 2008).

The treatment goals of care – tailored to patient need – may be preventative, restorative, supportive or palliative in intent (Dietz, 1980).

CancerControl Alberta's Supportive Care Council believes:

- The provision of Supportive Care services leads to optimized quality of life for persons who have or have had cancer, and their loved ones.
- Supportive care needs span the cancer care continuum, extending from cancer diagnosis through to survivorship and/or palliative care, and into bereavement.

• Supportive care refers to a multidisciplinary, integrated approach to care, that provides evidence informed, person-centred health care and support for the psychological, physical, emotional, social, spiritual, informational, cultural and practical needs of the person.

In partnership with patients and families, the vision is for CancerControl Alberta to develop a systematic and intentional approach to Supportive Care that will result in the capacity to respond to the supportive care needs of patients and families through their cancer trajectory (see Appendix 1 CCA Supportive Care Council Terms of Reference).

Alberta's Cancer Plan and What it Means for Supportive Care

Alberta's Cancer Plan provides the overarching rationale for Supportive Care services to be delivered to cancer patients, survivors, their families and caregivers. The Plan states that the psychosocial, physical, spiritual and palliative needs of patients, families and caregivers extend across the cancer trajectory and that meeting these needs is a responsibility of the healthcare system in collaboration, where appropriate, with community and volunteer organizations.

CCA's Supportive Care Council believes that where a supportive care intervention has therapeutic intent requiring clinical expertise, CCA has a responsibility to provide the service at its sites, or in collaboration with other healthcare

Strategy Six

Provide cancer patients, survivors, their families and caregivers with the best possible psychosocial, physical and supportive care throughout their cancer journey, introduce palliative care early in the course of the cancer treatment where appropriate.

Changing Our Future: Alberta's Cancer Plan to 2030

providers through intentional service delivery agreements and care pathways. The Plan is clear in its support of the concept that the system has a responsibility to optimize the health and quality of life of cancer patients, families and caregivers through the provision of necessary supportive care services.

Throughout this document, the intent and recommendations of the Alberta Cancer Plan have been considered; the Framework's recommendations both support and have the potential to enact the Plan.

Purpose

As an advisory board, the CancerControl Alberta's Supportive Care Council aims to inform the planning and development of comprehensive and integrated Supportive Care standards, programs and services that would contribute to the successful realization of Alberta's Cancer Plan, align with Alberta Health Service's 2014 – 2017 Health Plan and Business Plan, and contribute to the realization of CancerControl Alberta's Strategic Priorities. This Council has undertaken the creation of

A **Framework** is defined as: The basic conceptual structure of something, a set of ideas or facts that provide support for something, a supporting structure. (www.merriam-webster.com)

CancerControl Alberta's Supportive Care Framework to serve as a guiding and foundational document for the provision of supportive care for Alberta cancer patients throughout their continuum of care.

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As a living document and basis for future work this Framework will:

- ✓ Define supportive care within cancer care and facilitate better understanding among health care professionals and patients
- ✓ Represent the supportive care needs and preferences of patients and families
- ✓ Synthesize the evidence base that informs the provision of supportive care
- ✓ Outline potential models of care by which equitable and coordinated access to supportive care services may be achieved and sustained
- ✓ Identify and facilitate the understanding of the role of stakeholders and partner providers outside of CancerControl Alberta
- ✓ Provide an objective means to make recommendations and establish future priorities
- ✓ Describe a vision for the future state of supportive care for Alberta cancer patients

Principles

The following principles have been applied throughout the development of the Supportive Care Framework:

1. Care will be person-centred.

The care provided will respect patient and family values, preferences and needs. Health care professionals will review patient reported outcomes. All persons with or impacted by cancer require some level of supportive care. It is noted that family is defined by the patient.

2. Care will be evidence informed.

CancerControl Alberta provides evidence informed care – care that is supported by clinical guidelines and care pathways which include all services. Best evidence includes client values, clinical expertise and research results.

3. Access to Supportive Care will be enhanced.

All patients and families are informed of and have access to supportive care services. While this may be realized in different ways across the province, a responsibility exists to use technology, support from the tertiary centres, and collaboration with other areas of Alberta Health Services (AHS) and community agencies to enable reasonable access.

4. Care will respect diversity.

Patients and families will receive supportive care services that are respectful of and attend to their cultural and linguistic diversity, gender and sexual orientation, and differing abilities.

5. Care will be integrated and interdisciplinary.

Supportive Care will be integrated throughout the care continuum into clinical guidelines and care pathways, as required to optimize the quality of life of the person with cancer and their family. All health care providers are responsible for supportive care ranging from provision of information to referral to highly specialized physiotherapy, psychology etc. All providers will receive orientation and continuing education to help review patient reported outcomes, act upon identified priorities and refer as needed to specialist supportive care services.

6. Care will be provided through collaborative practice with other providers, primary care providers and community partners.

It is recognized that while all patients and families have supportive care needs, not all supportive care will be provided by CancerControl Alberta. Collaboration, coordination and managed transitions are required to provide continuity of care and access to appropriate services within the greater AHS and in the community.

- 7. Research and knowledge development is supported in Supportive Care disciplines and programs. Changes and developments in oncology care are resulting in residual impairments and quality of life challenges for those cured or in remission, those living with cancer as a chronic disease, and those whose life expectancy is curtailed due to cancer (end of life care). Research and knowledge development in supportive care disciplines and fields is critical to the future of cancer care.
- 8. Supportive care disciplines at the tertiary level in oncology have a specialized expertise. Tertiary providers have a responsibility to leverage their expertise across the system through education, mentoring, use of technology, and site visits.

Model of Care

The Supportive Care Council supports the tiered model of Supportive Care, developed by Margaret Fitch (M. I. Fitch, 2008). The model can be viewed from both the patient/family and provider perspective and lends understanding to the concept that all patients/families will, through their experience of living with cancer, require screening for needs, basic information and education and that this can be met through interventions by a variety of health care providers. It may also be self-directed.

Depending on the results of screening, patient reported outcomes and clinical assessment, many patients will require additional information and support – this might be classes, guided readings, one time consults or recommendations to deal with a relatively straightforward treatment-related symptom. Further, some patients have complex needs that require highly specialized providers e.g. end of life care, complex swallowing and nutritional needs. Each discipline-specific working group examined the applicability of this model to the services provided and determined examples of the different levels of service within their discipline.



Figure 1. Refined level of care needed for subsets of patients entering the cancer system. Adapted from Fitch, M. I. (2008). Supportive care framework. *Canadian Oncology Nursing Journal = Revue Canadianne De Nursing Oncologique, 18*(1), 6. Copyright 2010 by Canadian Association of Psychosocial Oncology. Reprinted with permission.



Figure 2. Adapted from Supportive Cancer Care Victoria. (2011). *Framework for professional competency in the provision of supportive care.* Australia: Supportive Cancer Care Victoria Project. Pg. 6. *Copyright 2011 by Supportive Cancer Care Victoria Project.* Reprinted with permission.

This view of supportive care describes a way of identifying patient and family services and delegating differing levels of need to the level of health care expertise required. This approach can improve system capacity. Additionally, CCA has the challenge of describing how to deliver those services across the province of Alberta. With its tertiary centres in Edmonton and Calgary, comprehensive regional centres in Lethbridge, Red Deer and Grande Prairie, a regional centre delivering systemic treatment in Medicine Hat and

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11 community centres, CCA must intentionally determine service delivery standards and systems for all. The recommended model of care delivery is based on the Hub and Spoke work done initially for telemedicine (Demaerschalk et al., 2009)

Using this model, CCA can intentionally plan the full scope of services in any discipline or specialty program that will be available at its tertiary, regional and community sites. The Supportive Care Council recommends that the highest level of expertise along with the largest range of services be in "hubs" located in Calgary or Edmonton or both. The greatest expertise will develop, and already exists in those centres due to patient volumes, proximity to tertiary level acute care and surgical services, and affiliations with academic research and preprofessional training universities in large urban settings. Comprehensive regional centres now provide a full range of diagnostic and treatment options for breast, prostate, lung, gastrointestinal and advanced cancer patients. This will require



development of expertise in Supportive Care services in the regional centres to meet the needs of this growing patient population. As expertise grows within a regional centre, it will move towards becoming a "hub" for some of the needs in the communities around them. This will serve to facilitate comprehensive cancer care closer to home but will also add to the available support for the community and rural patient and clinician "spokes."

The goal of consultative services from hubs using visiting specialists in Supportive Care services, or through use of Telehealth, is intentional sharing of expertise throughout the CCA network. Evidence-based care is transmitted from the "hub" to the "spokes" (Schumacher Clinical Partners, 2015). It is noted that careful attention to the education and empowerment of the "spokes" is vital. Using a system of mentoring, staff education, and provision of expert consult when needed, much of the mid-level care can effectively occur in regional, community and rural settings (Schumacher Group Medical Executive Council, 2015).

Methodology

The Supportive Care Framework has been developed using the evidence model developed by David Sacket. This model recognizes scholarly evidence (research based), clinical expertise, and patient values, needs and preferences to inform the recommendations and future direction of the work (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996).



Figure 3. The work of the Supportive Care Framework involves the intersection of evidence, clinical experience and patient values. Adapted from Sackett, D. L., Rosenberg, W. M. C., Gray, J. A. M., Haynes, R. B., & Richardson, W. S. (1996). Evidence based medicine: What it is and what it isn't: It's about integrating individual clinical expertise and the best external evidence. *BMJ: British Medical Journal, 312*(7023), 71-72. Adapted with permission from BMJ Publishing Group Ltd.

Patient and Family Values, Needs and Preferences

The following sources of input from patients and families served as the evidence-based representative of patients' preferences and values:

- ✓ Patient and Family Surveys were conducted in the spring of 2015. The surveys were distributed electronically to the roster of advisors in Calgary and to the volunteers at the Cross Cancer Institute. Paper surveys with postage-paid, return envelopes were delivered to attendees at the 2015 spring "Living your Best Life with Cancer and Beyond" symposia held at tertiary and regional centres. Paper copies were also made available at the Cross Cancer Institute for those interested. Eighty-four responses were obtained and analyzed. (See Appendix 2 Engagement Report).
- ✓ Patient experience reports and recommendations from the Joint Patient Partner Day hosted by the Alberta Cancer Foundation (ACF) and CCA in April 2015. (Rose, Lechelt, & Allatt, 2015)
- ✓ Data from the Ambulatory Oncology Patient Satisfaction Survey conducted in 2014 relating to supportive care (See Appendix 3)

- ✓ Patient/family advisors were provided an opportunity to participate in the Patient Education workshops and reviewed draft recommendations.
- ✓ The Calgary PFAC reviewed and discussed the overall recommendations on February 24, 2016.

OLiterature Review

A rapid review of the literature was conducted. Rapid reviews are a systematic and efficient approach for synthesizing evidence quickly, typically for the purposes of helping decision-makers in the health care field respond in a timely manner to urgent and emerging needs. In the absence of a standard protocol for rapid reviews, the six steps below were followed (see Box 1).

- The project planning team identified the efficacy of supportive care interventions at particular stages of the cancer journey as a priority by using the data collected through the engagement process.
- In order to narrow the topic and guide the reviews, the project planning team developed a question that could be answered and applied across the eight identified areas of supportive care.
- 3. Workgroups, comprised of clinical experts in each field of supportive care, were organized to ensure content experts reviewed the evidence. For each

Box 1. Rapid Review Approach

- 1. Needs assessment
- 2. Question development and refinement
- 3. Systematic literature search
- 4. Screening and selection of studies
- 5. Data extraction and quality assessment
- 6. Narrative synthesis of included studies

workgroup, Knowledge Resource Services (KRS) librarians developed and conducted a systematic literature search for each of the workgroups using terms provided by clinical experts in those workgroups. The search strategies for each workgroup are were limited to English Language, Adults, 2010-2015, and the databases MEDLINE, CINAHL, and PsycINFO. Due to the lengthy nature of this document, it is available by request (Supporting Document 1. Supportive Care Framework Search Strategies for All Disciplines). Although primary studies can be included in rapid reviews, the evidence was limited to systematic reviews and meta-analyses. Depending on the number of relevant studies identified, the search was expanded to 2005-2015, single RCTs, and a grey literature search was also performed by searching relevant specialty associations and organizations. Retrieved records were inputted into Excel and the reference manager database RefWorks.

- Screening was conducted by two workgroup members (one with clinical expertise and one with methodological expertise) according to the inclusion/exclusion criteria (Supporting Document 2. Inclusion-Exclusion Criteria for All Disciplines; available on request) by reading the titles and abstracts. If there was disagreement, the full text was read.
- 5. The extraction and assessment of the evidence was conducted by one member of the workgroup and then reviewed by the other members of the workgroup. All the systematic reviews were assessed according to the strength of the evidence based on a classification system created by the Joanna Briggs Institute (Supporting Document 3. Joanna Briggs Institute Systematic Review Appraisal Criteria; available on request).

For each systematic review, the population, intervention, comparisons and outcomes were extracted and described narratively (Supporting Document 4. Literature Review Summary Tables for All Disciplines; available on request).

The Knowledge Management portfolio of AHS was instrumental in facilitating and conducting the literature review. A full bibliography is also available on request.

Clinical Expertise

Input from CCA clinicians, national and international clinicians, and recognized experts local and further afield was solicited as the evidence-base, reflective of the wisdom of practice derived from clinical expertise and experience:

- ✓ A survey was sent out to a wide selection of Alberta clinicians of varied disciplines. Seventy-five responses were received and analyzed.
- ✓ Focus groups were held with CCA's Systemic Treatment and Radiation Treatment Councils.
- ✓ A rapid E-scan was done nationally and internationally identifying supportive care services.
- ✓ Key informant interviews were held with 24 Canadian experts and 13 international experts.
- ✓ Consultation with the CCA Supportive Care Council, populated with Alberta's supportive care experts and patient advisors, was done at each step in the framework development.
- ✓ Recommendations were developed in consultation with discipline specific working groups comprising of CCA clinicians and others (see Appendix 4, Consultation Rubric).
- ✓ Topic specific surveys were sent to clinicians involved in specialty programs and navigation.
- ✓ Consultation was done with AHS's Primary Care portfolio (including chronic disease management).

The Engagement and Patient Experience and Knowledge Management portfolio of AHS was instrumental in the design, delivery and analysis of the engagement work. The full report: *Results of a Comprehensive Engagement Process on Supportive Cancer Care for CancerControl Alberta* is appended to this document (Appendix 2).

Discipline specific working groups were organized and met in the fall of 2015 to synthesize all the information and formulate recommendations. Each group worked on definition, role, application of the model, existing and potential internal and external partnerships, review of the evidence and recommendations. The work was drafted and over subsequent iterations, the group had an opportunity to provide feedback.

The Screening for Distress Intervention and the Relationship to Supportive Care Services

One of the key challenges for care providers is identifying and prioritizing patient needs in the context of

type and timing of support. In an effort to aid communication and service support between patients and care providers, a much needed practice standard has been developed to ensure routine and regular collection of the patients' perspective regarding their concerns and symptoms. This intervention, entitled **Screening for Distress**, is to ensure timely and appropriate identification and management of distressing symptoms and concerns as identified and prioritized by patients.

The Screening for Distress intervention provides valuable insight into the acute symptom burden the patient is experiencing, and what the patient defines as their primary concerns. Since patients' distress can change as they move through their cancer journey, conducting the Screening for Distress intervention multiple times facilitates the delivery of person centred care as a standard of care. This intervention, combined with clinical pathways, individual clinical assessment, and the response by the health care practitioner, drives the supportive care interventions for patients and their families.

The screening is done routinely using the "Putting Patients First" (PPF) tool (see Appendix 6) and, according to their scope of practice, health care practitioners develop a plan to address symptoms collaboratively with the patient, family and caregiver as appropriate. This response is guided in part, by localized, site based resource plans. This allows for a graduated response to the symptoms described by the patient ranging from the provision of information and self-management technique discussion, to complex, specialty-program intervention (Alberta Health Services, 2015c).

The Screening for Distress Intervention is foundational to the delivery of Patient and Family Centred care and is consistent with AHS's Patient First Strategy (Alberta Health Services, 2015b). Patient and Family Centred Care sees patients and families as integral members of the health care team, and encourages their active participation in all aspects of care, including as partners in decision-making, planning, implementation, and evaluation of existing and future care services.

The Canadian Partnership Against Cancer (2012), describes the following reasons for screening:

- The high incidence of distress in cancer patients (35-45%)
- It addresses the psychosocial, practical and physical concerns
- It gives health care providers the opportunity to better understand the concerns of their patients

I believe there should be a more whole person approach to the services provided. Throughout the journey, the health care team should be checking in, looking for clues, using the screening for distress and even their own experience based on other patients they have treated in similar stages or situations and what their needs were, to better bring up and perhaps, even recommend a service or two that might prove relevant to the patient at that time. Keep doing this throughout.

~Patient Engagement Report

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• It recognizes that since needs change over the cancer disease trajectory, distress must be screened at regular intervals.

CCA has adopted the Screening for Distress intervention as a practice standard for all its sites. In order for screening to have impact, it must be linked with a clinical response to the concerns expressed. Patients and families have indicated they believe in this process but they have stressed that when they fill out the PPF, they need the health care practitioners to review it, talk to them about it, and respond to it (Rose et al., 2015). The response of health care practitioners to patient reported symptoms and concerns will range from:

- provision of information regarding symptom management or appropriate resources/support programs
- early referral to specialized supportive care services
- coordination with service providers elsewhere in AHS, external service providers and in complex cases, to specialty, multidisciplinary teams like Pain and Symptom Management, Palliative Care, and Oncology Rehabilitation Medicine.

Efforts are underway to develop a feasible process to enter the PPF data into the clinical EMR. When this is accomplished, CCA will have a repository of patient reported measures to drive Supportive Care service planning and care delivery at the level of the individual, the clinic, the site, and the province.

Gaps, Opportunities and Priorities for Action

When I first arrived at the Cancer Centre (Out of Province) and met with my oncologist about my treatment plan, I was scheduled to begin chemotherapy the following week. After meeting with my oncologist, the nurse came into the room and gave me an education pamphlet. On the cover of the pamphlet was information on three classes that I was required to attend and was already enrolled in. The first was a "Chemotherapy" class that all patients starting chemotherapy had to attend before they were allowed to begin treatment. The second was a "Nutrition During Treatment" class. The last was a "Fitness Assessment" class. At the Fitness Assessment class, resources within the Cancer Centre and community resources were discussed. In addition, other forms of supportive care were introduced (spiritual care, psycho-social, sexual and reproductive health, etc.). So, I was well versed and introduced to all of the various complementary supports that were available to me. At various intervals throughout my care, these resources were reintroduced in case my needs had changed at any given point. The supportive care aspect was well integrated into my care and was considered part of my overall treatment. As a result, I didn't feel alone. Instead, I felt well supported while going through this very traumatic, life-altering ordeal.

Then, 9 months after my treatment began, I moved to Calgary, Alberta to be with my husband. At this point, I had had surgery, chemotherapy and radiation but needed lifelong maintenance chemotherapy to maintain my health. I felt completely lost almost immediately. I was not informed of any classes or supports. I needed to research this information on my own. The problem was that I didn't even know where to start looking. I asked my oncologist and was told to lean on my family and personal support network!!! It was years before I learned about Spiritual Care, Wellspring, and Art Therapy. I had a mental breakdown from stress before I learned about the psycho-social supports that I am now receiving. It was a rough couple of years. Everything that I learned, I learned from other patients and no patient had a complete picture of what was available. I have found the supportive care services are incomplete, ineffective and not well advertised.

~Patient (Calgary)

As a result of the engagement work with patients and families, clinicians and a thorough literature review, a number of gaps in the supportive care system were identified. These gaps present opportunities to work toward, to better meet the needs of the patients, families, and clinical providers (see Table 1.).

Table 1. Gaps and Opportunities

GAP	Opportunities	
Patient, family and clinician awareness and knowledge of the scope and availability of supportive care services is limited.	 To ensure that information on services and how to access them is readily available by: Providing and maintaining an inventory of supportive care services and programs Developing a robust external website Facilitating timely and appropriate referral by health care providers to Supportive Care Services and specialty programs Providing culturally appropriate education and information materials for patients and families Developing individualized treatment management plans Including education about Supportive Care Services in staff and patient/family orientations 	
There are a lot of services listed that I was not aware of. Not sure where someone would get this information. ~Patient		
Significant differences exist in service availability and accessibility across the province, including at times, the two tertiary centres.	 To improve access and system capacity by: Adopting a model for current Supportive Care Services that ensures intentional planning, specialty professional practice standards, implementation of the Hub and Spoke model for each service⁽²⁾ and specialty programs⁽²⁾ Ensuring future program planning is provincial in scope, intentional in the application of the Hub and Spoke model, and includes patient and family advisors Establishing minimum service standards and staffing levels for tertiary, regional and community sites Developing and supporting partnerships through the optimization of Telehealth, education, mentoring, telephone consultation, outreach programming, and other emerging technologies Conducting a current state gap analysis to understand current service and plan for the future 	
So much of the information about cancer treatment and follow up is not available in rural areas ~Patient		
Information on the services required by patients and families, the services currently used, and benchmarks for planning core service levels is lacking.	 To improve the information available for service planning by: Establishing, collecting, and standardizing a minimum dataset to build a profile of service requirements and future needs Working with other agencies in Canada to develop benchmarks and service standards for Supportive Care Services 	

GAP	Opportunities	
	 Providing programs and services determined by best evidence, patient needs and preferences 	
Supportive Care Services are underresourced and variable across the province	 To improve service levels across the province by: Creative use of self management, education materials, web based interventions Developing intentional partnership with other areas of AHS, and community providers to enhance services and prevent duplication where appropriate Establishing comparable core supportive care teams and services at tertiary and regional sites using the Hub and Spoke model to extend the reach of clinical expertise and speciality programs to more rural and remote sites Instituting comprehensive supportive care teams within tertiary and regional cancer centres that enables the provision of oncology expert care in the following areas: Psychocology, Social Work, Spiritual Health, Physiotherapy, Occupational Therapy, Speech Language Pathology, Navigation, Nutrition, Art Therapy, and Patient Education Using available information, benchmarks and best evidence, determine the need for enhancing the resource level of Supportive Care Services in a measured and planned manner across the province endeavoring to establish comparable service levels at tertiary and regional sites 	
Patient satisfaction declines for people who have been on treatment for extended periods of timeI.	 To improve the patient experience for those on treatment for extended periods of time by: Engaging patients and families to better understand their changing needs and expectations throughout a lengthy cancer trajectory Using this information, determine the need for and develop a model of care for this population Gathering and analyzing available data to better understand opportunities to improve the patient experience across time, particularly for those who live with chronic and sustained illness 	
Lack of referral to specialized Supportive Care Services contributes to untreated impairment.	 To ensure impairments are optimally addressed and managed by: Implementing routine and consistent screening for physical and psychosocial impairments with timely and appropriate referral to specialty supportive care services Enhancing self management through the development and use of an individualized "Treatment Management Plan" Including Supportive Care screening and the response to that screening in clinical care pathways and clinical care guidelines and for transitions in care 	

GAP	Opportunities		
	Creating an order set for Supportive Care Services		
	[Patients and families all require some level of Supportive Care Services. A minimum of 25% of survivors (Cheville & Basford, 2014; Macmillan Cancer Support, 2013a) may be left with untreated impairments like incontinence, mobility or nutrition issues after completion of treatment that could be mitigated with Supportive Care Therapies. Some literature has found up to 90% of breast cancer patients (Cheville & Basford, 2014) have an impairment requiring a supportive service].		
These services are very, very important for anyone with a diagnosis of cancer. I believe that all should be free of charge as income is definitely down for most people receiving treatment and it is all healthcare. ~Patient			
Supportive Care needs of patients in transition are not optimally considered or managed.	 To facilitate transition of care by: Beginning intentional transition planning early in the care trajectory that includes supportive care services (Treatment Management Plan) Considering the recovery and/or palliative needs of the patient and family early in the care trajectory Providing support and communication strategies for transfer of care from one health care team to another or a single clinician to another 		
Supportive Care Services are not fully integrated into the clinical care pathways or model of care.	 To successfully provide whole person care, Supportive Care services need to be fully integrated. This can be accomplished by: Including supportive care services in site and provincial tumour groups Developing provincial supportive care services standards and benchmarks Supporting research and teaching opportunities in the Supportive Care Services Utilizing the oncology specialty expertise that exists at the tertiary sites to support provision of those services in regional and community setting (Hub and Spoke) 		
Inconsistent accommodation for diverse and vulnerable populations.	 To enhance accomodation and accessibility by: Developing an First Nations, Métis and Inuit strategy for CCA Developing cultural competence throughout CCA with accommodation to diverse needs Providing patient and staff education that supports accessibility 		
Inconsistent access to specialty programs.	To utilize recommended criteria for existing and new specialty programs including: • Ensuring a provincial approach with intentional planning		
e.g. early palliative care for those	for levels of service (Hub and Spoke) at all sites		

GAP	Opportunities	
diagnosed with advanced cancer, young adult programs, sexual health and others	 Creating a structure, committee, and/or person with a mandate to ensure provincial standards and access Ensuring clear identification of population to be served and what service will be provided Identifying, developing and providing any necessary provincial patient/family or staff education 	
With few exceptions, clinical research in supportive care services is limited in scope, support and structure.	 To encourage, support and enhance opportunities for clinical research in the disciplines and specialty programs of supportive care through: Intentionally considering funding opportunities, Leveraging existing research expertise and Considering development of a research "hub" for different areas 	
Symptom management processes and outcomes are inconsistent across the province	 To improve patient experience and outcomes by: Creating provincial symptom management guidelines and patient education resources Providing staff with consistent access, orientation and updates to resources Consistently following through with patient issues identified on the Screening for Distress tool Using care pathways to proactively identify and address symptom management needs 	

• A Treatment Management Plan is a concept that includes tracking of recommendations/referrals to optimize patient's health as they move through the cancer care trajectory. This concept, if agreed to, will require development and piloting to become a reality. Ultimately, we believe that transition planning and planning to optimize health and quality of life begins early in the care pathway.

© Service is one of Rehabiliation Medicine, Nutrition, Patient Education, Navigation, Spiritual Health, Psychosocial, Creative Arts Therapy

ΦSpecialty Programs are multidisciplinary programs designed to address complex supportive care needs that require several disciplines. Examples are palliative care, sexual health,

Based on provincial results Ambulatory Oncology Patient Satisfaction Survey 2015

Domains of Supportive Care

The term Supportive Care covers several domains: physical, emotional, social, psychological, spiritual, cultural, practical and informational. These domains are addressed through the consistent application of the evidence model and the model of care, across departments and providers. These domains have been further organized into three main categories (Physical, Emotional and Informational). The Physical category includes Nutrition Services and Rehabilitation Medicine (Physiotherapy, Occupational Therapy and Speech Language Therapy). The Emotional category includes the emotional, social, psychological, spiritual and practical domains. These are presented through the departments of Psychosocial Oncology (comprised of Social Work, Psychology and Psychiatry), Spiritual Health and Creative Arts Therapies. These form a spectrum of care that empowers patients to choose a modality that works for them and allows staff to target interventions appropriately, according to need. Finally, the Informational category includes Cancer Patient Navigation and Patient and Family Education.

As described in Figure 2, every health care practitioner in oncology has responsibility and skill at some level in all or most domains; clear demarcations in patient focused care do not exist. Finally, as the cultural domain permeates all work in cancer care, it is not dealt with as a separate entity in this section. It is noted as a gap and targeted for future work in CCA.

Physical Domain of Supportive Care Services

Nutrition Services

Through the course of my head and neck cancer diagnosis, treatment and recovery, I worked closely the team of dietitians. The relationship began early as my weight started to drop. The stress of the situation in part, brought on gout and it was clear very quickly that the guiding principles of nutrition, if followed would play a key role in a successful outcome. Surgery went well and the nutritional team supported my hydration, balanced nutrition and sufficient calorie intake as radiation and chemo would follow shortly. The nutrition team supported me as a feeding tube was installed - I simply could not eat enough. I remember being asked to increase my protein intake to aid with the healing. Towards the end of treatment, we spent considerable time together as we worked to reduce my dependency on the tube and if I could only eat so much.... ensure I was eating the right things.

The team was so helpful to me that recently one of my friends was diagnosed with cancer and although I had a lot of advice for him, I did suggest that he dial himself into the nutrition team before anything else.

~Patient (Edmonton)

CancerControl Alberta

Within AHS the unique role of dietitians is to:

- Have an in-depth scientific knowledge of food and nutrition and integrate this knowledge with their training in social sciences, education, health promotion, communication and management to help people achieve optimal health.
- Educate clients/patients, families, communities and other health care professionals about food and nutrition.
- Provide nutrition counselling to promote behaviour change.
- Promote nutritional and overall health, food security and food safety through the development and delivery of food and nutrition education, programs and policies. (Alberta Health Services, 2013a)

The role of dietitians within CCA is to provide evidence informed nutritional support to oncology patients. The role includes:

- Participate as an integral part of the multidisciplinary team to provide nutritional expertise;
- Provide screening, counselling and follow up to cancer patients;
- Assess nutritional status and the design of interventions to optimize that status;
- Translate research into practices within clinical guidelines and care pathways.

The Nutrition Care Process is a systematic, problem solving model that dietitians use to guide critical thinking and address nutrition-related problems. The Nutrition Care Process contains four distinct but interrelated and connected steps: nutrition assessment, nutrition diagnosis, nutrition intervention, and nutrition monitoring and evaluation.

Credentials and Requirements of the Dietitian

All dietitians are licensed with the College of Dietitians of Alberta. Oncology dietitians report through the Nutrition Services portfolio of AHS and are assigned to various CCA sites. It is recognized that a level of orientation to, knowledge of and experience in oncology is required to work with cancer patients. To facilitate the development of a collective expertise and leadership in oncology nutrition services, it is recommended that a provincial lead for oncology is appointed. This role would:

- Provide leadership in the development of Nutrition Practice Guidelines and associated nutrition education resources (including evidence review).
- Provide support by orientating the dietitians to working with cancer patients, and facilitating "network" meetings and "lunch and learns" for dietitians who want to connect, share and enhance knowledge.
- Offer "hot line" support to regional and community dietitians working with oncology patients.
- Provide (as required) nutrition education to other health professionals working with cancer patients.
- Support nutrition-related research.

Supporting Evidence for Dietitians

Patient and Family Values, Needs and Preferences

In the patient engagement survey, clinical nutrition was the service that patients indicated they used the most. While patients (and clinicians) indicated routinely on the surveys they did not know many of the services were available, or where to get them, they did know to ask or seek out nutrition services. Considering the information about nutrition services and dietitians is no more available than any other service, it is interesting that patients/families were aware of its availability. That may signify they recognize how integral it is to their health status, and certainly, how often it is their appetite and ability to nourish themselves that is impacted by cancer treatments. Patients and families did indicate this service should be covered under the provincial health plan. During the Patient Partner day (Rose et al., 2015), patients and families did advocate for early screening and early access to support resources, including dietitians.

O Literature

The high risk of malnutrition for cancer patients is the primary reason for ensuring integration of dietitians into the multidisciplinary care teams. 40 – 80% of cancer patients suffer from some degree of malnutrition, depending on tumour subtype, location and staging, and the treatment strategy. Malnutrition is associated with increased morbidity and mortality in cancer patients (Gomez Candela et al., 2010). It can lead to cachexia, a specific form of malnutrition that includes: loss of lean muscle mass, muscle wasting, and impaired immune, physical and mental function. Cachexia is associated with poor treatment response, increased susceptibility to treatment-related adverse events, and poor outcomes (Argiles, 2005). In patients with advanced cancer and in different stages of cachexia, individualized diet counselling improves energy intake, quality of life, and nutritional status versus the addition of nutritional supplements alone (Balstad, Solheim, Strasser, Kaasa, & Bye, 2014; Colomer et al., 2007; Mazzotta & Jeney, 2009).

The evidence supports the use of malnutrition screening tools as a standard of practice in oncology care (Gavazzi, Colatruglio, Sironi, Mazzaferro, & Miceli, 2011); (Biggs, 2012). Outcomes such as quality of life and symptom control are significantly improved with individualized nutritional counselling from a registered dietitian/nutrition specialist as part of the multidisciplinary team (Cheung, Pizzola, & Keller, Jul 2013; Millar & Davison, 2012). Evidence supports the use of individualized diet/nutrient modifications and interventions based on a thorough nutritional assessment which includes cancer type/location and stage of treatment (chemotherapy/radiation/surgery). This will optimize the benefit or reduce the risk of certain tumour types and response to treatments (Aune et al., 2012; BenArye, Polliack, Schiff, Tadmor, & Samuels, Dec 2013; Henson CC, Burden S, Davidson SE, & Lal S, 2013; Ma, Yu, Xiao, & Cao, 2015; Sun, Wang, & Hu, 2012; van der Meij, van Bokhorst-de van der Schueren, M.A., Langius, Brouwer, & van Leeuwen, 2011). The evidence shows that nutritional intervention improves quality of life during end of life palliative care (Gillespie & Raftery, 2014; Langius JA et al., 2013; Marin Caro, Laviano, & Pichard, 2007). Both intuitively and supported by evidence, there may be costs savings from a system perspective through preventing and ameliorating malnutrition in cancer patients (Snider et al., 2014).

There is also increasing evidence of a role for dietitians in providing nutrition support and counselling in survivorship to improve outcomes and impact the risk of recurrence (Bazzan, Newberg, Cho, & Monti, 2013).

O Clinical Expertise

Clinicians indicated that nutrition services were one of the top three support services they refer to in CCA. They reported being very aware of dietitians (clinical nutrition) with need for specialist intervention as a primary reason for referral. Ease of referral and a feedback loop would be appreciated by clinicians.

The availability of dietitians, malnutrition services and obesity risk reduction were noted by multiple respondents nationally and internationally as necessary supportive services in an oncology care system.

Role and Application of the Model of Care

The provincial availability of clinical nutrition services to oncology patients should be a standard of care. Routine malnutrition screening along with integration of the Nutrition Care Process (the systematic, problem solving model that dietitians use to guide critical thinking and address nutrition-related problems), is critical to optimizing the health status of oncology patients. [See Figure 4, next page.]



*refers to patients and families/support persons

Figure 4. Nutrition Services Model of Care. Adapted from Fitch, M. I. (2008). Supportive care framework. *Canadian Oncology Nursing Journal = Revue Canadienne De Nursing Oncologique, 18*(1), 6 . Copyright 2010 by Canadian Association of Psychosocial Oncology. Adapted with permission.

Partnerships

Partnerships and collaborative, integrated systems are essential to providing smooth transitions and continuity of care to patients and their families. Dietitians in CancerControl require support to improve existing linkages and forge new ones. The Primary Care portfolio, encompassing chronic disease management, provides an opportunity to enhance availability of nutritional services to patients being discharged back to the community, or for whom cancer is chronic and requires support closer to home.

Nutrition services has partnered with Wellspring Calgary in the provision of cooking classes and other educational programs. There is also opportunity to partner with HealthLink to have a dietitian easily available to answer nutrition related questions. Partnerships with others in AHS and in the community will not impact the need for acute clinical nutrition for patients being diagnosed or in treatment. It does, however, offer an opportunity to improve transitions and post-acute follow up care. It is noted that the most important partnership is the AHS Nutrition Services portfolio and CCA. Resource allocation, collaboration on provincial, oncology specific patient education materials and full integration into the tumour group structures and other CCA initiatives is essential to quality nutritional care for oncology patients.

The nutritional aspect of my cancer treatment was such an important part of my total cancer care. Radiation was debilitating and without the dietitian's help, I don't think I would have made it through the 30 sessions. Her positive attitude, caring and professional advice, suggestions and practical tips made a total difference in my journey through radiation and my ongoing recovery. I am very appreciative that she was there for me and grateful for her care.

~Patient (Edmonton)

Recommendations

Further to the consideration of the evidence including the literature, patient needs and values and clinical expertise, the Nutrition working group developed recommendations for Nutrition Services in CCA, using the *Alberta Quality Matrix for Health* as a framework for the discussion. A summary of the recommendations, along with their relevant indicators, are included in Table 2. Please note that the recommendations are not in hierarchical order, however the top three recommendations have been identified.

Alberta Qua	lity Matrix for Health
Appropriatenes	ss: Health services are relevant to users' needs and are based on accepted or evidence-based practice.
Acceptability: H	lealth services are respectful and responsive to user needs, preferences and expectations.
Accessibility: He	ealth services are obtained in the most suitable setting in a reasonable time and distance.
Effectiveness: +	Health services are provided based on scientific knowledge to achieve desired outcomes.
Efficiency: Reso	purces are optimally used in achieving desired outcomes.
Safety: Mitigate	e risks to avoid unintended or harmful results.

Table 2. Nutrition Services Recommendations

Re	commendation	Dimension of Quality Matrix that is addressed
1.	A provincial lead for Nutrition Services in oncology is appointed as the point person for guideline development, team integration, provision of orientation to dietitians new to cancer care and to support other health professionals delivering nutrition education as well as patients.	Effectiveness Efficiency
2.	Malnutrition screening is implemented across all sites on referral.	Accessibility Efficiency Safety Appropriateness
3.	Dietitian resources (FTE) are increased from the current level to ensure standard of care at tertiary and regional sites.	Appropriateness Effectiveness Safety Accessibility
	Capacity is available within resources at the tertiary sites to support and mentor those in the community providing care to oncology patients.	Accessibility Safety Appropriateness
	The provincial lead work to develop partnerships and pathways for patient care with Alberta Healthy Living, Primary Care Networks, HealthLink and community agencies like Wellspring.	Acceptability Effectiveness Appropriateness Efficiency
	There is dietitian capacity to conduct research and move emerging evidence into practice.	Efficiency Effectiveness Appropriateness
	Algorithms are developed so that all patients reporting issues with weight loss and appetite on the "Putting Patients First" tool are given a prescription for education or a referral to the dietitian.	Accessibility Acceptability Safety
	CCA Provincial Patient Education and Nutrition Services work collaboratively to develop standardized oncology patient and family education – print, web based, classes, outreach.	Accessibility Effectiveness Acceptability
	A nutrition component is integrated into transition notes and briefs in consultation with the dietitians.	Acceptability Accessibility Safety Effectiveness
	Formal linkages are developed with CCA navigators and tertiary triage coordinators (Snider et al., 2014) to ensure early intervention for those with malnutrition or at risk of malnutrition.	Accessibility Efficiency Safety

Rehabilitation Medicine

My post care team at the Cross cancer Institute in Edmonton was lifesaving, full of expertise, positive, motivated to help and compassionate in assisting me in a much needed battle. It was the Speech-language Pathologist (SLP) that helped me to overcome my fear and gain confidence to start eating again after choking so many times while previously trying. It was the SLP that gave me vocal exercises to gain back speech and articulation. Along with the other members of my care team, my SLP, was hugely instrumental in getting me started on my healing process, without her and the others I can't imagine where I would be at this point in my journey.

~ Patient (Edmonton)

Cancer rehabilitation is a health care specialty that provides therapeutic intervention to assist patients, survivors and families in preventing or mitigating the physical and psychosocial impact of impairments and functional limitations imposed by cancer or its treatment (Franklin, Delengowski, & Yeo, 2010); (Silver, Baima, Newman, Galantino, & Shockney, 2013; Silver & Baima, 2013). Cancer rehabilitation professionals may work with patients, survivors and families with the goal to optimize life participation at any point from diagnosis through the trajectory of cancer (Cromes Jr, 1978). Therapeutic interventions aim to promote independence, minimize disability and improve quality of life. Rehabilitative treatment goals are important throughout the entire cancer continuum, and may be preventative, restorative, supportive or palliative in nature and may change over time (Dietz, 1980). Many acute, late and long-term consequences of cancer and cancer treatment are predictable and amenable to cancer rehabilitation.

Credentials and Requirements of the Rehabilitation Professional

Cancer rehabilitation services are provided by university prepared, typically Masters or PhD, and licensed health care professionals representing a number of unique health care disciplines.

Currently, within CancerControl Alberta, there are four key disciplines involved in the delivery of rehabilitation medicine.

Physiotherapy is regulated by the Health Professions Act. Physiotherapists must be registered with *Physiotherapy Alberta College and Association*. An autonomous, client-focused health profession which applies a collaborative approach to goal directed care, by focusing on the musculoskeletal, neurological, cardiorespiratory and multi-systems (Canadian Physiotherapy Association, 2012). Physiotherapy is a primary care service that is anchored in movement sciences and aims to enhance or restore function of multiple body systems. The profession is committed to a person-centered approach of rehabilitation that incorporates a broad range of physical and physiological therapeutic interventions .

Occupational Therapy is also regulated by the Health Professions Act. Occupational Therapists must be registered with the *Alberta College of Occupational Therapists*. Occupational therapy helps manage physical, cognitive and/or affective impairments and the dysfunction that these impairments create. Purposeful and meaningful activities are used to restore people's functioning and to prevent disability. Occupational therapists not only examine the physical effects of an injury or disease, but they also address the

psychosocial, community and environmental factors that influence function. Occupational therapy works to break down the barriers which impede individuals in their everyday activities (Canadian Association of Occupational Therapists 2016). Within the oncology context, occupational therapy specializes in enhancing function, participation and comfort across the cancer trajectory.

Speech Language Pathology is the third rehabilitation medicine health care discipline regulated by the Health Professions Act. Speech-language pathologists (SLPs) must be registered with the *Alberta College of Speech-Language Pathologists and Audiologists*. SLPs have clinical training and educational background in speech production, language understanding and expression, stuttering, voice health and swallowing disorders (Alberta College of Speech-Language Pathologists and Audiologists and Audiologists 2016). Their expertise includes prevention, identification, evaluation, and treatment of congenital and acquired communication and swallowing disorders (Ontario Association of Speech-Language Pathologists and Audiologists 2010).

Future consideration of additional roles to this portfolio

Physiatry (also known as "Physical Medicine & Rehabilitation") is a medical specialty that requires 5 years of postgraduate training after medical school, and is regulated by the College of Physicians and Surgeons. Unlike many medical specialties, it does not focus on a single body organ system, but rather focuses on the overall body and how it functions. Within physiatry, cancer rehabilitation is an emerging subspecialty with fellowship training programs in several major cancer centres in North America. Cancer rehabilitation physiatrists subspecialize in the diagnosis of cancer-related complications, and collaborate with cancer specialists and an interdisciplinary team to coordinate and deliver medical and therapeutic treatments that will optimize the physical and psychosocial well-being and functioning of each individual.

Certified Exercise Physiologist is an exercise specialist with a minimum of 4 years of university education. The *Canadian Society of Exercise Physiology* (CSEP) administers a formal certification process. Within the scope of practice of CSEP certified exercise physiologists may perform exercise safety screening, fitness assessments, prescription of exercise and lifestyle counselling. These health professionals work with both well and unwell populations.

Supporting Evidence for Rehabilitation Medicine

Patient and Family Values, Needs and Preferences

The results of the engagement survey, pertinent to rehabilitation medicine, were limited by the fact that patients are not routinely referred to Rehabilitation Medicine and many patients and families are generally unaware of the breadth of rehabilitation medicine services. Patients and families emphasized that these health care services need to be provided by health care providers with cancer expertise. In some communities, access to rehabilitation medicine services may be available closer to home; however, oftentimes these are generalist clinicians with little or no expertise in the management of cancer or cancer treatment-induced impairments. Patients seem most familiar with physiotherapy; likely due to the larger proportion of physiotherapy services within CancerControl Alberta than other rehabilitation medicine disciplines. Patients did indicate that they value physiotherapy and exercise. Patients and families did indicate that AHS should cover the costs of physiotherapy and occupational therapy, palliative care, pain and symptom management and help with tiredness and fatigue. These are all services with a strong rehabilitation component. They indicated that they would be willing to pay for exercise, such as yoga.

Patients have indicated on repeated AOPSS that they do not receive adequate support on return to work and relationships and would value that support.

○Literature

The available scientific literature was reviewed (see methodology) to support rehabilitation medicine's impact on health-related cancer outcomes.

High Level of Evidence – level 1 systematic reviews

- Breast cancer patients can achieve short-term gains (up to 1 year) (Khan F, Amatya B, Ng L, Drummond K, & Olver J, 2013) including mitigating impairments, social adjustment, and participation with inpatient and ambulatory multidisciplinary rehabilitation programs (Khan).
- Physical functioning, psychosocial parameters, and quality of life (QoL) across tumour groups are positively influenced with exercise (Cramer, Lauche, Klose, Dobos, & Langhorst, 2014; Ferrer, Huedo-Medina, Johnson, Ryan, & Pescatello, 2011; Keogh & MacLeod, 2012) Exercise is a well-researched intervention in cancer populations. Multiple high quality systematic reviews report and support the role of exercise across tumour groups, and across disease trajectory to improve numerous physical and emotional domains, including health-related Quality of Life measures and measures of physical fitness.
- Depressive symptoms and specific cancer impairments such as cancer-related fatigue are
 positively influenced by supervised exercise (Bourke et al., 2013; Craft, Vaniterson, Helenowski,
 Rademaker, & Courneya, 2012; Meneses-Echávez, González-Jiménez, & Ramírez-Vélez, 2015;
 Velthuis, Agasi-Idenburg, Aufdemkampe, & Wittink, 2010). A Cochrane review found teaching
 behaviour change techniques (goal setting, practice and self-monitoring) in a supervised
 environment more effective than non-supervised methods. Supervised exercise also has a larger
 effect on depressive symptoms and cancer-related fatigue.
- Cancer-related fatigue (CRF) is amenable to exercise (Cramp & Daniel, 2008; Keogh & MacLeod, 2012; Silver, Baima, & Mayer, 2013a; Tomlinson D, Diorio C, Beyene J, & Sung L, 2014; Tomlinson, Diorio, Beyene, & Sung, 2014). Silver suggests that exercise's powerful effect on CRF lowers fatigue levels by 40- 50%.
- Mood disturbances, including depressive and anxiety symptoms, can be treated with exercise (Carayol et al., 2013; Craft et al., 2012). Systematic review and meta-analysis found modest positive effects on depressive symptoms, most notably with supervised programs. Supported by meta-analysis of 56 RCT (Duijts, Faber, Oldenburg, van Beurden, & Aaronson, 2011) showing exercise was an effective intervention to improve depression, body image and health-related QoL.
- Functional outcomes, such as improved shoulder mobility following breast cancer treatment, are achieved with targeted therapeutic exercise (D. N. Chan, Lui, & So, 2010; Egan et al., 2013) Hu). Physiotherapy interventions improved shoulder range of motion and function (McNeely ML et al., 2012).

- Post stem cell transplant patients experience improved cardiorespiratory fitness, lower extremity strength, and fatigue when provided with cancer rehabilitation (Persoon et al., 2013; van Haren, Inge E. P. M. et al., 2013). A beneficial effect was found on post-transplant recovery with the best results coming from exercise started before or just after transplantation versus after hospitalization.
- Sleep quality for cancer patients and survivors is statistically improved with walking and walking combined with other forms of exercise. Several systematic reviews concluded rehabilitation efforts yield a statistically significant improvement in sleep quality. Walking and walking combined with other forms of exercise can improve sleep at all phases of cancer trajectory . (Chiu, Huang, Chen, Hou, & Tsai, 2015; Ferrer et al., 2011; Langford DJ, Lee K, & Miaskowski C, 2012).
- Sexual health and functioning is enhanced for men with prostate cancer with cancer rehabilitation and psychosocial interventions (Chisholm, McCabe, Wootten, & Abbott, 2012). Direct care psychosocial interventions improved men's sexual function.
- Lymphedema volume and lymphedema symptoms, including quality of life, pain, psychosocial distress, function, are effectively managed with lymphedema therapy (Ezzo et al., 2015; McNeely ML et al., 2012; McNeely et al., 2010; Stuiver et al., 2015). Research points to strong evidence supporting the role of compression therapies in producing a moderate effect in reducing lymphedema volume. Manual lymph drainage has been shown to yield a small added benefit to overall lymphedema volume reduction in a breast cancer population.
- Voice and vocal function significantly improved with voice therapy. Voice therapy results in significantly better voice quality and self-rated vocal function in patients treated with radiation therapy for laryngeal cancer (Tuomi, Andréll, & Finizia, 2014). Patients treated with radiation therapy for laryngeal cancer and early glottis carcinoma reported significant sustained voice improvements with voice therapy (Honocodeevar-Boltežar & Žargi, 2000)
- Preventative swallowing therapy can preserve swallowing function following chemo-radiation treatment of oropharyngeal cancers (Hutcheson KA & Lewin JS, 2013; Paleri V et al., 2014; Russi EG et al., 2012). Research suggests that head and neck cancer treated with chemo-radiation has a significant impact on swallowing function and consequently health outcomes and Quality of Life. Preventative swallowing exercises result in functional improvement, improved quality of life outcomes, less dependency on feeding tubes and fewer hospital admissions than usual.
- Pain can be reduced with exercise-based therapy following cancer treatments. Several systematic reviews have illuminated the role of cancer rehabilitation in pain management including reduction in shoulder pain in patients treated for head and neck cancer (Carvalho, Vital, & Soares, 2012) and prevention of post-operative pain in breast cancer patients . A Cochrane review concluded, cancer survivors undergoing exercise interventions experience a larger reduction in pain versus the comparison group (Mishra et al., 2012).

Moderate Level of Evidence - level 2 and 3 systematic reviews

• A wide range of cancer-related impairments is mitigated with rehabilitation (Egan et al., 2013). Rehabilitative interventions improve physical functioning, fatigue, pain, sexual functioning, cognitive functioning, depression, employment, return to work, nutrition, and participation.
- Inpatient rehabilitation services have acceptable cost-effectiveness (Mewes, Steuten, Ijzerman, & van Harten, 2012). Inpatient rehabilitation services are associated with improvements in physical outcome measures and fatigue. Studies showed acceptable cost-effectiveness rations, which produced significant health gains. Savings were found to be in the range of 16,976 to 11,057 Euros per quality adjusted life year.
- Patients with advanced cancers can benefit from cancer rehabilitation (Salakari, Surakka, Nurminen, & Pylkkänen, 2015). Patients with advanced cancer are willing to and can participate in rehabilitative interventions yielding improved physical performance and several domains of Quality of Life.
- Sleep quality is positively impacted with acupuncture and education in sleep hygiene practices (Budhrani, Lengacher, Kip, Tofthagen, & Jim, 2015). 1-year post-chemotherapy breast cancer survivors were still reporting poor sleep quality. Acupuncture and sleep hygiene practices positively impacted measures of sleep quality.
- Functional status of brain tumour patients is improved with cancer rehabilitation interventions (Formica et al., 2011; Khan F et al., 2013). A meta-analysis found rehabilitation intervention improved the functional status of brain tumour patients by 36%. Multidisciplinary rehabilitation can produce gains in shoulder impairment, social adjustment and QoL.
- Cancer rehabilitation helps increase return to work rates across all tumour groups (de Boer et al., 2011)). 14 RCTs found multidisciplinary interventions (physical, psychological and vocational) lead to higher return to work rates as compared to psychological interventions, physical training or medical interventions.
- Urinary and fecal incontinence can be reduced with cancer rehabilitation (Baumann, Zopf, & Bloch, 2012);(Lin, Granger, Denehy, & Frawley, 2015; MacDonald, Fink, Huckabay, Monga, & Wilt, 2007). Exercise, including pelvic floor muscle training, improves urinary continence and hastens return to continence for these men. Urinary incontinence is a common impairment in this patient population that can lead to decreased QoL, social isolation, and reduced participation. There are promising results indicating that post-operative pelvic floor muscle training reduces the severity of fecal incontinence, stool frequency, and incontinence episodes in colorectal patients (Lin et al., 2015).
- Post-surgical physiological outcomes may be positively influenced by prehabilitation, specifically exercise, prior to cancer surgery for prostate, lung, and colorectal patients (Singh, Newton, Galvão, Spry, & Baker, 2013; Valkenet et al., 2011). Rate and duration of continence in prostatectomy patients is improved with pre-surgical exercise training. Further research is required in this area; however, two randomized controlled trials for non-cancer related surgeries have reported prehabilitation yielded reduced hospital length of stay and complication rates (Singh et al., 2013; Valkenet et al., 2011).
- Trismus can be relieved with cancer rehabilitation interventions including jaw exercises and mobility devices (Cousins, MacAulay, Lang, MacGillivray, & Wells, 2013; Scherpenhuizen, van Waes, Janssen, Van Cann, & Stegeman, 2015). Patients provided with physiotherapy had reduced trismus than patients who did not receive physiotherapy. Furthermore, those who did not perform jaw

exercises had a persistent deterioration in mouth opening ability 2-3 years after treatment (Cousins et al., 2013; Scherpenhuizen et al., 2015).

Low Level of Evidence – level 4 systematic reviews

- Rehabilitative interventions can prevent cancer-related impairments from progressing to disability (Bentley, Hussain, Maddocks, & Wilcock, 2013; Cheville, Kornblith, & Basford, 2011). Despite this understanding, there is a general lack of referral to rehabilitation services (Cheville et al., 2011). Systematic screening for impairments before they progress to disability is strongly recommended. In a single study (273 thoracic cancer patients), half of the patients had occupational therapy needs at time of diagnosis, including self-care and provision of adaptive equipment (Bentley et al., 2013).
- Cancer rehabilitation improves coping ability in male cancer survivors. Men cope better with difficulties presented by the cancer experience including changed life perspective, masculinity, desire to get back to normal, and the meaning of work when provided with cancer rehabilitation (Handberg, Nielsen, & Lomborg, 2014).
- Cancer rehabilitation improves functional abilities and length of stay is decreased for patients with metastatic spinal cord compression (Eriks, Angenot, & Lankhorst, 2004; McKinley, Conti-Wyneken, Vokac, & Cifu, 1996). A prospective cohort study found improvements in mobility, ambulation, self-care and transfers associated with rehabilitation interventions.
- Improvements in mobility, ambulation, self-care, and transfer ability were realized in a single study (non-systematic review) examining the role of rehabilitation in patients with neoplastic spinal cord compression (McKinley et al., 1996). Most significantly, wheelchair transfers, upper and lower extremity dressing, and toilet/tub transfers were improved following rehabilitation interventions (McKinley et al., 1996).

OClinical Expertise

Clinicians surveyed across CCA indicated that within the full scope of cancer rehabilitation practice, they were most aware of lymphedema management. This survey has clearly identified the lack of awareness of health care providers to the depth and breadth of health care services that cancer rehabilitation could potentially offer. In questions

My story and my journey started with a diagnosis of breast cancer. The surgery caused injury to my right shoulder I managed the pain in my shoulder and arm the best that I could and wondered if I would ever get any range of motion back. Then I met the physical therapist at the Central AB Cancer Centre. I began receiving physical therapy. Today, I have at least 80% range of motion back and only minor pain compared to the unbearable pain I experienced at the start. My quality of life and mental health has improved 100% thanks to physical therapy. I am able to sleep more comfortable, do more around the house and use both arms to embrace my grandchildren. I am forever grateful for what the physiotherapist has done for me, on my journey to recovery.

> ~Patient (Central Alberta Cancer Centre)

related to service gaps, clinicians indicated that there is a need for more opportunities to engage patients in physical activity and provide exercise consultation, provision of rehabilitation interventions to address sexual health concerns, and pain and symptom management. The perceived reason for lack of availability of more Rehabilitation Medicine services includes lack of resources and from one provider's viewpoint, *"because cancer care still functions from a biomedical/disease model. These types of services are considered ancillary. And there is discord between what AHS (CCA) values and what patients want."*

The environmental scan confirmed that rehabilitation medicine is a developing health care specialty within the context of Canadian cancer care. While it is not yet offered at every cancer centre in Canada, it has a very strong presence in other parts of the world including the United States, United Kingdom and Australia. For example, the STAR (Survivorship Training and Rehab) Oncology Rehab Program has now provided cancer rehabilitation specialization training and hospital certification to hundreds of cancer centres and hospitals throughout the United States. MD Anderson Cancer Center website indicates that they have "more than 100 oncology rehabilitation professionals and staff dedicated to optimizing participation and quality of life of people affected by cancer." (MD Anderson Cancer Center, 2016). Cancer rehabilitation appears in the top programs and services recommended for development, a recognition of the growing awareness of the need and the growing body of evidence to support this health care specialization. Detailed information is available in the Engagement Report on the location of programs in Canada.

Role and Application of the Model of Care

Cancer rehabilitation is unique due to cancer's often progressive nature and the diversity of impairments that can result from cancer diseases' impact on body symptoms and/or the potential for deleterious side effects from anti-cancer treatment (Marciniak, Sliwa, Spill, Heinemann, & Semik, 1996). As an established, evidence-based means to improve Quality of Life and physical functioning, there is a role for cancer rehabilitation throughout the cancer care trajectory (Gerber, 2001). More recently, the care continuum has been extended to support the inclusion of a prehabilitation phase.

Cancer rehabilitation is vital. Remediable functional decline is a main cause of emotional distress among cancer patients and the loss of autonomy and compromised self-care abilities leads patients to perceive themselves as an increased burden on caretakers (Silver, Baima, & Mayer, 2013b). Banks et al concluded, "The risk of psychological distress in individuals with cancer relates much more strongly to their level of disability than it does to the cancer diagnosis itself" (Silver et al., 2013b).

Cancer rehabilitation is a cost effective intervention, which may reduce patient burden on other areas of the health care system and society in general. Cheville concludes that proactive cancer rehabilitation can significantly diminish the prevalence and impact of cancer-related impairments. Greater availability of cancer rehabilitation professionals can reduce the medico-economic burden of cancer (Cheville, 2005). In addition to medico-economic benefits, cancer rehabilitation may also offer socio-economic benefits. Although it is difficult to quantify the indirect costs of cancer survivorship (such as lost income, caregiver burden, transportation, equipment needs, etc.) one Polish study estimates that work loss due to cancer accounts of 0.8% of the country's GDP (Silver et al., 2013b). In 2013, Alberta's GDP was 331.9 billion. If the Polish findings are applied, Alberta would need to account for 2.655 billion in work loss due to cancer.

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Given the limited availability of well organized, comprehensive Oncology Rehabilitation Medicine programs nationally, and the interest of Physiatry and others in building such a program, CCA has a unique opportunity to develop a leading program and with that, to significantly impact the quality of life.



*refers to patients and families/support persons

Figure 5. Rehabilitation Medicine Model of Care. Adapted from Fitch, M. I. (2008). Supportive care framework. *Canadian Oncology Nursing Journal = Revue Canadianne De Nursing Oncologique, 18*(1), 6. Copyright 2010 by Canadian Association of Psychosocial Oncology. Adapted with permission

Partnerships

Rehabilitation Medicine works collaboratively and in partnership with a wide range and internal (to CCA and AHS) and external service and care providers. These include but are not limited to:

Internal

- Health Professions Strategy and Practice: Allied Health professional practice portfolios
- CCA Tumour groups and care teams local and provincial
- CCA Specialty Clinics: AYA, Pain and Symptom Management, Bone Marrow Transplant, Sexual Health Clinic (OASIS)
- AHS: Acute care hospitals, palliative and hospice care, extended care facilities, rehabilitation hospitals, Home care, Palliative homecare
- AHS: Primary and chronic disease management
- AHS specialty programs: iRSM, Home Nutrition Support Programs, Palliative Care

External to CCA/AHS

- Alberta Health: Alberta Aids to Daily Living, Assured Income for Severely Handicapped
- Workers Compensation Board
- Health Canada: Non-insured health benefits for First Nations and Inuit
- Primary health care (family physicians, dentists)
- Private providers: physiotherapy clinics (non-CRP), occupational therapy practices, certified lymphedema therapists, prosthetists and orthotists
- Canadian Lymphedema Framework
- Academic and research institutions: University of Alberta, University of Calgary, Athabasca University, MacEwan University, Norquest College
- Survivorship Programs and Community Cancer Agencies

Recommendations

Further to the consideration of the evidence including the literature, patient needs and values and clinical expertise, the Rehabilitation Medicine working group developed recommendations for Rehabilitation Medicine Services in CCA, using the Alberta Quality Matrix for Health as a framework for the discussion. A summary of the recommendations, along with their relevant indicators, are included in Table 3. Please note that the recommendations are not in hierarchical order, however the top three recommendations have been identified.

Alberta Quality Matrix for Health
Appropriateness: Health services are relevant to users' needs and are based on accepted or evidence-based practice.
Acceptability: Health services are respectful and responsive to user needs, preferences and expectations.
Accessibility: Health services are obtained in the most suitable setting in a reasonable time and distance.
Effectiveness: Health services are provided based on scientific knowledge to achieve desired outcomes.
Efficiency: Resources are optimally used in achieving desired outcomes.
Safety: Mitigate risks to avoid unintended or harmful results.

Table 3. Rehabilitation Medicine Recommendations

Recommendation	Dimension of Quality Matrix that is addressed
 Fully integrate rehabilitation medicine into standard of care, cancer care pathways, and clinical care guidelines. It is noted that this will require staffing enhancements. 	Accessibility Efficiency Effectiveness Safety Appropriateness Acceptability
 Facilitate a provincial cancer rehabilitation approach through the creation of an appointed leader to develop practice expectations, standards, research and networks. 	Effectiveness Accessibility Efficiency
 Add Physiatry to the core medical services available at the tertiary cancer centres. 	Accessibility Efficiency Effectiveness Safety Appropriateness Acceptability
Formally recognize the role and capacity required for Rehabilitation Medicine Practitioners at the tertiary centres to provide consultation and mentoring to regional cancer centres and community practitioners.	Safety Accessibility Efficiency
Implement screening and timely referral for impairments related to cancer disease or its treatments at multiple points in the care continuum, including prehabilitation.	Appropriateness
Establish provincial triage and wait time criteria for rehabilitation services.	Efficiency Safety
Provide Speech language Pathology at a service level, including prehabilitative swallowing therapy, primarily at the tertiary centres with capacity to ensure periodic visits to regional centres and Telehealth consultation in support of community practitioners.	Accessibility Efficiency Safety Effectiveness Appropriateness

Recommendation	Dimension of Quality Matrix that is addressed
Ensure the inclusion of cancer rehabilitation in multidisciplinary sexual health programs.	Appropriateness Acceptability
Incorporate individualized exercise prescription into care processes and clinical pathways. Given the irrefutably strong evidence for exercise, a role for certified exercise physiologists within CCA should be a future consideration.	Acceptability Effectiveness Appropriateness Efficiency
Develop vocational rehabilitation program(s) at the tertiary centres with provincial oversight to provide expertise, consultation and advocacy.	Acceptability Accessibility Effectiveness Efficiency
Include specialized inpatient rehabilitation medicine in any future inpatient site development e.g. New Calgary Cancer Centre, expansion of the Cross Cancer Institute	Effectiveness Accessibility Appropriateness Efficiency

I truly believe that exercise has been the single most valuable component in my recovery to date, and I firmly believe that it should become an integral part of treatment for all types of cancer.

~Patient (Calgary)

Emotional, Social, Psychological, Spiritual and Practical Domains of Supportive Care Services

Creative Arts Therapies

I was stunned by the insights that came into my head and out of my mouth, as I participated in group discussions and onto the page in my journal. These Supportive Care Services literally changed my life.

~Patient (Edmonton)

Creative Arts Therapies "use arts modalities and creative processes for the purpose of ameliorating disability and illness and optimizing health and wellness" (National Coalition of Creative Arts Therapies Association, 2016). Modalities include music therapy, drama therapy, psychodrama, art therapy, creative writing, poetry therapy and dance/movement therapy. Creative arts therapies can connect people with their emotions and trauma when it is too difficult to articulate in words.

In oncology, the Creative Art Therapies assist cancer patients and their families to promote and maintain mental and emotional health in face of the distress that often arises at different times through the care continuum. This includes at the time of cancer diagnosis, during treatments, when transitioning back into life post treatment, and/or when facing end of life.

CCA uses a range of Creative Arts Therapies (CAT) with Art Therapy practitioners being the most common providers of CAT in CCA. In the rest of this document the term 'Creative Arts Therapies' (CATs) will be used when talking about the service and the term 'Art Therapist' will be used when speaking about the person(s) providing therapy service.

Credentials and Requirements of the Art Therapist

Art Therapists practice "a mental health profession in which clients, facilitated by the art therapist, use art media, the creative process, and the resulting artwork to explore their feelings, reconcile emotional conflicts, foster self-awareness, manage behavior and addictions, develop social skills, improve reality orientation, reduce anxiety, and increase self-esteem" (American Art Therapy Association, 2016).

Arts Therapists are university prepared¹ specialists who use art modalities (journaling, music, visual art, etc.) as therapeutic tools to assist cancer patients in recognizing, processing and coping with their distress and to help build resiliency. Art therapists make use of interventions based on current and emerging practice. At this time, while Art Therapists are included in the HSAA collective agreement, work has not yet been done at the broader AHS level to develop an AHS-wide role description and role clarity document. This may be a

¹ Although there are post graduate diploma programs in Canada, Healing Arts in CCA is employing Master's prepared Therapists with memberships in recognized professional associations.

result of the staff often being soft funded, and generally being limited to the CancerControl and pediatric systems.

The figure below identifies how art therapy is used through two intervention pathways. This is considered a "continuum of practice," as Art Therapists use both conceptual pathways depending on the context and patients' needs.



Project by: Cathy Malchiodi & www.joshkale.com @2015

Figure 6. Dichotomy of how art therapy is used. Malchiodi & Kale (2015). Art therapy: It's not just an art project. Retrieved from <u>https://www.psychologytoday.com/blog/arts-and-health/201507/art-therapy-it-s-not-just-art-project</u>. Permission to reprint.

Supporting Evidence for Creative Arts Therapies

● ● Patient and Family Values, Needs and Preferences and Clinical Expertise

There are limitations to the supportive care framework engagement process with both Patient and Family and Clinical stakeholders, as evident in responses that reflect a general lack of familiarity with art therapy and existing arts-based programming. Three to four months prior to the surveys, Healing Arts was only available in CCA Edmonton, and only two days per week onsite at the Cross Cancer Institute. Considering the lack of awareness of Healing Arts programming from participants involved in the Supportive Care Framework engagement process, responses relating to whether someone would pay for arts-based supports cannot be considered directly relevant.

When patient and family members who participated in arts based group programs completed evaluations in 2014, they provided a highly positive rating with an overall enjoyment score of 9.6/10 for Edmonton based groups.

O Literature

A *rapid e-scan* was done by AHS Clinical and Patient Engagement portfolio that looked at supportive care services offered in Cancer Centres across Canada. This was supplemented by a more detailed environmental scan done by members of the Healing Arts team. Art therapy, music therapy or other forms of creative arts supports were identified at oncology centres in British Columbia, Alberta (current *Healing Arts* programming), Saskatchewan, Manitoba, Ontario, Quebec, and Nova Scotia. Additionally, in the United States, the National Cancer Institute provides for arts-based supports. There are several American and international sites that are being referenced in the ongoing work of developing the Alberta program.

Published literature about Creative Arts Therapies show:

- It can improve cancer patients' quality of life, and emotional and physical state (Bradt, Dileo, Grocke, & Magill, 2011); (Bradt, Dileo, & Shim, 2013); (Puetz, Morley, & Herring, 2013); (Zhang et al., 2012). Meta-analysis evidence from the literature suggests that CATs can have a positive impact on quality of life (QOL) and reduce anxiety, depression and pain symptoms in adult cancer patients (strength of evidence is strong and moderate).
- It supports caregivers of cancer patients (Lang & Lim, 2013). A systematic review found that art therapy was highly effective in reducing anxiety, stress and negative emotionality in family caregivers of cancer patients. CATs helps to facilitate caregiver's psychosocial wellbeing, spiritual support and bonding, thus improving quality of life (evidence is limited).
- It positively impacts adults and children with symptoms of trauma, based on the neurodevelopmental model of trauma (van Westrhenen & Fritz, 2014). CCA Art Therapists work extensively with dependent children of cancer patients who are dying or have died. This is a potential future avenue of research, as clinical expertise and common sense would indicate that distressed children and families require support and care during the potentially traumatic experience and/or profound loss to prevent ongoing heightened distress issues in the future (such as Complicated Grief, Post-Traumatic Stress Disorder, Reactive Attachment Disorder, etc.) and costs to society.
- That listening to music, particularly music of choice, reduces pain symptoms and affects vital signs related to relaxation (strong evidence) (Zhang et al., 2012). Music therapy and music listening are a safe, low cost and practical intervention to support patients and families (Zhang et al., 2012).

One review identified the effects of creative arts therapies as similar to other alternative therapies (e.g. acupuncture, massage therapy, mindfulness-based therapy, exercise and yoga) on anxiety, pain, depression and quality of life (Puetz et al., 2013). While this article reviewed therapist-lead groups, it also included research on artist-lead initiatives. Art Therapists have a professional designation with specialty training to support patients through the use of the arts, which differs greatly from the training of artists. Since this distinction is not made in the research, the above conclusion cannot be assumed to be true for creative arts therapies and at best indicates direction for future research.

The collective systematic and meta-analytic evidence reviewed supports the use of CAT in oncology care and identifies no risk for children and adult populations.

Role and Application of the Model of Care

The CATs working group believes that Creative Arts Therapies should be considered an integral part of the CCA service mix that supports the emotional, psychological and spiritual needs of patients and their families. CATs approach care through creativity, the whole body and links the lower, middle, and higher brain processes for healing and understanding. CATs are a unique therapeutic avenue, which some individuals and families may prefer to traditional counseling and find extremely meaningful. CATs are easily adapted to suit the developmental needs of a diverse range of ages and abilities because they facilitate sensory, action-oriented and nonverbal processing of emotional and cognitive information. The current role of Art Therapists working with dependent children of adults living with cancer is an important component of current practice and one that is unique to them within the CCA system.

In CCA, Art Therapists are part of a broader service team known as *Healing Arts*. Within Healing Arts programming, creative arts therapies are the core care modality. In addition to providing therapy services, the Healing Arts team facilitates the use of arts to benefit patients and families through a friendlier and warmer health care environment (e.g. music performances) and activities that foster "in-the-moment" coping (e.g. arts activity carts before appointments and during treatment). The Art Therapist's professional knowledge related to interventions where the art process is used as a coping mechanism (to support self-soothing, distraction or connection) helps innovate and support the safe and appropriate use of arts-based activities outside of therapy for the diverse oncology population. [See Figure 7, next page].

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*refers to patients and families/support persons

Figure 7. Creative Arts Therapies Model of Care Adapted fromFitch, M. I. (2008). Supportive care framework. *Canadian Oncology Nursing Journal = Revue Canadianne De Nursing Oncologique, 18*(1), 6. Copyright 2010 by Canadian Association of Psychosocial Oncology. Adapted with permission.

Partnerships

Partnerships enable a small team to optimize support for patients and families through:

- Delivery of Creative Arts Therapies that are most suited to the care environment and acute needs of patients and families;
- Expanding the reach of therapeutic art modalities like music performance and art activity carts.

The former relies on knowing other non-governmental organizations in the community with arts-based programming accessible by oncology patients and families. A working relationship has been developing between the Healing Arts program at the Tom Baker Cancer Centre and Wellspring Calgary to ensure programs do not duplicate service targets and simultaneously share learnings and information.

The latter is done through partnerships with CCA colleagues – such as Spiritual Care providers and Volunteer Resources – to support safe volunteer lead art-based activities in certain areas of the care centre.

A future partnership with Child Life Specialists and pediatric Art Therapists has been identified during this process with both the CATs and Psychosocial working groups. Presently, there are no services offered at the Alberta Children's Hospital for dependent children of adults with cancer and there are no outpatient CATs services for children with cancer or dealing with a family member with cancer.

Recommendations

In consideration of the evidence, including the literature, patient needs and values and clinical expertise, the CATs working group developed recommendations for use in CCA, using the Alberta Quality Matrix for Health as a framework for the discussion. A summary of the recommendations, along with their relevant indicators, are included in Table 4. Please note that the recommendations are not in hierarchical order, however the top three recommendations have been identified.

Alberta Quality Matrix for Health

- Appropriateness: Health services are relevant to users' needs and are based on accepted or evidence-based practice.
- Acceptability: Health services are respectful and responsive to user needs, preferences and expectations.
- Accessibility: Health services are obtained in the most suitable setting in a reasonable time and distance.
- Effectiveness: Health services are provided based on scientific knowledge to achieve desired outcomes.
- Efficiency: Resources are optimally used in achieving desired outcomes.
- Safety: Mitigate risks to avoid unintended or harmful results.

Table 4. Creative Arts Therapies Recommendations

Recommendations		Dimension of Quality Matrix that is addressed
1.	Healing Arts is a core component of supportive care and is a person centred choice for the treatment of the psychological/emotional/social/spiritual needs of patients and families, and is a major resource for dependent children of adults with advanced cancer.	Acceptability Accessibility Appropriateness Effectiveness
2.	Creative arts therapies are available to patients and families at CCA regional sites through the enhanced use of technology, site visits and facilitated programs, working in collaboration with local staff.	Accessibility
3.	Healing Arts is a key service in creating an environment in tertiary and regional centres that supports patients, families and staff through intentional use of art and music in the hallways, waiting rooms and patient service areas.	Acceptability Appropriateness Efficiency

Psychosocial Oncology

My story involves my deceased husband's 14 month journey with CNS Lymphoma. We used the Lymphoma psychologist as soon as he was diagnosed and throughout the cancer journey for both Larry and me as the main caregiver. She worked as a mediator for us to work through the shock, anger and disbelief that this was happening to us. She gave us the communication skills and strength to undergo the 6 chemotherapy treatments and the stem cell transplant that he was hospitalized for approximately 3 months in total.

We started a consult with the palliative care in the hospital and community. The social worker started the necessary paper work and nursing staff helped us cope with the extreme side effects of the dexamethasone medication. They were a huge resource for both us to enable Larry to enjoy as best as possible quality of life –time with family, golfing with friends and enjoying the house he built. There is no way I would have been able to carry out his wishes without the help of both the psychosocial services and the palliative team.

~Caregiver (Calgary)

Psychosocial oncology is a specialty in cancer care concerned with the understanding and treatment of the social, psychological, emotional, spiritual and functional (practical and rehabilitative) aspects of cancer, and at all stages of the disease trajectory from prevention through bereavement. Psychosocial oncology involves a whole-person approach to cancer care that addresses a range of human needs that can improve or optimize the best possible quality of life for individuals and their networks affected by Cancer.

Credentials and Requirements of the Providers

Psychosocial oncology is a specialty area staffed with a variety of providers. Social workers, psychologists, psychiatrists, spiritual care specialists, and art therapists all have a role in meeting the emotional, social, psychological, spiritual and functional concerns of cancer. Each provider is university prepared (Bachelors, Masters, PhD, MD) within their specialty and then develops oncology expertise usually through supervised field training – practica, fellowships, and internships. In Alberta, Social Work and Psychology are regulated professions under the Health Professions Act. As such, Social Workers must register with their regulatory college, the Alberta College of Social Workers (ACSW), and possess a valid Provisional or General Practice Permit, if they are functioning within the regulated scope of practice for the Social Work profession. Similarly, psychologists must register with the College of Alberta Psychologists and hold a practice permit as a member. Psychiatrists register with the College of Physician and Surgeons.

Within CCA, social workers, psychologists and psychiatrists are available at the tertiary sites, while social workers provide the support at the regional and community sites.

(Note that spiritual care and art therapy are dealt with in different sections of this report; however, a spectrum of specialists working collaboratively is the recommended model).

Supporting Evidence for Psychosocial Oncology

Patient and Family Values, Needs and Preferences

It was clearly indicated from the patient and family perspective that distress is prevalent and psychosocial support is required (results from the Supportive Care Framework Patient and Family survey, the AOPSS, the Patient Partner Day and in consultations with the Calgary Patient and Family Advisory Council). In the Framework survey, patients and families indicated they view the screening for distress intervention as key to identifying their needs but they do not always know what emotional and psychological supports are available to them. They identified accessibility as an issue, noting that programs are not available in regional and rural sites and that even in urban sites; services were concentrated at a distance from their homes. During the ACF/CCA Patient Partner Day, it was noted that distress is significant during the time from diagnosis to consultation (and earlier) and that administering the screening for distress intervention before the first consult and providing access to appropriate services would be valuable. Emotional support (possibly spiritual care) should be available to patients and families for "difficult conversations" and staff should receive training to deliver bad news. The AOPSS results indicate that the provincial percentage of positive responses to questions on emotional support hover, along with the national average, around 58%, clearly leaving room for improvement across the province.

For "practical needs," patients and families indicated that help with finances, transportation and return to work were all key needs and intervention was required before the patient was registered with CCA.

I have been through the experience of breast cancer twice. During my first experience with breast cancer, I joined a support group at the Cancer Centre, led by a psychologist. This group made a huge difference in my journey. The group helped us explore our cancer experience through discussion, art, visualization and meditation. I am a very private person and it is difficult for me to share my innermost thoughts and feelings. This group helped me to feel safe, to be able to share what I was experiencing and to reach out to others in the group.

~Patient (Edmonton)

O Literature

Psychosocial oncology has a longer history of integration within cancer centres than most of the supportive care services and has a well-established research base. For this reason, literature from greater than five years ago was included. Significant contribution to this has been made by CCA staff, most recently in the area of the 6th Vital Sign – Distress. Ongoing research is well established within CCA Psychosocial Oncology programs. While recognizing the work is not fully comprehensive, the review of the literature did yield the following results:

Cognitive behavioural therapy (CBT) and counselling are shown to significantly improve anxiety and depressive symptoms among cancer patients with elevated symptoms (Andrews, 2013; Barsevick, Sweeney, Haney, & Chung, 2002; Chien, Liu, Chien, & Liu, 2014; Faller et al., 2013; Hart et al., 2012; Parahoo et al., 2013; Uitterhoeve et al., 2004).

- The evidence suggests that CBT is also effective in dealing with distress (Tatrow & Montgomery, 2006) and insomnia, in patients with cancer (Howell, D., Currie, S., Mayo, S., Jones, G., Boyle, M., Hack, T., Green, E., Hoffman, L., Simpson, J., Collacutt, V., McLeod, D., and Digout, C., 2009).
 Psychotherapy is shown to reduce depressive symptoms significantly among advanced cancer patients (Akechi, Okuyama, Onishi, Morita, & Furukawa, 2008).
- In pain management, the strength of the evidence is strong, demonstrating psychosocial (CBT, relaxation, hypnosis and experiential interventions, supportive expressive group therapy) and psychoeducational interventions have meaningful effect on pain severity, interference and improves cancer pain management (A. G. Edwards, Hulbert-Williams, & Neal, 2008; Goodwin et al., 2001; Osborn, Demoncada, & Feuerstein, 2006; Sheinfeld Gorin S et al., 2012; Tatrow & Montgomery, 2006).
- Evidence indicates that peer support programs can improve emotional functioning. The most effective models were found to be the one-on-one, face-to-face peer support model and a group internet peer-support model (Hoey, Ieropoli, White, & Jefford, 2008; Sheard & Maguire, 1999; Zabalegui, Sanchez, Sanchez, & Juando, 2005).
- There is also evidence that suggests that peer support programs could have negative effects on the psychological functioning of patients, particularly those who started out satisfied with their level of emotional support provided by their partner and/or family members (Helgeson, Cohen, Schulz, & Yasko, 2000).
- Evidence suggests that yoga interventions, particularly those that encourage practice at home, can significantly improve sleep quality among breast cancer patients up to 3 months post intervention (Chiu HY, Chiang PC, Miao NF, Lin EY, & Tsai PS, 2014). They can also have a positive effect on a patient's overall quality of life (breast cancer) and emotional well-being (Harder H, Parlour L, & Jenkins V, 2012).
- A number of high quality random controlled trials support the use of mindfulness based therapy to alleviate or improve symptoms of anxiety and depression for cancer patients and survivors (Piet, Wurtzen, & Zachariae, Dec 2012).
- Literature demonstrating the need for practical social work intervention was limited in this review. Colleen Nelson did describe in a paper for the Canadian Cancer Society in Manitoba the financial challenges of having cancer (Nelson, 2010).

O Clinical Expertise

Clinicians within the province are aware of psychosocial oncology and responded that they refer most often to social work and psychology. Furthermore, staff from psychosocial oncology should be fully integrated in clinical practice and should be available across the province, not only at the tertiary sites. Care should be taken to build on the excellence in research and practice that exists within CCA, and to ensure it is leveraged, both within the framework and future work. It was also noted that capacity in the community should continue to be built and enhanced.

In the e-scan and key informant work, vocational rehabilitation and programs for memory and cognition (both of which involve psychosocial oncology) were identified as upcoming programs. Online support groups

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(CancerChat Canada) are used in various jurisdictions to expand the reach of the programs. Three suggestions offered by key informants were identified as critical to a quality supportive care program: dealing with complex patient and family needs in consultation with teams of specialists (including psychosocial providers), building the capacity of front line staff, and ensuring patient and family access to counselling and psychiatry.

Based on their knowledge of the literature, their clinical expertise and experience, CCA psychosocial oncology specialists believe that professionally facilitated support groups are the safest and most efficacious way to deliver peer support, recognizing that peer support is only one of many possible modalities to use in dealing with patient and family psychosocial issues.

Role and Application of the Model of Care

Psychosocial oncology professionals have a well-established and evidence-based role within oncology care and, therefore CCA. This includes:

- Provision of a variety of person-centred therapeutic interventions to address emotional and psychological distress, and improve coping strategies for individuals and families
- Facilitation of referrals to psychiatry when indicated
- Coordination with mental health services
- Provision of support groups
- Provision of web-based interventions, classes, bereavement and loss counselling
- Support in the social and practical areas of need e.g. resource counselling, connection with government agencies and other community supports.

Psycho-oncologists share: (i) a common domain of practice, (ii) paradigm of psycho-Oncology, (iii) evidencebased methods of practice, and (iv) domain of practitioner (specialist, generalist, spirituality, art therapy, etc.). The Canadian Association of Psychosocial Oncology (CAPO) has established standards of care in psychosocial oncology. [See Figure 8, next page].



*refers to patients and families/support persons

Figure 8. Psychosocial Oncology Model of Care. Adapted from Fitch, M. I. (2008). Supportive care framework. *Canadian Oncology Nursing Journal = Revue Canadienne De Nursing Oncologique, 18*(1), 6. Copyright 2010 by Canadian Association of Psychosocial Oncology. Adapted with permission.

Partnerships

Psychosocial oncology works in collaboration with a wide range of healthcare providers internal to CCA and AHS providers and external. Within CCA and AHS, the following are key partners:

- Addictions and mental health
- Palliative care
- Pain and symptom management
- Grief support
- Allied health professionals
- Primary care/chronic disease management
- Neuropsychology
- FCSS and Seniors Health
- Home care
- Aboriginal Health
- Interpretation services
- Site clinical staff
- Navigators

External to CCA and AHS are:

- Provincial and federal government services
- Community partners e.g. Wellspring and Canadian Cancer Society
- Covenant Health
- Housing and transportation programs
- Other community agencies

This is not necessarily an exhaustive list, but rather reflects the groups that psychosocial professionals work with most often in dealing with the full range of patient and family emotional, psychological, spiritual and functional needs.

After I was diagnosed with cancer May 2014 until now, supportive care service was not known to me, or very little aware of it. Most of my info I went through the internet to find – finally found a psychologist to see me but appointments are very far apart. So technically, I was to deal with it on my own, with great stress on our marriage and family life. Today was the first information I've received in the last year.

~Patient Engagement Report

Recommendations

Further to the above evidence, the Psychosocial working group developed recommendations using the Alberta Quality Matrix for Health as a framework for the discussion. A summary of the recommendations, along with their relevant indicators, are included in Table 5. Please note that the recommendations are not in hierarchical order, however the top three recommendations have been identified.



Table 5. Psychosocial Oncology Recommendations

Recommendation	Dimension of Quality Matrix that is addressed
 Create a provincial psychosocial team with a leader appointed to develop practice expectations, standards, research and networks. Give serious consideration to the creation of a provincial reporting structure. 	Efficiency Accessibility Effectiveness
 Conduct a needs assessment for a cognitive rehabilitation service (in collaboration with Rehabilitation Medicine). 	Appropriateness Effectiveness Acceptability
3. Establish linkages and care pathways with <i>Addictions and Mental Health</i> to ensure timely intervention to optimize cancer treatment.	Accessibility Safety Appropriateness
Establish networks to provide access to psychiatry across the province, i.e. tertiary, regional and community sites.	Acceptability Effectiveness Appropriateness Efficiency Safety
Ensure services are responsive to patient and family need with different modalities, use of technology, varied hours, and geographic distribution.	Efficiency Effectiveness Appropriateness
Leverage the current expertise in psychosocial research and teaching to other sites and other supportive care.	Effectiveness Efficiency
Develop a vocational rehabilitation program (requiring therapeutic interventions) in collaboration with rehabilitation services and others.	Accessibility Effectiveness Acceptability Efficiency

Recommendation	Dimension of Quality Matrix that is addressed
Develop connections and care pathways to services for dependent children of adults with cancer e.g. child life specialists, Art Therapist.	Accessibility Safety Effectiveness
Ensure integration into tumour groups for clinical care and operational planning.	Accessibility Efficiency Safety
Ensure professionally facilitated groups within CCA sites are consistent with best evidence in target populations and service offerings. Use the standards of the Canadian Group Psychotherapy Association.	Efficiency Effectiveness Appropriateness Acceptability
Determine and strive for appropriate service levels and staff mix at tertiary, regional and community sites using benchmarking, evidence review, experience and patient reported outcomes.	Efficiency Effectiveness
Ensure tertiary sites have both the capacity and the mandate to provide support and consultation to staff at regional sites and other sites (CCA, AHS or community) in the province.	Safety Acceptability
Increase capacity and accessibility for patients and families throughout the province through use of a variety of technological and therapeutic modalities. This may require examination of the efficacy of web- based therapy for target patient groups.	Acceptability Accessibility Efficiency
Determine effective ways of responding to patient identified need for support on referral to CCA and possibly before the first consult.	Acceptability Accessibility Appropriateness
Continue to provide services through a mix of professional staff to enable person-centred care and effective use of staffing resources.	Acceptability Accessibility Efficiency Effectiveness

Spiritual Health

Lori could not stop crying. A 61-year-old patient receiving radiation therapy, the news that she will likely die within mere months left Lori shaken and overwhelmed. Concerned about having her go home in such distress, the staff called for support from spiritual care. Thus began a months-long series of meetings in which Lori reviewed her life and faced her death, coming to a greater understanding of herself, her needs, and her resources.

Though her childhood was marked by cruelty and chaos, Lori found comfort in the quiet of church. She described her image of the divine as one of a benevolent, gentle father figure, an image that stills her fears about her dying. Though she no longer participates in formal religion, she is able to draw on her internalized faith through prayer and imagery.

While sharing some of her life story with her spiritual care provider, Lori was able to receive positive commentary about the courage and strength evident in choices she made along the way.

~ Spiritual Health Practitioner & Patient (Edmonton)

Spirituality is the experience of relationship with self, with others (inclusive of family, friends, communities, and pets), and with Other (God[s], nature, what is of ultimate significance). Spiritual well-being is "the experience of connection in relationship with self, others, and Other" (Pritchard, 2014). Spiritual suffering is "the experience of loss of connection/disconnection in relationship with self, others, and Other" (Pritchard, 2014).

Within CCA, Spiritual Health is described using the above definitions. A person may undergo spiritual suffering because of the crisis presented by a cancer diagnosis, coping with cancer treatments, and the experience of living and dying with cancer.

Credentials and Requirements of the Providers

Spiritual Health Practitioners are theologically and clinically trained to provide spiritual and emotional support for patients, families and staff. The Alberta Health Services Provincial Spiritual Care Professional Practice Council explains spiritual care professionals as specialists in spiritual care service delivery to persons of any or no religious affiliation. They are employed by AHS to address spiritual care needs of all who use AHS services. They are an integral part of the multidisciplinary team and work within the medical system to assess and address spiritual care needs (Alberta Health Services, 2013b).

Spiritual health practitioners are intensively trained in the relational and spiritual dimension of health care. They bring personal, theological, and psychological wisdom in the assessment and support of patients navigating existential and religious questions, which often surface during transitional periods such as illness, disability, and rehabilitation. Spiritual health practitioners are uniquely trained to offer in-depth spiritual assessment and counsel to patients in theological, religious and/or spiritual distress, and to support varying spiritual and religious practices either directly or in consultation with or referral to spiritual/religious communities. The profession also provides guidance in bioethical decision making and informal, emotional support of team members. In both leadership and education capacities, the spiritual health practitioner is uniquely mandated within AHS to build capability for spiritual health within the interdisciplinary team.

Evidence for Spiritual Health Practitioners

Patient and Family Values, Needs and Preferences

The Patient and Family Engagement did not yield much information about Spiritual Health. The results indicated it was one of the services patients and families didn't know existed or it wasn't available at their site. During the Patient Partner Day, patient and family advisors clearly recommended that Spiritual Health should be available to all patients/families involved in "end of life" or "life altering" discussions. The AOPSS results were consistent in indicating that CCA can improve in the area of emotional support and Spiritual Health is a component of that care.

O Literature

In the review of the literature, the evidence suggests that spiritual care can have a positive impact on cancer patients' wellbeing (Ahmadi, Darabzadeh, Nasiri, & Askari, 2015; Schreiber & Brockopp, 2012; Sinclair & Chochinov, 2012; Visser, Garssen, & Vingerhoets, 2010). Evidence further suggests that patients in the terminal phase of their illness receiving spiritual care are less likely to visit emergency departments or be admitted to hospital (Balboni et al., 2011; Candy et al., 2012). There is evidence that patients want to discuss their religious beliefs with their healthcare providers but physicians and other clinicians struggle to provide appropriate care. Meeting the spiritual needs of patients in a proactive, routine and professional manner requires the integration of spiritual health practitioners within oncology teams (Cobb, Dowrick, & Lloyd-Williams, 2012; A. Edwards, Pang, Shiu, & Chan, 2010; Sinclair & Chochinov, 2012). Evidence is limited but does suggest that spiritual care can reduce distress, anxiety and depression among cancer patients (Moeini, Taleghani, Mehrabi, & Musarezaie, 2014; Oh & Kim, 2014).

O Clinical Expertise

In the engagement and consultation phase, it was found that clinicians referred most often to nutrition and counselling, including spiritual health. It was noted that a spiritual health practitioner is available only at the tertiary centres (CCI and TBCC) which does not meet the criteria of provincial accessibility. Patient and family advisors have recommended that spiritual health practitioners be available for difficult conversations between clinicians and patients/families, in particular those conversations when news was being delivered that there were no further treatments and transition to end of life care was being arranged (Rose et al., 2015).

Role and Application of the Model of Care

Spiritual care is the role of both the spiritual care professional (Manitoba Health, 2007), and the interdisciplinary team (Manitoba Health, 2012) where the "use of self" (Davis, 1994) is the primary tool of care. This contemporary vision of health care constitutes interdisciplinary team members enabled to provide generalist functions of spiritual screening, and history-taking, (Brémault-Phillips et al., 2015; Pritchard, 2014) and the certified spiritual care professional providing the specialist role of depth-assessment/care. (Puchalski, C. M., & Ferrell, B, 2010)

Spiritual health practitioners are theologically and clinically trained to provide spiritual and emotional support for patients, families and staff. Utilizing the model of care, the role can be described as follows:

All patients are screened at points of care on the continuum, using the CCA "Putting Patients First" form. This allows every patient the opportunity to identify spiritual health as a concern. There is a common clinical role with other supportive care professionals within CCA to:

- Provide counselling
- Facilitate patient coping resources, and assisting patients and families to access their best wisdom and capacity to find/make meaning during the cancer experience
- Provide spiritual and emotional support at crisis points
- Provide access to other resources as required i.e. depression, psychiatric issues
- Provide a supportive presence, listening to peoples' hopes and fears in the midst of crisis, suffering, loss or recovery

The role includes:

- Spiritual assessment and intervention
- Facilitating rituals and sacraments (e.g. Sweetgrass, sacrament of the sick)
- Decision-making support and supportive care for patients and families at end-of-life
- Collaboration with community religious leaders as requested
- Serve as a resource to the care team on topics such as communication, religious and cultural awareness, grief and bereavement, compassion fatigue, and spiritual needs assessment.

(Alberta Health Services, 2013b)

It is recognized that currently the evidence is most available for spiritual care intervention in palliative settings and studies are more limited in the oncology ambulatory setting. However, the reality of CancerControl Alberta is that tertiary care, including palliative, is provided daily in the ambulatory setting. Difficult conversations, advanced care planning and transitions to end of life care are managed on a regular basis. The Spiritual Health Working Group believes that spiritual health practitioners should work collaboratively with other providers seeking to reduce distress and anxiety amongst cancer patients and families and that Spiritual Health is an integral part of interdisciplinary care. This also provides an opportunity to best match the needs of patients and families with the skills and training of the providers.

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Compassionate care is an important component of the person-centred approach being taken throughout CCA and AHS. Spiritual Health Practitioners can provide support to patients, families and staff in the provision of person centred care. Examples of Spiritual Health needs in oncology include: the search for meaning in the face of a potentially life limiting disease, existential despair, a need to examine personal values and priorities, feelings of hopelessness and spiritual crisis/resolution. (M. I. Fitch, 2008). Within the experience of current providers, these symptoms and needs also present: intractable suffering, pain, complex pain and symptom management, abandonment by God.



*refers to patients and families/support persons

Figure 9. Spiritual Health Model of Care. Adapted from Fitch, M. I. (2008). Supportive care framework. *Canadian Oncology Nursing Journal = Revue Canadienne De Nursing Oncologique, 18*(1), 6. Copyright 2010 by Canadian Association of Psychosocial Oncology. Adapted with permission.

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Partnerships

Spiritual health practitioners have a key role in the inpatient setting in coordinating and facilitating access to Religious Community Visitors for patients. Religious Community Visitors (RCV) are specialists in religious care service delivery to persons of particular religious affiliation. (Alberta Health Services, 2013b)

As care in the ambulatory setting is episodic and short term, RCVs work in the inpatient setting where care has been taken to ask and record a specific religious affiliation of a patient and they wish to have a visit. This is not a replacement for a spiritual health practitioner that works as a member of the multidisciplinary team and provides care to all.

Within the regional and community cancer sites, there is no CCA staffing associated with Spiritual Health. Partnerships with the host hospitals and their spiritual care professionals might open this service more fully to cancer patients. To support that, providers from the tertiary sites could consider Telehealth or other forms of mentoring and support.

Recommendations

Further to the consideration of the evidence including the literature, patient needs and values and clinical expertise, the Spiritual Health working group developed recommendations for Spiritual Health in CCA, using the Alberta Quality Matrix for Health as a framework for the discussion. A summary of the recommendations, along with their relevant indicators, are included in Table 6. Please note that the recommendations are not in hierarchical order, however the top three recommendations have been identified.

Alberta Quality Matrix for Health Appropriateness: Health services are relevant to users' needs and are based on accepted or evidence-based practice.	
Acceptability: Health services are respectful and responsive to user needs, preferences and expectations.	
Accessibility: Health services are obtained in the most suitable setting in a reasonable time and distance.	
Effectiveness: Health services are provided based on scientific knowledge to achieve desired outcomes.	
Efficiency: Resources are optimally used in achieving desired outcomes.	
Safety: Mitigate risks to avoid unintended or harmful results.	

Table 6. Spiritual Health Recommendations

Recommendation		Dimension of Quality Matrix that is addressed
1.	Referral to Spiritual Health is available to all cancer patients with spiritual distress and suffering. Spiritual Health services are offered to patients and families during and after life altering discussions, during transitions to end of life care and other times of spiritual distress.	Acceptability Accessibility
2.	Screening for spiritual distress is provided to all cancer patients. Front line staff is provided training in screening for spiritual distress.	Accessibility Efficiency
3.	Appoint a CCA provincial lead for Spiritual Health, with responsibility to liaise with and build capacity with religious community visitors, liaise with spiritual health care providers in host hospitals (increasing access for regional and community patients), and to work with other portfolios to increase access to Spiritual Health services (Palliative Home Care).	Accessibility Effectiveness Appropriateness
	Ensure availability of Spiritual Health resources in culturally sensitive and multi-modal formats.	Accessibility Effectiveness
	Integrate Spiritual Health Practitioners into the multidisciplinary teams and the multidisciplinary care processes,	Appropriateness
	Provide an active and integral link from inpatient care to religious community visitors. Inpatients will be asked if they would like to provide information on their religious affiliation, if any.	Accessibility Appropriateness
	Improve and increase the use of technology to enhance accessibility to Spiritual Health services in regional and community centres (incorporated into new patient systems),	Acceptability Accessibility
	Improve the access to spiritual support, in collaboration with psychosocial oncology and other supportive care services, through the use of groups – meditation, spirituality, existential therapy, grief support – where evidence supports the efficacy of this approach	Accessibility
	Create designated sacred space or access to designated sacred space in each centres. If that is not possible, then ensure access to an appropriate quiet room environment for Spiritual Healthcare.	Acceptability
	Spiritual Health Practitioners provide short term and episodic care to other providers experiencing distress related to a crisis event.	Safety

Note: The nomenclature of Spiritual Health Practitioner is relatively new and was chosen for use in this report by the Spiritual Health working group. The nomenclature used relative to this professional group is currently being discussed by the Canadian Association of Spiritual Care and by the Alberta Health Services Provincial Spiritual Care Professional Practice Council and it may be changed in the future.

Informational and Practical Domains of Supportive Care Services

Cancer Patient Navigation

One of our patients received a terminal diagnosis. As the navigator, I was able to help him (and his family), organize everything so they could move east where they would have family to rely on.

~Navigator (Community Oncology)

Navigation is defined as a "proactive, intentional process of collaborating with a person and his or her family to provide guidance as they negotiate the maze of treatments, services, and potential barriers through the cancer journey" (Canadian Partnership Against Cancer, 2010).

Credentials and Requirements for Navigators

Navigators in CCA are registered nurses with oncology expertise, who participate in a comprehensive orientation when they move into a navigator role. In this role they collaborate with community resources, acute care services, clinical staff, social workers and other allied health providers to ensure patients and families receive individualized supports as required during their transition into the cancer system, on their journey through it, and beyond.

Currently in Alberta, through the generous support of the Alberta Cancer Foundation, the Cancer Patient Navigation program has generalist cancer patient navigators situated in 10 of 11 community cancer centres, as well as the four regional cancer centres. The tertiary centres have a complementary, but distinct care coordination model including tumour group specific first contact and tumour triage nursing roles. Tumour group specific navigators also exist within the comprehensive breast care program. These latter programs focus more exclusively on patient care needs related to particular segments of the journey than the generalist cancer patient navigation program within the community and regional centres that provides support across the entire cancer trajectory.

Supporting Evidence for Navigation

Patient and Family Values and Needs

In a variety of patient engagement venues, including the AOPSS, there is a clear message that patients and families appreciate and benefit from interaction with a navigator. Patients indicate that the time between learning of the possibility of cancer, undergoing testing, and finally receiving a referral, is a time of high stress and uncertainty and that access to a navigator during that phase of their journey improves their experience (Rose et al., 2015). It is recommended that all patients, including those at tertiary centres, have access to a navigator who can provide information, connection with supports, and assist with early practical issues. The patient and family component of the *Engagement Survey* also gave positive feedback on the value of their interactions with a navigator.

"I received excellent care. Very efficient with the nurse navigator."

The AOPSS survey indicates a significant difference in the results in the domains of Access to Care and Emotional Support within Community Oncology (CO) settings and the two tertiary sites. The satisfaction levels in CO in both domains have improved since the introduction of navigators in 2012. In comparison, at the tertiary sites, the satisfaction percentage since 2012 (the last survey year) either decreased or remained unchanged. Although it is impossible to draw a direct correlation from these results, it is conceivable that the difference may be due to the introduction of navigators in CO, since in general there are fewer supportive care service providers in these sites than at the tertiary centres.

O Evidence

Navigation is a key component and an effective strategy to improve the delivery of person-centred care to cancer patients, with the majority of navigation programs focusing on patients who are newly diagnosed, have complex needs, and who are from rural and remote communities (Cancer Journey Portfolio, 2012). Cancer patient navigation improves continuity and coordination of care, facilitates timely access to services, and improves system efficiencies, thus improving the overall patient experience of care (Cancer Journey Portfolio, 2012; Fillion et al., 2012; McMullen, 2013). In other words, cancer patient navigation allows for the right care, by the right provider, at the right time.

Numerous studies have shown the benefits of an effective navigation program. In the literature, patients report less anxiety and higher satisfaction with care, understand their treatment plan better, access required services, cope better with their diagnosis, in addition to feeling better prepared for consultations and treatments (Cancer Journey Portfolio, 2012; Fillion et al., 2012).

A diagnosis of cancer is always an unexpected and challenging event for patients and families (Fitch, M., Porter, H. & Page, B., 2009). However, those who live in rural and isolated urban centres face additional challenges in accessing and coordinating care. Often, patients must travel significant distances to access specialized care, as their home community may have a limited number of health care providers with oncology expertise and knowledge (Cantril C & Haylock PJ, 2013). Research has demonstrated that rural patients who receive help from a navigator experience a statistically significant decrease in their distress after being connected to a navigator (Swanson & Koch, 2010).

In Canada, professional navigation originated in the early 2000s with the establishment of two professional cancer patient navigation programs in the provinces of Nova Scotia and Quebec (Fillion et al., 2012). Since then, numerous navigation programs have been initiated across the country, and as of 2011, some type of professional cancer patient navigator support has been instituted in every province as well as one territory in Canada (Cancer Journey Portfolio, 2012; Pedersen & Hack, 2010). Nationally, it is oncology nurses who most often take on the role (Cancer Journey Portfolio, 2012).

O Clinical Expertise

Clinicians reported that Patient Navigation was a service they referred patients to reasonably often when caring for a patient from a community outside of Edmonton and Calgary. Patient Navigation is a service that clinicians, physicians and administrators believed should be available for all patients. This includes access to people who can answer patient questions over the phone, and provide guidance at every step in the process to help with the logistics of service coordination and access to services from diagnosis through treatment.

"Anything that supports transition through the system is of benefit. Patients need help transitioning so they can experience integrated service delivery"

Role Application of the Model of Care

The Cancer Patient Navigation Role:

- 1. Contributes to maintenance or improvement of health outcomes, level of independence and quality of life to the fullest extent possible
- 2. Improves individual and family cancer care experiences, particularly during key transitions on their cancer journey and transitions between health systems
- 3. Enhances individual capacity for self-care
- 4. Facilitates timely access to supports and services
- 5. Contributes to continuity and coordination of care and enhances communication between health care providers, and with patients and families
- 6. Enhances the efficiency of the cancer care system through appropriate use of resources, reduced effort and duplication of services, and effective, timely communication
- 7. Collaborates with key community stakeholders to increase the capacity within communities to better care for cancer patients. [See Figure 10, next page].



*refers to patients and families/support persons

Figure 10. Cancer Patient Navigation Model of Care. Adapted from Fitch, M. I. (2008). Supportive care framework. *Canadian Oncology Nursing Journal = Revue Canadienne De Nursing Oncologique, 18*(1), 6. Copyright 2010 by Canadian Association of Psychosocial Oncology. Adapted with permission.

Partnerships

The primary partnership within navigation is between the patient (and family) and the navigator. However, helping patients overcome barriers to care requires close partnerships with a variety of health care providers, systems, community agencies, and not-for-profit organizations. These partnerships developed both within CCA and in the local context and include:

- Primary Care Networks and primary care providers
- Mental Health services, Home Care, Palliative Care, local acute in-patient services, surgical programs
- Social Services agencies
- Specialty services in AHS such as nutritional support, rehabilitation, and chronic disease management
- Cancer Care teams at tertiary and regional sites in CCA

Recommendations

Further to the consideration of the evidence including the literature, patient needs and values and clinical expertise, the Navigation working group, using a survey method, developed recommendations for Navigation Services in CCA, using the Alberta Quality Matrix for Health as a framework for the discussion. A summary of the recommendations, along with their relevant indicators, are included in Table 7.

Please note that the recommendations are not in hierarchical order, however the top three recommendations have been identified.

 Alberta Quality Matrix for Health

 Appropriateness: Health services are relevant to users' needs and are based on accepted or evidence-based practice.

 Acceptability: Health services are respectful and responsive to user needs, preferences and expectations.

 Accessibility: Health services are obtained in the most suitable setting in a reasonable time and distance.

 Effectiveness: Health services are provided based on scientific knowledge to achieve desired outcomes.

 Efficiency: Resources are optimally used in achieving desired outcomes.

 Safety: Mitigate risks to avoid unintended or harmful results.

Table 7. Cancer Patient Navigation Recommendations

Recommendations		Dimension of the Quality Matrix that is addressed
1.	Provide access to navigation services for all newly referred CancerControl patients, including those referred to tertiary sites. Access to navigation services must span their illness trajectory, including key transition points where patients are moving between health systems or care providers and when complex symptom management is required. It is recognized that the current Community Oncology Navigation model may require adaptation for tertiary sites.	Safety Accessibility Acceptability Appropriateness Effectiveness
2.	Have navigators provide access to the Screening for Distress intervention to facilitate early access to supportive care services and immediate practical supports at new patient intake.	Safety Acceptability Effectiveness Appropriateness Efficiency
3.	Have navigators work in close collaboration with social workers to facilitate links to practical needs and community based supports early in the illness trajectory.	Accessibility Effectiveness Appropriateness Efficiency

Patient and Family Education

The gentleman and his wife had attended one of the NPI sessions that I had presented. He informed me that the session had really helped him, his young wife, and two small children deal with her cancer diagnosis. How satisfying and what a confirmation to know that these NPI education sessions do indeed make a difference and help new patients cope with the cancer diagnosis.

~ Cancer Survivor and Volunteer (Edmonton)

(The New Patient Information Session (NPI) is presented by volunteers to new patients at the Cross Cancer Institute. A cancer survivor participates in each session.)

Cancer patient education focuses on persons affected by cancer, families, and significant others from the time of diagnosis through treatment, and then on to survivorship or palliative and end of life care (Education Committee, Cancer Journey Action Group, Canadian Partnership Against Cancer, 2009).

Cancer Patient and Family Education describes a structured program and approach to empower the patients and families dealing with cancer with the knowledge and information they need to be full partners in their care. It includes any definable activity or resource that supports the learning and behaviour of persons affected by cancer. Patient education plays a major role in empowering patients and families with cancer (Cancer Care Nova Scotia, 2016).

Educating patients about their disease, treatment, side effect management and quality of life can reduce patient anxiety, enhance coping, reduce decisional conflicts, promote patient autonomy and improve the experience for patients and families. Patients who understand their disease and treatment have greater adherence with therapy, which translates into better outcomes.

CancerControl Alberta's (CCA) Provincial Patient Education Committee has developed the following vision and principles to guide the work of the program here in Alberta.

Vision Statement & Principles

CCA patients and families have access to timely, culturally relevant, person-centred information that assists them in understanding their disease and care pathway and enables them to be full partners in their care.

Patient education:

- 1. Will be evidence-informed using research, clinical expertise, patient/family values and expressed needs.
- 2. Will foster self-management, knowledge sharing and empowerment (Partners in Care).
- 3. Must be person-centred and integrated into care pathways.
- 4. Must be culturally relevant, available in multiple formats, multiple languages and based on adult learning principles.
- 5. Is the responsibility of all care providers.

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- 6. Involves continuous quality improvement to ensure the quality of patient education materials and programs.
- 7. Will be developed in partnership with other CancerControl groups and programs, and will leverage existing services within AHS where possible.

Significant components of education include prevention and screening. These are not addressed in this document as this is part of *Alberta Prevents Cancer*.

Credentials and Requirements of the Patient Education Providers & Specialists

Provision of information and the education of persons affected by cancer is the responsibility of everyone working within CCA. All health care providers must be able to teach effectively and provide pertinent and appropriate information at key points in the care continuum. Front line managers and leaders must ensure that resources and site environments are appropriate for a person-centred approach to teaching and learning. The Patient Education Specialists (program staff) have the responsibility to ensure that patient information is current, available, and appropriate and strive to ensure resources are available in a variety of modalities that can be tailored to the individual learning needs of patients and their families.

Program staff may have diverse backgrounds since their role includes research, facilitation, and organization. They must have skills with individual learning styles, principles of adult learning and plain language skills, as well as sensitivity to issues of diversity. Skill with and knowledge of databases, web-based learning and presentation styles are all required. Through hiring practices, skill development and collaborative work, these skills are developed within the program team.

Supporting Evidence for Patient and Family Information and Education

The evidence supporting the need for a robust and comprehensive provincial patient education program within CancerControl Alberta comes from several sources, specifically: a comprehensive literature search, the patient and family engagement survey, Patient Partner Day, AOPSS, feedback from clinical experts, and an environmental scan.

O Patient and Family Values, Needs and Preferences

In the patient and family engagement survey, patients believed the single most important support service is education about their cancer treatment. As a group of services, the informational support services (patient and family education about cancer treatment, workshops and conferences on cancer topics and special classes) were utilized the most.

The patient and family participants during the CCA/ACF Patient Partner Day expressed:

- Patients require an inventory of all support services
- Education needs to be personalized, culturally sensitive, Alberta specific, available in multiple formats and accessible during the period between suspicion of a cancer diagnosis and the consultation with an oncology specialist
- Orientation to cancer sites needs to be available in flexible and varied formats
- Information and help should be provided to support and enhance self-management
- Support in treatment decision making is needed so patients are well informed, understand their options and do not feel rushed

In the 2014 AOPSS data, approximately 65% of patients noted they received the informational support they required. Based on the assumption that *all* patients require some information, there is room for improvement. Similarly, the survey indicated that 36% of people did not believe their families and caregivers had received adequate information to support their care. Enabling easy access to cancer-related information for patients – in particular information about how they can deal with emotions and physical changes, changes in activities, fatigue, nutrition and financial cost – has been identified as a top priority area for improvement in CCA.

O Literature

The Canadian Partnership Against Cancer published a document in 2009 which states that patient education supports the positive outcomes of quality cancer education, including improved:

- System knowledge and/or understanding of disease
- Treatment adherence
- Symptom management
- Ability to cope
- Self-management and self-care
- Quality of life

(Education Committee, Cancer Journey Action Group, Canadian Partnership Against Cancer, 2009)

The evidence in the literature suggests that education interventions (any mode or combination) with the primary goal of orienting new cancer patients and caregivers to the cancer facility can reduce distress among new cancer patients (R. J. Chan, Webster, & Marquart, 2012). This speaks to both the need for general system or process knowledge and the positive impact that knowledge can have in stress reduction.

In general, Johnson et al. finds there are three characteristics of patient education interventions that have the highest levels of effectiveness: (1) multiple education methodologies implemented together, (2) programs that employ interactive techniques and (3) repeated or multiple exposures/exposures over time (Johnson et al., 2011). Individualized education is also imperative. Literature demonstrates that using individualized knowledge transfer interventions for cancer pain improved pain management knowledge, skills and attitudes in physicians, nurses, patients and families as well as improved pain control (Cummings et al., 2011; Lee et al., 2014; Ling, Lui, & So, 2012; Mayyas, 2015).

Non-adherence to oral chemotherapeutic agents is described, by the World Health Organization, as the single most modifiable factor that influences cancer treatment outcomes. Improved provider-patient communication and education is recommended. Patient education is considered key to improved treatment adherence but no current systematic reviews demonstrate the effectiveness of patient education (Arthurs, Simpson, Brown, Kyaw, & Shyrier, 2014). Patient education using evidence-based educational resources,

along with weekly follow-up, telephone communication, drug package reminders and calendars are strategies that may guide patients to improvement in adherence to medications (Arthurs et al., 2014). Investment in improved patient education in the area of adherence to oral chemotherapy regimens may be worthwhile. Non-adherence may be associated with increased resource use and costs. Patients with lower than 85% adherence during the first-year of imatinib therapy had higher inpatient costs, non-imatinib pharmacy costs, and outpatient costs compared with those who had an adherence of 85% or more (Hohneker, Shah-Mehta, & Brandt, 2011).

With respect to symptom management, one pertinent example concerns the issue of fatigue. Fatigue is known to be a prevalent symptom causing distress among cancer patients and the evidence suggests that patient education programs directed at managing this symptom do in fact reduce cancer-related fatigue (Du et al., 2015).

Patient education has been shown to increase patient disease and treatment knowledge and self-efficacy (self-management, patient decision support, ability to cope) (Ryhänen, Siekkinen, Rankinen, Korvenranta, & Leino-Kilpi, 2010; Salonen, Ryhänen, & Leino-Kilpi, 2014).

Virtual informational or supportive interventions (defined as those that used the Internet for delivery such as online support groups, caregiver forums, virtual communities, smartphone applications, or online platforms for caregiver information) have a positive impact on the quality of life of caregivers of patients with cancer (Kuijpers W, Groen WG, Aaronson NK, & van Harten WH, 2013).

O Clinical Expertise

Clinical experts within Alberta were less aware of informational support services than other supportive services, such as physiotherapy and nutrition, and indicated they did not refer patients/families to classes or workshops. They would also like to see services available equitably across the province.

The environmental scan and key informant surveys/interviews yielded the following on Patient Education:

- A strong patient education program is an essential supportive care service
- Needs must be geared to individual patient/family learning styles
- Pre-treatment (radiation, chemotherapy, and surgery) education is needed to alleviate anxiety, and prepare patients for the procedure, treatment or transition
- A comprehensive Patient and Family library should be available with specific disease information and staffed with trained volunteers, and a trained medical librarian
- Classes should be available in multiple formats and Telehealth should be used to leverage resources provincially
- A self-management training program should be available in the future

Role and Application of the Model of Care

Patient and family education is the responsibility of all in CCA. However, it is recognized that a core program with dedicated staff is required to develop:

- Print and web-based information , as well as maintain and ensure it is current, diverse and available;
- Standards and evaluation for teaching patients and families, in conjunction with provincial staff education;
- Any patient education material needed for existing or new care guidelines/pathways, in conjunction with the GUidelines Research Unit (GURU);
- Classes and workshops that meet patient needs.

[See Figure 11, next page].

I don't believe it is enough to hand someone a binder full of info and pamphlets at their initial appointment and expect them to access everything that is offered that they need, based on the fact that "well, you were given the brochure."

~Patient Engagement Report



*refers to patients and families/support persons

Figure 11. Patient and Family Education Model of Care. Adapted from Fitch, M. I. (2008). Supportive care framework. *Canadian Oncology Nursing Journal = Revue Canadienne De Nursing Oncologique, 18*(1), 6 . Copyright 2010 by Canadian Association of Psychosocial Oncology. Adapted with permission.

Partnerships

The Patient and Family Education program staff must work collaboratively with internal (CCA and AHS portfolios and programs) and external partnerships.

Within CCA, the ability to provide an optimal information/education experience in a person-centred environment will require collaborative work with a variety of stakeholders. First and foremost is working with patients and families. Including patient and family advisors on CCA committees has provided substantial insight. They are in the best position to describe their needs and provide feedback on what works well, along with what needs improvement. Close collaboration is also required with additional stakeholders such as Professional Practice (clinical educators especially), Knowledge Resource Services, clinical experts, GURU, Cancer Registry, Volunteer Resources, and others. Outside of CCA but within the greater Alberta Health Services and Alberta Health, there is a need to collaborate with other patient education portfolios in AHS, MyHealthAlberta, primary care networks, and the like.

There is room for collaboration and resource leveraging with pharmaceutical companies and community resource groups (e.g. Wellspring) within the province. Nationally, there are excellent, well-established patient and family resources in various jurisdictions and there is a willingness by these organizations to share (e.g. the Canadian Partnership Against Cancer [CPAC], Cancer Patient Education Network [CPEN], Canadian Cancer Society, and other disease specific groups e.g. Ovarian Cancer Canada). It may ultimately be advantageous for CPAC to work with CPEN to establish a national repository of information in multiple formats. Working together, existing resources can be built upon and leveraged to produce a comprehensive and reputable program.

Recommendations

Further to the above evidence, the Patient Education working group developed recommendations using the Alberta Quality Matrix for Health as a framework for the discussion. A summary of the recommendations, along with their relevant indicators, are included in Table 8. Please note that the recommendations are not in hierarchical order, however the top three recommendations have been identified.

Alberta Quality Matrix for Health

- Appropriateness: Health services are relevant to users' needs and are based on accepted or evidence-based practice.
- Acceptability: Health services are respectful and responsive to user needs, preferences and expectations.
- Accessibility: Health services are obtained in the most suitable setting in a reasonable time and distance.
- Effectiveness: Health services are provided based on scientific knowledge to achieve desired outcomes.
- Efficiency: Resources are optimally used in achieving desired outcomes.
- Safety: Mitigate risks to avoid unintended or harmful results.

Table 8. Patient and Family Education Recommendations

Recommendation	Dimension of Quality Matrix that is addressed
1. Develop an Alberta specific website for patient and family education and information.	Accessibility Efficiency Appropriateness
 Leverage the CCI model of the Patient and Family Information Service, with CCA developing Patient and Family Information Services at Tom Baker Cancer Centre and the four regional cancer centres. 	Appropriateness Effectiveness Accessibility
3. Harmonize core patient education resources across all sites.	Accessibility Safety Appropriateness Efficiency
Develop a communications strategy for patient education to ensure awareness and accessibility for staff within CCA, AHS, and community partners.	Acceptability Effectiveness Appropriateness Efficiency
Work with GURU and others to embed patient education into care pathways and guidelines throughout the care continuum.	Efficiency Effectiveness Appropriateness Safety
Provide patient education resources in multiple modalities e.g. print, digital, classes, workshops, Telehealth, and webinars.	Accessibility Acceptability Safety
Develop an events page on the CCA external website to communicate public events and educational opportunities.	Accessibility Effectiveness Acceptability
Include education resources and classes as part of the Supportive Care Order set/Education prescriptions.	Acceptability Accessibility Effectiveness
Develop evaluation measures and utilize regularly for all services (e.g. ongoing classes, orientation, toolkits) so that quality, efficiency, and effectiveness is maintained.	Accessibility Efficiency Safety Effectiveness
Leverage existing education videos and materials from benchmark organizations as much as possible (with permission).	Efficiency

Recommendation	Dimension of Quality Matrix that is addressed
Ensure all new patients receive orientation to the cancer system in tertiary and regional centres in the modality that works for them (in collaboration with navigators).	Effectiveness Efficiency Appropriateness Acceptability
Ensure that care providers are trained and supported to teach effectively and that they have easy access to patient and family education resources.	Effectiveness Safety Efficiency Appropriateness
Develop lifestyle management classes, workshops, and material that are considered standard of care (working with patient reported outcomes and others).	Appropriateness Acceptability Efficiency Effectiveness
Incorporate cultural diversity and accessibility into all programming and information.	Safety Appropriateness Accessibility
Approach CPAC about developing a national repository of patient education information.	Efficiency Accessibility

My husband was diagnosed with a Glioblastoma Multiforme Gr. 4, 18 months ago. This has been a terrible journey we have been on, with many complications. When a patient and their caregiver go to the orientation at The Cross they are in shock. Even if the various departments are mentioned, your mind cannot process all the information. I am disappointed in how information is transmitted to patients at such an emotionally complex time in their lives. Hopefully changes can be made.

~Caregiver (Edmonton)

Specialty Programs

I was diagnosed with Hodgkin's disease and finished with treatment four years ago. As a patient, I attended an information session that focused on young adults that were battling or had battled cancer and I felt a sense of connection as finally, I believed there were others like me going through a very similar situation. Personally, I dealt with a strong feeling of isolation and anxiety going through my treatment that I couldn't talk to anyone about because I felt like they wouldn't understand. I still deal with these feelings and I strongly believe that the addition of support groups that have set meetings would strongly benefit young adults battling cancer or who have battled cancer.

~Young Adult Patient (Edmonton)

Full exploration and analysis of the evidence for Specialty Supportive Care Programs within CCA was beyond the scope and resources of this project. However, the Supportive Care Council identified criteria for designating a Specialty Supportive Care Program, along with undertaking delineation of the requirements for establishing such programs. This work was undertaken in person at a Supportive Care Council meeting in fall 2015, as well as through a survey of key informants within CCA who are known to have clinical expertise and/or a research interest in Specialty Supportive Care programming. The survey was sent to 32 participants and there was a 75% response rate. Presently, Specialty Supportive Care Programs comprise the following within CCA in some format: palliative care, young adult, sexual health, genetic screening, and survivorship/transitions of care. The criteria were also informed by the engagement work with national and international key informants.

The Supportive Care Council has agreed on the following criteria as key to designation and as drivers for the development and provision of Specialty Supportive Care program(s):

- The program addresses a currently unmet health care need and/or underserved patient population
- The program serves a distinct subpopulation of oncology patients who share unique and complex health care needs
- Specialty programs address health care needs that cross tumour groups and disease types, and therefore, do not have oversight through the provincial tumour group structure
- The complexity of the patient population is best addressed with multi, trans, and interdisciplinary teamwork and programming, which involves several health care professions including supportive care disciplines working together with the patient and family in partnership
- Care requires specialty health care knowledge, skills and expertise specific to the population being served
- Care may require specialized equipment and/or technology
- Access to care requires provincial collaboration and coordination

Recommendations

With the Supportive Care Council, the following recommendations were developed, using the Alberta Quality Matrix for Health as a framework. A summary of the recommendations, along with their relevant indicators, are included in Table 9. Please note that the recommendations are not in hierarchical order, however the top three recommendations have been identified.

Alberta Quality Matrix for Health Appropriateness: Health services are relevant to users' needs and are based on accepted or evidence-based practice. Acceptability: Health services are respectful and responsive to user needs, preferences and expectations. Accessibility: Health services are obtained in the most suitable setting in a reasonable time and distance. Effectiveness: Health services are provided based on scientific knowledge to achieve desired outcomes. Efficiency: Resources are optimally used in achieving desired outcomes. Safety: Mitigate risks to avoid unintended or harmful results.

Table 9. Specialty Program Recommendations

Recommendations		Dimension of Quality Matrix that is Addressed
1.	Conduct a gap analysis of existing specialty programs and based on findings, develop plans that ensure provincial accessibility.	Accessibility Appropriateness
2.	Utilize patient reported outcomes and best practices across the industry to support the development of specialized care required by a subpopulation of patients.	Appropriateness Acceptability Effectiveness
3.	Plan from conception for provincial access for future specialty programs. (It is noted that access and programming likely will not be equal or identical at all sites. Rather, elements, such as information are widely available and efforts are undertaken to provide more comprehensive access through use of technology, travelling specialists, patients being referred to tertiary sites for support, mentoring and support of professionals at community sites and in primary care where required).	Accessibility Efficiency
	Intentionally apply the Hub and Spoke model to the development and implementation of Specialty Supportive Care programs.	Accessibility Efficiency
	Appoint a provincial lead or champion with the expertise, time and resources to plan a standardized provincial program, who is accountable for overall provincial program deliverables.	Effectiveness Efficiency
	Incorporate evaluation into future program development, including identification of resources (systems and staff) required to enable ongoing evaluation and QI.	Effectiveness Efficiency
	Include education (patient and professional) as core program components.	Safety Effectiveness
	Employ communication strategies to ensure knowledge of and access to the specialty service.	Accessibility

Community Agencies and Associations

In Alberta, numerous community agencies and associations external to Alberta Health Services (AHS) provide services to cancer patients and their families. Recognizing that these organizations can play an essential and complementary role in helping to meet the needs of cancer patients and their families, CancerControl Alberta has a vested interest to work collaboratively and establish partnerships with the volunteer sector, cultural, and community organizations. Currently, there are many examples of collaboration and partnerships between CCA and various agencies. CCA routinely utilizes patient education material developed and supplied by the Canadian Cancer Society, and by community associations and agencies; there are jointly sponsored programs/events such as, a head and neck cancer support group at Wellspring Calgary and CCA clinical experts presenting at agency events. There is, however, a consensus that further opportunities for partnership and collaboration exist. While the desire and interest is large, there is little by way of formal AHS policy, guidelines, or directives to assist in standardizing processes and criteria that would specify when, with whom, and how to enter into formal and informal partnerships with organizations external to AHS.

Engagement with various community agencies and associations within Alberta helped to increase understanding and inform the resulting framework recommendations. Organizations were contacted, surveyed, and multiple opportunities for discussion were facilitated to gain understanding about their mandates, their view on a future relationship with CancerControl Alberta, and their insight on how to best align collective efforts in a complementary and coordinated manner to better serve Alberta cancer patients.

In early November 2015, 20 different community cancer agencies were sent a survey. The survey requested responses, including text, on the following:

- What is the mandate and target population?
- How does the agency differentiate their services from those of CCA?
- Does the agency provide peer support?
- How does the agency recommend structuring collaboration and partnership with CCA?
- Does the agency see the CCA's *Sources of Help* booklets as an avenue for informing patients of their work?
- As the CCA web presence develops, what criteria should be used to determine which links to community agencies are on the website?

Survey responses were collated and recommendations formulated in draft form. These were then reviewed at an in person meeting with the agencies in January 2016 and with Wellspring Edmonton in a meeting in March 2016. The response rate for the survey was 52%.

In general, the overall mandate of the community agencies and associations (from their perspective) may include one or more of the following:

- provide education and information to cancer patients and families
- undertake an advocacy role

 improve the quality of life of cancer patients and families/caregivers through the provision of nonclinical programs, practical services, emotional, and peer support (formal and informally by providing a platform to connect with others)

Uniformly, the survey respondents, CCA's TBCC Patient and Family Advisory Council, the participants at the Patient Partner Day, and patient advisor members of CCA's Provincial Patient Education Committee espouse the value of peer support. A number of the community agencies surveyed provide some level of peer support either through trained volunteers, (telephone, face-to-face, or on-line) or incidentally, through group activities.

Further learnings from the community engagement survey included:

- 60% of the respondents indicated that collaboration and partnership should be structured
- 91% indicated that it would be productive for CCA to have a designated person responsible for working with community agencies (multiple respondents indicated that the agencies should also have a point person).
- 25% indicated that a regular newsletter would be helpful

There was strong support for a CCA's *Sources of Help* type of directory and including links to community agencies on the CCA external website.

Process and Criteria

To establish partnership recommendations, the Supportive Care Council consulted with AHS Legal, AHS Community Engagement and Communications, CCI Cancer Information Centre (Volunteer Resources), and community agencies. Cancer care attracts a wide spectrum and variety of not-for-profit and commercial enterprises, all who have an interest in providing information and services to people who have or have had cancer. Without explicit direction from Alberta Health Services, it is prudent for CCA to establish its own common understanding of some processes and criteria that would outline a consistent approach to when, with whom, and how to responsibly enter into formal and informal partnerships with organizations external to AHS. CCA should consider both formal and informal relationships.

a) Informal – Proposed Criteria for Information Sharing Partnerships:

- Non-profit organization, government or government sponsored/funded organization
- Health-related educational material shall be from a reliable source (Alberta Health Services, 2015a). Within CCA this would include one or more of the following:
 - National or provincial organizations
 - Material that is used by at least two other Canadian Cancer Centres
 - o Material approved by the CCA Provincial Patient Education Committee
- Health care information is evidence-based
- Information about service(s) provided by non-profit organizations would be restricted to non-clinical services or services that are supplementary (enhanced care) to health care provided by Alberta Health Services. Non-clinical is defined as a service delivered by a layperson that does not have a targeted and individualized therapeutic intent. It is appreciated that many non-clinical services may indeed improve quality of life and overall wellness.
- Information provided to patients and families does not:

- endorse, provide quotes, or allow the AHS name to be used in any third party press releases, advertising, promotional material, or other formal communications. (level 1 Policy on Community Engagement and Communications – document #1106)
- o function as advertising or engage in activities that could be construed as advertising
- o pose a risk to patient safety
- Partnership with community agencies or organizations that do not meet the above criteria may be considered on a case-by-case basis through a defined appeal process.

b) Formal – Proposed Criteria for Shared Responsibility Partnerships

- Non-profit organization, government or government sponsored/funded organization
- Information or material used or distributed would be from a reliable source, such as:
 - o national or provincial organization
 - o material and/or services are endorsed by at least two other Canadian Cancer Centres
 - o material reviewed and approved by the CCA Provincial Patient Education Committee
- Health care is evidence-based
- Partnership addresses an identified need/gap in service
- Performance standards and service expectations are agreed upon by both parties
- Services do not pose a risk to patient safety
- Written agreement signed by both parties (Memorandum of Understanding)
- Partnerships abide by defined guiding principles (see Appendix 6)

Partnership with community agencies or organizations that do not meet the above criteria may be considered on a case-by-case basis through a defined appeal process.

Recommendations

The following are recommendations relevant to guiding CCA's future collaboration and partnerships with Community Agencies and Associations.

Recommendations		Dimension of Quality Matrix that is Addressed
1.	Clearly designate the responsibility for information sharing, fostering connections and collaboration with community agencies and associations.	Effectiveness
2.	Establish standardized criteria and processes for partnering with community agencies and organizations and ensure adherence to these standards across CCA.	Effectiveness Appropriateness Safety
3.	Define and implement an appeal process for organizations that do not meet outlined criteria for partnership.	Accessibility
	Vet all information sharing requests from organizations that meet the CCA partnership criteria through the Provincial Patient Education Committee to support provincial harmonization.	Appropriateness

Recommendations	Dimension of Quality Matrix that is Addressed
Avoid duplicating non-clinical support/practical services already offered by community agencies and organizations.	Effectiveness
Utilize Inform Alberta as a repository of information about community agencies and associations.	Effectiveness
Ensure local information on community programs is available (e.g. <i>Sources of Help</i>) for patients and other stakeholders.	Accessibility
Use legal disclaimers when providing health care or other information not prepared or critically evaluated by Alberta Health Services.	Safety
Develop written agreements, by way of Memorandum of Understandings, for all shared responsibility partnerships.	Effectiveness Appropriateness

Summary

CancerControl Alberta will provide care to approximately 16,000 newly diagnosed patients in 2016. For these newly diagnosed patients, the five year relative survival rate is 63%. By 2030, the estimated number of new cases in Alberta will increase 40% to 22,400. (Canadian Cancer Society, Statistics Canada, 2015). With the ongoing development of new treatments and the increasing number of people living with cancer as a chronic disease, the need for supportive care services to address cancer-related impairments and maintain quality of life will continue to grow. Up to 25% of cancer survivors have impairments or issues that significantly affect their long term health, as well as their ability to live well or work. These include bowel or urinary incontinence, crippling fatigue, sexual difficulties, heart problems, bone issues, and psychological and vocational problems. (Macmillan Cancer Support, 2013a; Macmillan Cancer Support, 2013b). Evidence affirms the need for interventions to mitigate the impact of cancer and its treatment and to improve the quality of life of patients and families, wherever they may find themselves along the cancer trajectory. While the large majority of Alberta cancer patients tell us their cancer care was good, very good or excellent (2014 AOPSS survey), improvements can be made. Consistently patients, families and clinicians have described the need to improve the cancer care experience, particularly within the realm of whole person care and supportive care.

The Supportive Care Council believes that the health system has a responsibility to provide care that does not just "treat the tumours" but also optimizes the health and well-being of patients and families. Organizing, resourcing, collaborating and partnering with patients and families will be needed to make it happen.

Defining the role of CCA is not a simple undertaking, as the path of each individual differs depending on disease, treatment, health status, economic status, region of the province, and the resources available locally within the health system and community at large. Significant investment is required to empower patients and families, through personalized management plans, website development, service information as well as targeted, individualized supports. Further strategic investment must be made in forging collaborative partnerships and structured transitions with primary care and other areas of AHS.

CCA's role in the provision and development of Supportive Care services is multifaceted, comprising seven key elements, as featured in Table 10.

CancerControl Alberta

Table 10. Seven Elements of Supportive Care Services



Partnership with Patients and Families. Ensuring patients and families are partners in the development, improvement and future planning of Supportive Care Services that are respectful of diversity. Further, through the provision of individualized plans (*Treatment Management* or Living your Best with Cancer), patients and families are assisted in developing self-management health optimization strategies and supported to utilize existing services.



Direct provision of Supportive Care Services. Providing services to deal with distress and impairments caused by the diagnosis of cancer, the disease and/or its treatments, throughout the trajectory from diagnosis through to treatment completion and beyond. Cancer related impairments are identified early through the Putting Patients First Intervention, clinical assessment and judgment and addressed through appropriate referral to supportive care services.



Referral to Other Specialty Services in AHS. Creating patient care pathways and smooth transitions of care where an impairment/distress requires a level of specialty service that is not available within CCA (for example: cardiology).



Partnerships and Transitions of Care. Working collaboratively with other portfolios in AHS, and with Community Agencies to deliver services that complement the specialized oncology expertise within CCA. Examples include delivering classes on nutrition, lifestyle programs through the primary care portfolio, addictions care and transitions to primary care at end of treatment.



Supported Service Delivery. Fostering healthcare partnerships through either a shared care model or hub and spoke model would improved capacity to provide care closer to home, improve access and effectiveness.



Advocacy. Advocating for improvements to support patients and families where CCA recognizes that services are inadequate to support the needs of cancer patients (e.g. Mental Health, Rehabilitation).



Teaching and Clinical Research. Taking a lead role in the provision of oncology specialty teaching and clinical research in Supportive Care Services.

Moving Forward: Priorities for Action

From the national and international engagement efforts, the literature review and listening to the voices of patients and families, the evidence is clear – Supportive Care Services are a key component of a comprehensive cancer care system. They are fundamental to person-centred care, optimizing the health of people living with cancer while reducing the burden of cancer to society as a whole. While Supportive Care is a key component of cancer care, it is evident that CCA cannot and should not be the primary provider for every conceivable supportive service. Delineating the role of CCA is complex and will vary depending on patient need, geography and availability of external partners and programs. CCA's responsibility and role in the provision of Supportive Care may take several forms: that of a primary provider, consultant, researcher and collaborator. CCA's Supportive Care clinical services should focus on the treatment of impairments or conditions caused directly by cancer or cancer treatment and on individualized, targeted interventions.

The range and breadth of gaps, opportunities and recommendations in this report presents a challenge to CCA in identifying priorities for action. Throughout the process, key themes did emerge.

It is clear that CCA does not have structures to drive or influence province-wide changes and improvements or ensure accountability in Supportive Care services.



Develop a model of leadership and provincial accountability that fosters and enables programmatic standards and practices within supportive care, including specialty program development, across CCA.

As this report is designed to be foundational, it provides perspective regarding the functions of comprehensive Supportive Care services. However, further information is required on existing services, their distribution, as well as current resource levels as a base line for implementation of the recommendations and identification of priority areas for investment.



Undertake a current state and gap analysis of CCA Supportive Care Services including disciplines and specialty programs. Identify priority areas for investment.

Supportive Care services are not currently well integrated within CCA. This is evident in a number of the gaps identified throughout the work. To begin improvement in the patient experience of care processes and transitions, integration must be improved.



Integrate Supportive Care services into site and provincial tumour teams, clinical guidelines, care pathways, care teams, staff orientations, performance standards, and patient and family orientation in a more intentional manner.

CancerControl Alberta

As the nature of cancer care is changing, with more people living with cancer, supportive care services are internationally and nationally recognized as integral to a comprehensive cancer care system. The Supportive Care Council believes that the health system has a responsibility to provide care that optimizes the health and well-being of patients and families. Fully realizing Alberta's Cancer Plan to 2030 will require embracing a transformational change from a health care system that treats cancer to a health care system that treats people who have or have had cancer. CCA has a significant role in this transformation.

There are examples of supportive care excellence that exist within CancerControl Alberta that can be leveraged to provide provincial leadership in the growth and development of supportive care clinical and practice services. Implementation of the priority actions is the first step and will assist in creating a future where the patient experience of supportive care is fully realized.



If AHS provided me with access to supportive care services, my quality of life would vastly improve. I would receive the support that I need to balance my life with my treatments. My stress levels would decrease so that I can enjoy life with my daughter and husband. I could continue to be a productive member of society. I would feel whole despite the toxic treatments and their effects on my person both physically and mentally. I would be much better prepared for a transition into life beyond or with cancer.

~Person LIVING with cancer (Calgary)

List of Supporting Documents Available on Request

Supporting Document 1. Supportive Care Framework Search Strategies for All Disciplines

Supporting Document 2. Inclusion-Exclusion Criteria for All Disciplines

Supporting Document 3. Joanna Briggs Institute Systematic Review Appraisal Criteria

Supporting Document 4. Literature Review Summary Tables for All Disciplines

List of Appendices

- Appendix 1. CCA Supportive Care Council Terms of Reference
- Appendix 2. Engagement Report (Results of a Comprehensive Engagement Process on Supportive Cancer Care for CancerControl Alberta)
- Appendix 3. Ambulatory Oncology Patient Satisfaction Survey (AOPSS 2014) Supportive Care Summary
- Appendix 4. Consultation Rubric
- Appendix 5. Putting Patients First Form
- Appendix 6. Guiding Principles of Partnerships

Appendix 1. Council Terms of Reference

CANCERCONTROL ALBERTA SUPPORTIVE CARE COUNCIL

Date: June 3, 2013

Executive Sponsor

Executive Director, Community Oncology and Provincial Practices, CancerControl Alberta Chair

The council will be led by a dyad, at least one of whom will be a clinician. Meetings will be chaired alternately by one of the co-leads.

Accountability

The Supportive Care Council is accountable to the Senior Vice President, AHS CancerControl Alberta. The Council receives approval for decisions, policies, standards and new strategies and services from the CancerControl Executive Leadership Committee.

Vision

Building world-class multidisciplinary supportive care services that are integrated provincially throughout the cancer journey for all Albertans with cancer.

Supportive Care

As a Supportive Care Council **we believe** that:

- The provision of Supportive Care services leads to optimized quality of life for persons who have and/or who have had cancer and their loved ones
- Supportive care requirements span the cancer care continuum extended from cancer diagnosis through to survivorship and/or palliative care, and into bereavement
- Supportive care refers to a multi-disciplinary, integrated approach to care, that provides evidence informed, person-centered healthcare and support for the psychological, physical, emotional, social, spiritual, informational, cultural and practical needs of the person.

Guiding Principles

We will:

Steering the work of the Supportive Care Council will be the following, agreed upon guiding principles.

Be collaborative Show mutual respect Promote holistic and person centered care Be provincially equitable Ensure that initiatives endorsed by the Council are sustainable or have a sustainability plan Be evidence informed, considering a wide variety of informational sources Be integrated, comprehensive and inclusive in decision making Be pragmatic, linking practice and theory Address care gaps Endeavour to align work with organizational priorities

Objective

To plan and develop comprehensive and integrated Supportive Care standards, programs and services available to Albertans experiencing Cancer. Through recommendations to the CancerControl Executive Leadership group and working collaboratively with other AHS CancerControl Councils, the Cancer Strategic

Council Terms of Reference

Appendix 1

Clinical Network, the Provincial Tumour Team and multidisciplinary teams throughout CancerControl and AHS, ensure assessment and management of cancer patient and family supportive needs and provision of programs and services to meet and/or exceed their expectations.

Functions

- To develop common understanding and inventory of supportive care services available in CancerControl throughout the province identifying gaps in both services and human resources, and to establish workforce projections to address need,
- 2. Develop strategies and make recommendations to ensure reasonable equity in access to supportive services across AHS CancerControl recognizing differing operational realities,
- **3.** To ensure development and provision of supportive services across the province in accordance with relevant industry, AHS and CancerControl standards,
- 4. Establish priorities for improving supportive care service delivery across the province,
- **5.** To facilitate the development and coordination of provincial standards in philosophy, access, format and delivery of supportive care services in respect of operational realities,
- **6.** To identify and make recommendations for the development and monitoring of metrics on the utilization of, quality of, and outcomes of supportive care services,
- To provide direction and support for the development of potential research opportunities in supportive care including recommendations and proposed processes for operational implementation of successful projects,
- **8.** To work with internal and external stakeholders to ensure that external and research funding opportunities for Supportive Care are realized,
- **9.** To facilitate and recommend effective communication strategies regarding Supportive Care initiatives,
- **10.** To facilitate and recommend educational opportunities in supportive care for all CancerControl staff.

Annual Deliverables

- 1. Provide an annual report to CancerControl Executive Leadership, identifying achievements, barriers to performance and an ongoing strategic vision for Supportive Care that is in accordance with CancerControl priorities,
- 2. Provide recommendations on a 3 year provincial workforce plan that identifies workforce projections based on standards and benchmarks(where they exist), with updates annually,
- **3.** Annually provide the information required including new program proposals, budget implications for the CancerControl planning cycle.

Membership

Co-Leads

Co-leads will be elected for three-year terms, and may be reappointed at least once. Co-leads are evaluated annually by the SVP and Executive sponsor.

Selection of Council members

The Council will be constituted by permanent and rotating members. Rotating positions will be chosen annually by the co-leads, working with the permanent members of the Council to come up with a slate of

nominations. The term of the rotating members will be three years, with reappointment to the Council for a second term upon approval of the permanent members of the Council.

Each member has dual responsibility in representing both their particular discipline and in working collaboratively with overall stewardship for Supportive Care services.

Permanent: (12)

Director, Supportive Care and Patient Experience, CO Director of Psychosocial and Spiritual Resources, CCI Director, Supportive Care and Patient Experience, TBCC Director of Psychosocial Oncology, TBCC Coordinator, Spiritual Care-TBCC Manager of Rehabilitation Medicine-CCI

Medical Director of Palliative Care-CCI or Operational Lead of Palliative Care-CCI Medical Director of Palliative Care-TBCC or Operational Lead of Palliative Care-TBCC Community Palliative Care Physician Aboriginal Care CO Leader, Person Centred Care Integration

ExOfficio

Executive Sponsor Rad Vice President, Cancer Strategic Clinical Network Medical Director, Cancer Strategic Clinical Network Director, Planning C-MORE representative Co-leads, Radiation and Systemic Treatment CancerControl Councils

Term/Rotating Members (14)

Social Worker Psychologist Rehabilitation clinician Pharmacist Advanced Practice Nurse Radiation Therapist Nutrition Navigator Manager, Associate Centres and CCCs

Blood and Marrow Transplant Program Wellspring Calgary Patient Education Patient and Family Representatives Medical Oncologist Radiation Oncologist

Meetings

Meetings will be held monthly in person or by video conference. Additional meetings may be held at the call of the Co-leads.

Agenda and Minutes

Agendas will be prepared by the Chairs in consultation with the Executive Sponsor. All members may contribute agenda items. The agenda will be circulated a minimum of 48 hours prior to each meeting Minutes will be the responsibility of the recording secretary and will be sent out within 1 week of each meeting so that action items are clearly communicated. Circulation to the CancerControl Executive Leadership is the responsibility of the Executive Sponsor.

Quorum

50% of voting members will constitute a quorum. Alternates may attend with the approval of the Co-leads.

Decision Making

The committee will strive to make decisions by consensus but should a vote be requested or be necessary, 50% plus one of the attendees at the meeting constitute the majority.

Working Groups

At the direction of the Co-Chairs, working groups may be set up in response to a specific project or task. These may include groups addressing provincial functions such as workforce, measurement and quality of care. Responsibilities of Working Group Members include:

- Regular attendance at meetings
- Assisting with a clear agenda and focus for the group, including deliverables
- Ensuring that they contribute to regular reports that are provided to Council
- Making the Council Co-leads aware of issues or concerns within the group

Terms of Reference Review

The Supportive Care Council terms of reference are reviewed March of every year and must be approved by the CancerControl Executive Leadership Group.

Endorsed by Council: Draft June 3, 2013 Approved by CCELC: Annual Review Date: Mar 2014 Reviewed May 21, 2014





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Pictochart on front cover and throughout from http://piktochart.com/.

ACKNOWLEDGEMENTS

Research and Writing Team	
Sarah Singh	Consultant, Knowledge Management
Jennifer Dotchin	Sr. Consultant, Engagement and Patient Experience
Erin Fani	Consultant, Engagement and Patient Experience
Working Group Mem	bers
Deb Allatt	Co-Chair Supportive Care Council
	Lead, Provincial Patient Education, Patient Engagement and Supportive Care
Janice Yurick	Co-Chair Supportive Care Council
	Manager, Rehabilitation Medicine CCI
Donna Rose	Director of Planning, Cancer Care
Vivian Collacutt	Director, Supportive Care & Patient Experience Community Oncology
Sarah Singh	Consultant, Knowledge Management
Lisa Petermann	Sr. Consultant, Engagement and Patient Experience
Jennifer Dotchin	Sr. Consultant, Engagement and Patient Experience
Erin Fani	Consultant, Engagement and Patient Experience
Engagement and Pat	ient Experience Team
Anne Lemieux	Sr. Consultant, Engagement and Patient Experience
Marni Panas (Lonsultant, Engagement and Patient Experience
Katnie Irinn	ntern, Engagement and Patient Experience
Supportive Care Could	De diction On colonist
Alysa Fairchliù Amanda Kabataff	Radiation Therapiet
Alliallua Kabatoli Porru Pulta	Raulauoli Therapist Clinical Leady Daysbosocial Oncology and Dobabilitation Modicing. Tom Palvar
Dally Dultz	Concer Centre
	Calleer Celler
Bert Enns	Project Lead, Joint TBCC/Calgary Palliative/End of Life, TBCC
Brenda Hubley	Executive Director, Community Oncology and Provincial Practices
Christopher Ralph	Pharmacist
Cindy Railton	Nurse Practitioner
Deb Allatt	Co-Chair Supportive Care Council
_	Lead, Provincial Patient Education, Patient Engagement and Supportive Care
Janice Yurick	Co-Chair Supportive Care Council
	Manager, Rehabilitation Medicine CCI
Donna Rose	Director of Planning, CancerControl Alberta
Vivian Collacutt	Director, Supportive Care & Patient Experience CO
Margie McNeely	Physiotherapist
Linda Watson Krista Maradan	Director, Person-Centred Care Integration, Provincial Practices
Kilsta Maisuell	Acting Director Developsocial & Spiritual Descursos CCI
Jui Tui nei Ionnifor Dutka	Pharmacist CCI
Mona IIdowicz	Fila maches, con Director of Auglity Safety and Patient Experience Provincial Practices
Patty Tachynski	Dietitian Team Leader CCI
Sharon Watanabe	Director Palliative Care CCI
Susan Carr	Community Advisor
Tricia Hutchison	Social Worker . CO
Tim Buckland	Community Advisor
Paula Germann	Site Director - Cross Cancer Institute
Vanessa Krause	Medical Oncologist
Janine Giese-Davis	Psychosocial
Wilson Miranda	Spiritual Care Specialist
Joanne Stewart	Nurse Practitioner
Isabelle Ramsav	Registered Nurse
Shawn Staglag	Director Developsocial and Spiritual Care CCI
Shawn Steggles	Director- r sychosocial and spiritual Care CCI

BACKGROUND AND PURPOSE

Background

CancerControl Alberta provides comprehensive cancer care, diagnosis and treatment to Albertans. It operates within a fiscal reality and must prioritize services. Approximately **1 in 2** Alberta residents will develop cancer in their lifetime. Survival after diagnosis has improved over time resulting in more individuals alive with a prior cancer diagnosis. As of December 31, 2012, approximately **131,550** Albertans were alive who had previously been diagnosed with cancer.² Supportive care services are a rapidly evolving component of cancer care that has not historically been well funded or operationalized provincially or nationally.

Given this reality, specifically related to patient and family needs, the changing nature of the disease course and resultant symptoms and long term consequences of disease and/or treatment and current and incoming evidence, decisions must be made about the scope of the responsibility of the formal cancer system and how it must partner with others to provide a reasonably full scope of supportive care services to those that need it.

The **Alberta Cancer Plan** notes that Albertans with cancer will be provided with best possible supportive care services throughout the cancer trajectory (Strategy 6). In order for this to be operationalized, we must define what supportive care is in the Alberta context, how it will be provided and by whom, how it will be accessed and how it will be evaluated.

Supportive care is an overarching concept to describe all the help cancer patients and their families need beyond the medical, surgical or radiation interventions.

Supportive care is defined as the provision of the necessary services for those living with or affected by cancer to meet their physical, emotional, social, psychological, cultural, informational, spiritual and practical needs during the diagnostic, treatment, and follow-up phases, encompassing issues of survivorship, palliative care and bereavement.³ The goals of care, tailored to patient need, may be preventative, restorative, supportive or palliative in intent.⁴

Currently in Alberta, the following professionals are involved in addressing the supportive care needs of patients/families: social workers, psychologists, family physicians, palliative care physicians, spiritual care providers, registered Dietitians, registered nurses, physical therapists, occupational therapists, speech language pathologists, patient educators, clinical pharmacists, nurse practitioner, aboriginal navigator and coordinator and art therapists.

² Alberta Health Services. (2012) 2012 Report on Cancer Statistics in Alberta Summary. Surveillance and Report CancerControl Alberta. Pg. 4 http://www.albertahealthservices.ca/assets/healthinfo/poph/hi-poph-surv-cancer-summary-2012.pdf

³ Fitch, Porter, & Page, 2008, p. 22.

⁴ Dietz JH Jnr. (1980) Adaptive Rehabilitation in Cancer. Postgraduate Medicine, 68(1): 145-153.

As an advisory group, the CancerControl Alberta's Supportive Care Council aims to inform the planning and development of comprehensive and integrated Supportive Care standards, programs and services.

As a Supportive Care Council **we believe** that:

The provision of Supportive Care services leads to optimized quality of life for persons who have and/or who have had cancer and their loved ones

Supportive care requirements span the cancer care continuum extended from cancer diagnosis through to survivorship and/or palliative care, and into bereavement

Supportive care refers to a multi-disciplinary, integrated approach to care, that provides evidence informed, person-centered healthcare and support for the psychological, physical, emotional, social, spiritual, informational, cultural and practical needs of the person.

This Council has undertaken the creation of CancerControl Alberta's Supportive Care Framework to serve as a guiding document for provision of supportive care for Alberta cancer patients throughout their cancer journey. This framework document will:

- Define supportive care within cancer care and facilitate better understanding amongst healthcare professionals and patients.
- Represent the supportive care needs and preferences of patients and families
- Synthesize the evidence base that informs the provision of supportive care
- Outline potential models of care by which equitable and coordinated access to supportive care services across the province may be achieved and sustained
- Identify and facilitate the understanding of the role of stakeholders and partner providers outside of CancerControl Alberta
- Provide an objective means to make recommendations and establish future priorities
- Describe a vision for the future state of supportive care for Alberta cancer patients.

CancerControl Alberta's Supportive Care Council in collaboration with Alberta Health Services (AHS) Knowledge Management and Engagement and Patient Experience Departments designed a process (See flow chart) to collect evidence to inform the creation of a Support Care Framework for CancerControl Alberta. The results of the engagement process will be discussed in this report.



Supportive Care Framework Engagement and Development Process

Purpose

The purpose of this report is to capture patient and clinician comments and suggestions, and to provide an overview of recommended practices and services as obtained through interviewing provincial, national and international experts, and a rapid scan of current programs and services in Canada.

The engagement process of the project sought to:

- Outline potential models of care by which equitable and coordinated access to supportive care services may be achieved and sustained
- Represent the supportive care needs and preferences of patients and families and clinical expertise
- Describe potential components of a vision for the future state of supportive care for Alberta cancer patients

In order to achieve these goals, a three-prong engagement process was conducted which included the following:

- 1. Survey of patients and families across Alberta
- 2. Survey of physicians, clinicians, and administrators across Alberta
- 3. Environmental Scan of programs and services nationally and internationally

The survey of patients and families assessed: their level of awareness of supportive care services in Alberta, the importance of these services, services used, who they expected to pay for these services as well as how they wanted to learn about services. The survey also provided patients and families an opportunity to indicate which supportive care services they received and needed post diagnosis and any additional comments that they had about supportive care services in Alberta.

The survey of clinicians, physicians and administrators assessed: their level of awareness of supportive care services, services they recommended or referred to patients, the top three supportive care services they referred to patients, what services they believe are missing, and the criteria they believe CancerControl Alberta should use to determine which supportive care services to offer.

The first phase of the environmental scan undertook an online search for current cancer supportive services offered in each province in Canada, United States, New Zealand, Australia, and the United Kingdom. This scan identified Cancer Centres nationally and internationally which offered comprehensive set of supportive care services. Leaders at these Cancer Centres were interviewed about criteria used to determine necessary services, services that they would like to or plan to offer, as well as information about the evidence used to inform their decision making process (for a complete list of key informants see Table 3). The second phase included a validation of the environmental scan of services which identified critical patterns in service provision in Canada by interviewees. (See Addendum A).

METHODOLOGY AND LIMITATIONS

Methodology

The findings presented in this report reflect a summary of participants' responses to the patient and family, physician and clinician and national and international key informant surveys, and have been organized into broad themes based on analysis, synthesis and summary of all the survey responses. It is acknowledged that the key informant interviews may not represent every activity or service in a specific province or country.

Patient and Family Survey

A stakeholder assessment was conducted and the voice of patients and families was highlighted as an integral piece of the engagement process. Survey questions were crafted and vetted through the Supportive Care Council working group and then through patient engagement specialists. Paper surveys were disseminated through major 'survivorship events' in Edmonton, Red Deer, Medicine Hat, Lethbridge and Calgary and provided to patients at the Cross Cancer Institute. An electronic version was created in Survey Select so patients and families could complete it online through a link that was emailed to various distribution groups.

Clinician, Administration and Physician Survey

A stakeholder identification assessment was undertaken by the project team in order to ensure that the appropriate clinicians, physicians and administrators in Alberta would be consulted in order to inform the framework. This list included individuals who are both internal and external to Alberta Health Services and who represent a broad spectrum of disciplines and area of supportive cancer care. Survey questions were crafted and vetted through the Supportive Care Council core working group. An electronic survey was created in Survey Select and sent out to physician and clinician groups and individuals through; formal councils, key stakeholder requests and informal forwarding to colleagues. The majority of the interviews with clinicians were conducted over the phone in order to request further information from participants and to clarify their responses. Interviews were transcribed into the Survey Select link so all the responses were stored together.

Environmental Scan of Programs and Services

The environmental scan was a systematic rapid scan of electronic information found on public websites and grey literature searching. The scope was limited to Canadian provinces and territories and Australia, New Zealand, United Kingdom, and the United States. A scan of the Canadian provinces and territories provided a comprehensive picture of supportive care services and programs across Canada (See Addendum A) where the information was available electronically. Australia, New Zealand and the United Kingdom have been selected because they have similar public funding models as Canada and the United States was selected because it known to have leading programs in the field of supportive cancer care.

The search was done using Google in English and used a standardized information collection template. A comprehensive list of publically available information and programs was created, and available on SharePoint.

Environmental scans are considered a rapid review of information. The information gathered is considered incomplete until validated, but gives a snapshot of current work, as well as the breadth of depth of information available. Given that supportive care services are publically provided in Canada it was assumed that most information would be obtained online. However, the researchers found that despite up to 69% of cancer patients finding information about

their care online,⁵ that this information is not updated on a regular basis. There were a number of cases that researchers found missing information or programs that had been cancelled but not removed from online.

In total, 36 cancer centre sites were reviewed in Canada. This included all provinces and the territories.

In Scope: Regional cancer centres that provide programs; provincial cancer entities that provide programs.

Out of Scope: Alberta was excluded from this e-scan, national frameworks, supports offered by not for profits or other community supports, guidelines and practices, and academic literature. The project excluded the validity of the programs and did not attempt to make any value assumptions. An evaluation of the efficacy of these programs was not undertaken, as all information was taken with information asymmetry or "caveat emptor".

Leaders within the institutions were identified and contacted via email for a telephone interview. Survey questions were crafted and vetted through the Supportive Care Council and project core working group. An electronic survey was created in Survey Select and interviews were transcribed into the Survey Select link.

Limitations

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For the clinician and physician survey-the names of services on the survey were not consistent with the names of the services as understood by the interview participants (and those who provide the services). Also, the differences between recommending and referring were important for some participants. Some believed that these words should not be synonymous. For example: sometimes making a referral was out of their scope, but they did recommend that the patient speak with another provider about getting a referral for a service. The interviewers attempted to be as consistent as possible with the definitions of these terms and allowed the interviewee to determine their own definition during the interview process.

⁵ Huang GJ, Penson DF. Internet health resources and the cancer patient. Cancer Investigation. 2008;26(2):202–7. [PubMed]



RESULTS

Patient and Family Survey

A total of **84** paper and electronic surveys were completed by patients and/or families. The stars in the map below indicate the location of patients and family respondents. Respondents from all five AHS Zones completed the survey, representing both rural and urban centres (See Table 1. for a complete list of responses)



Highlights from the Patient and Family Survey

- Patients and families are generally unaware of the majority of supportive care services offered.
- Despite being generally unaware of the full spectrum of supportive care services, patients felt that they received the services that they needed immediately following their diagnosis.
- The **two services** that patients and families were **the most (and equally) aware of** is the **volunteer driver program** and **physiotherapy.**
- They were **very unaware** of **Cultural Support Services** (For example: Aboriginal Cancer Patient Navigators and language translation services).
- Patients believed that the single most important support service is patient and family education about their cancer treatment.

• Additional services that were **described as important** by patients & families included:

Services patients and families reported that they **expect AHS to pay for** include:

- Psychology
- Social worker
- Physiotherapy
- Occupational therapy
- Clinical nutrition
- Pharmacist support
- Palliative care doctor or nurse practitioner
- Pain and symptom management
- Help with tiredness or fatigue
- Transition nurses arranging for homecare
- Drug access coordinators
- Cancer patient navigator
- Patient and family education about your cancer treatment
- Information about after you cancer treatment and classes on cancer subjects

psychology, physiotherapy, clinical nutrition, exercise, help with fatigue or tiredness, patient & family education in cancer prevention and information about and after their cancer treatment.

- The service that was reported to be **used the most** by patients and families is **clinical nutrition (dietitian)**.
- The informational support services (patient and family education about your cancer treatment, information about after your cancer treatment, workshops or conferences on cancer topics, classes on cancer subjects) were utilized the most as a group of services- this is excluding Patient and Family Education in Cancer Prevention which had a very low utilization response.
- The number one service that patients and families believe that AHS should pay for is **transition nurses arranging for homecare.**

- The highest number of respondents who answered the 'Expect to Pay Yourself' column answered that they expect themselves to pay for: Art Therapy, Art Groups, Yoga, Accommodation and Transportation and Help with legal documents like personal directives.
- Patients and families commented that information on a program or service should include the following: how much it costs, how it is provided, where it is provided, when it is provided, a description of the service and who provides it.
- The majority of patients and families would like to **be informed about supportive care services** by all mechanisms (email, pamphlets/information sheets, websites and referral) but the number one way specifically identified by patients and families to learn about programs is **from a referral by their health care provider**.
- It is of the utmost importance to patients that services **are provided by people who are experts in cancer care.**

Key Themes from the Patient and Family Survey

Continuity of Care with Specialists and Health Care Providers. Patients and families noted that within their care pathway that they would like to have the same care providers and to have their care provided in the same place. The comments made were specifically around treatment care.

"When you have cancer it would be nice to be treated as a 'whole medical person' instead of going back and forth to your family doctor."

"I never saw the same physician or resident more than once. I saw the same nurses more often. I would especially have liked to see my surgeon during my hospital stay after surgery but never did, only residents who were good but not the same and weren't in the operating room for my surgery."

Grateful for Care Received. Patients and families are grateful for the care that they have received and they cite specific cancer centre locations and physicians/clinicians who have helped them through their cancer journeys.

"I received excellent care. Very efficient with the nurse navigator. Excellent surgeons. Programs very informative and well worth attending."

"I cannot exaggerate the positive climate at Cross Cancer. It is truly beautiful."

Did Not Receive or Unaware of Services. There are patients and families who were unaware of supportive care services and who report that in hindsight they would have liked to

have accessed those services. Also- there are patients and families who were aware of servicesbut who could access those services for various reasons.

"After I was diagnosed with cancer May 2014 until now, supportive care services was not known to me, or very little aware of it. **Most of my info I went through the Internet to find-**finally found a psychologist to see me but appointments are very far apart. So technically I was to deal with it on my own, with great stress on our marriage and family life. Today was the first information I've received in the last year."

"There are a lot of services listed above that I was not aware of. Not sure where someone would get this information"

"There are many services that were easily accessed while there were others I was unaware of or were unavailable at the time that I needed them."

Care Coordination and Provider Communication. Patients and families felt that their care was not being coordinated throughout the system and that different areas of the system were not following up due to a lack of communication between providers.

"I had problems with the lack of coordination and communication between the emergency room at Foothills and the Tom Baker –expectations for off hours care during intensive chemo. Resident's start from scratch and much is done that is not relevant – [these things wouldn't be done] if they were better informed. No follow up as files are not transferred."

"Lack of coordination between some areas and lack of a patient portal creates unnecessary stress."

Location of Services (Access). Patients and families indicated that supportive care services were unequally distributed throughout urban areas as well as between urban and rural areas. This had an impact on access.

"I would like to see more programs available in South Calgary. Especially programs like psychological support. I find myself not accessing some programs due to the fact that many are in north Calgary."

"So much of the information about cancer treatment and follow up is not available in rural areas..."

Providing Information to Patients and Families "Patient First." Patients and families would like to receive information about supportive care services in an easy to digest way that doesn't overwhelm them shortly after their diagnosis.

"I believe there should be a more whole person approach to the services provided. Almost as importantly, I don't believe it is enough to hand someone a binder full of info and pamphlets at
their initial diagnosis appointment and expect them to be able to access everything that is offered that they need based on the fact that 'well you were given the brochure'. Throughout the journey, the health care team should be checking in, looking for clues, using the screening for distress and even their own experience based on other patients they have treated in similar stages or situations and what their needs were, to better bring up and perhaps even recommend a service or two that might prove relevant to the patient at that time. Keep doing this throughout."

"It would be fantastic to have a "Patient login" on the AHS website for patients to log in with their AB health number, and then be able to navigate to what is relevant for them. Eventually this could be expanded/linked/replaced by the patient portal, which would have direct access to health information, as well be able to fill in Screening for Distress forms in advance of appointments etc. But for now just a patient log in would be helpful given how much information is available and how overwhelming it can be (could have some filters for searching)."

AHS Providing the Services (Cost). Patients and families are passionate about AHS providing supportive care services to cancer patients and families who need them free of charge and that cost should not be a barrier to receiving services.

"These support services are very very important for anyone with a diagnosis of cancer. I believe that all should be free of charge as income is definitely down for most people receiving treatment and it is all healthcare."

"I had many services provided to me without having to seek them out and that my journey with cancer more bearable. Cutting costs in cancer treatments and services would be inhumane. This is a tough road to take; a cancer victim needs all of the help they can receive."

Clinician, Administration and Physician Survey

A total of **75** clinicians, physicians and administrators completed the survey either by telephone interview or electronic survey. Over **27** clinical areas were surveyed (See image for areas included)



Highlights from the Clinician, Administration and Physician Survey

• Clinicians and physicians are **most aware** of **psychologists**, **social workers**, **spiritual care specialists**, **Dietitians**, **pharmacists**, **lymphedema care**, **pain and symptom management**, and **palliative care doctors or nurse practitioners**.

- The single service that they are reportedly **most aware** of is **dietitian (clinical nutrition)**.
- They are less aware of the informational support services (education on cancer prevention, during treatment, after treatment, workshops and classes) and the community liaison nurses.
- They reported that they **refer to many services** but **not as many as they are aware of.**
- The **top services** that they reported **referring to most are**:
 - o social work
 - o palliative care doctors or nurse practitioners
 - o pain and symptom management
 - o psychology
 - o **nutrition**
- **Patient request** and **need for specialist intervention** are the top two reasons for referring a patient to a supportive care service.
- **Criteria** to use for deciding which services to offer: **talk to patients**, **talk to front line clinicians**, consult the **literature and best practices**, **focus on** doing those things that will **increase quality of life for patients**.

Key Themes from the Clinician, Administration and Physician Survey

Most Frequent Supportive Care Programs /Services

Respondents indicated that the following programs were in their 'top list' of supportive care services that they refer to, recommend or endorse:

Ranked in order of number of times mentioned as one of the top three services:

- 1) Social Work
- 2) Psychology
- 3) Nutrition
- 4) Rehab (PT, OT, SLP)
- 5) Palliative Care/Home Care & Psychosocial Programs in General (including Spiritual Care)
- 6) Patient Navigation
- 7) Pain and Symptom Management
- 8) Pharmacy

Program/Service Needed or Wish Was Available

Enhancing/expanding/integrating existing services: Clinicians, physicians and administrators shared that they would like to have access to more of the services already being offered. In addition to more services, they also believe that services should be integrated and available across the province.

"Integrative health support, combined modalities need to be "one stop shop" for patients. More importantly ALL patients in all of the province NEED access to ALL of the above services and support."

"Most urgent need is for psychological services and social work services. Neither is available in our community."

"More spiritual care is needed because counsellors don't go around talking to people. Spiritual care practitioners meet people in their own places and conditions- patients are likely to share more with staff where they are at."

Psychological Services: Clinicians, physicians and administrators would like to specifically see greater access and capacity for psychological services.

"I wish there was a psychiatric nurse available M-F at the CCI for patient consultations. Great to have a psychiatrist for 2 clinics/month, but psych nurse on site would be very helpful to those patients with previous mental challenges."

"Crisis intervention when they immediately receive their diagnosis, a listening ear, help getting home, help to process the diagnosis."

"Psychologist is needed- there are overwhelmed and over worked social workers who at times may be working beyond their scope of practice due to no access/resource in place to provide psychology counselling."

Navigation/Transitions: Patient navigation through the system is a service that clinicians, physicians and administrators would like to see more of for their patients. Beginning with a single point of entry, help for patients navigating their initial diagnosis and their disease specifically, through to treatment and post treatment. There is a recommendation for access to people who can answer the phone, and provide guidance at every step in the process and can help with the logistics of service coordination.

"Case management- we have it but it needs to be enhanced. Really need to help the client navigate the system. Help patients avoid telling their story several times." "Anything that supports transition through the system. Navigators may not be throughout the entire province. Patients need help transitioning so they can experience integrated service delivery"

"Would love to have a single point of entry. If you get a cancer diagnosis then you should have to through one point to get into the system. We have created a lot of silos."

Specific Programs/Initiatives: Linking with the comments above outlining what respondents believe is missing - there are specific programs/initiatives that were on the wish lists of clinicians, physicians and administrators in Alberta. These are not limited to but include: indoor healing gardens, quiet rooms on the units and outpatient areas, more opportunity for physical activity, classes on vaginal dryness and painful intercourse, music program (musicians coming into the centre), expanded volunteer driver program, exercise consultant/physiology/ kinesiology, pain and symptom management and greater housing options for out of town patients.

"I would definitely recommend a music program, I contact the community and ask musicians to come in to play and sing- Christmas caroling was a big hit- the patients loved it."

"More opportunity for physical activity -nowhere to go in winter- they [patients] walk the same halls."

"More survivorship workshops or programs offered locally."

The perceived reasons why Supportive Care services are not being offered include:

Lack of Resources: There is a lack of resources: human resources, space and funding.

Culture of Medical Oncology: The culture of cancer care is influenced by the medical model which is disease based and not person based.

"Because cancer care still functions from a biomedical/disease model. These types of services are seen as ancillary. And there is discord between what AHS values and what patients want"

"The entire health system is focused on acute care and so post-acute services receive very little attention and funding."

"Because nonurban centres are second class where healthcare support is concerned."

The Criteria and Processes CancerControl Alberta Should Use To Determine Programs/Services

Understand patient need and talk to patients: The number one criteria that clinician, physicians and administrators believe that CancerControl Alberta should use to determine services offered is to undertake a scan of patients' needs and to understand their concerns.

"Ask the people of AB what they want- the patients- but they need to see a drop down menu of specific services so they know what they are saying yes to – what they really want. They would now be informed."

"Patient needs- we can't be everything to everyone. Where is it that we can get our biggest bang for our buck? We come up with solutions before we know what the patient needs are."

Access: The respondents believe that one criterion to use for determining supportive care services is access. Equitable access from one centre to another and between rural and urban centres.

"The ability to make something accessible provincially."

"Equitable access- ensuring that Albertans outside of TBCC and CCI have equal access to specialized services."

Ensure decisions are evidence based and consult the literature and best practices: Many respondents agree that one way to determine which services to offer is through investigating best practices, promising practices and the established literature. One respondent cautions against only using this method though, as they feel that *"sometimes the most important/real things do not have an evidence base to support them-love, family, spirituality."*

"Evidence basis for improving quality of life."

"If the goal of supportive care is to optimize quality of life- look at studies of cancer patients and see what is important to them."

Additional Themes

Treat the whole patient: Cancer is a difficult journey, and patients need to be supported more holistically; their emotional and psychosocial concerns need to be addressed. We need to move beyond treating the diagnosis and focus on helping patients live with long term deficits and have a high quality of life.

"Integrate the whole person in the care."

"We diagnose and treat patients with difficult diseases and treatments. We need to be able to provide the care that allows them to survive and have a good quality of life."

"Understand the needs of the patient and family and relate those needs to their overall psychosocial health and broader family situation."

Awareness, Access, & Availability: Staff are not aware of all of the programs and services available for their patients and families, and they are not sure where to or how to learn more about the services. There are regional/zone differences within the province in regards to the type of services available to cancer patients; many respondents feel rural communities do not receive the same level of services that are available in urban centers. There is inconsistency in the types of services available across the province, and respondents hope that a provincial framework will be able to improve the inconsistencies.

"I did not know there were so many services available. How do I access these services for my patients and families, and how do I learn about new services?"

"Not sure how patients are finding out about resources. Need a better way to create awareness of these programs and services."

"These services are largely urban based, the rural areas still struggle for the most basic support services."

Provincial Framework: Staff would like to see the provincial framework build upon the already successful programs and services within CancerControl Alberta, as well as be integrated with initiatives already underway within Alberta Health Services, including: Palliative/End of Life framework, Advanced Care Planning, Patient Reported Outcomes and the Collaborative Practice Model. Staff would also like to see resources better utilized within the new framework, and ensure that the appropriate stakeholders have been included in the framework's development.

"Worry about diluting the existing strengths (i.e. TBCC is a world leader in psychosocial care). We shouldn't lose them with a provincial framework but rather build upon it."

"Wonder about the fit with Advanced Care Planning and supportive care."

Environmental Scan of Programs and Services and National and International Key Informant Interviews

A total of 24 Canadian and 13 international key informants were interviewed, from the United States, Autralia, New Zealand and the United Kingdom (See Table 3 for a full list). The key informants were identified as leaders within Cancer Centres that provided comprehensive cancer supportive care services.

*Below is a map of Canada and the United States indicating the location of key informants marked with a star. Informants were also from Australia, New Zealand and the United Kingdom but are not represented below.



North American Map from: <u>http://www.wildlifeandroads.org/search/</u>

Highlights from the Environmental Scan of Programs and Services in Canada

*Based on results confirmed by key informant interviews (see full results in Table 3 A)

• **Core services** offered at every cancer centre include: nutritional care, counselling, and patient education services

The type and breadth of services and programs available vary across the cancer centres with the **Princess Margaret** offering the most comprehensive set of programs and services

- All the centres provide programs and services related to **Health**, **Wellness and Survivorship** and offer a wide range of services that include: mindfulness program, stress reduction program, relaxation program, transition program, expressive arts program, and cooking classes.
- Most cancer centres partner with the 'Look Good, Feel Better Program' to help patients with appearance related issues

Highlights from National and International Key Informant Interviews

*Please see Table 3 for a complete list of key informants

- Most sites **offer online supports groups** to reach patients in their communities and in rural areas
- Depending on the needs related to the geographical location some centres and cancer agencies have developed programs and services that **serve specific population needs**. For instance, At the Vancouver Cancer Centre special counsellors are hired to work with Mandarin and Chinese populations, while in New Zealand services are provided in Maori language.
- Need to **set criteria** for patients to access services for complex needs
- **Survivorship programs** should be offered to patients that don't need an oncologist but are not well enough to see a family physician
- Programs and services development should be **context specific (ensuring that these are focused on appropriate and individual needs)** and serve unmet patient and clinician needs. Professionals working in oncology should have **oncology training**
- **Use the literature to** see what kind of treatment patients need at each juncture and crisis intervention point and critical junctures
- **Top programs and services recommended**: Palliative Care/ Rehabilitation/Occupational Therapy/ Pain Management; Patient and family counselling and psychiatry; Social work; Strong patient education

• **Top requests:** Expand services so more patients can access them; Electronic health record to transition patients; Evidence based programs for self-management; Spiritual care

Unique International Elements

United States

- The US has a unique private/public health system. Funding for cancer supportive services is covered by both private and public funds. The profit made from insurance company's payment for chemo and radiation therapies is used to cover supportive care.
- "In the US, the revenue generated from therapy costs paid by insurance, is used to cover supportive cancer care. Because hospitals compete for patients it's in our best interest to have as many supports as possible.
- The National Cancer Institute (NCI) designated cancer center program recognizes centers around the country that meet rigorous criteria for world-class, state-of-the-art programs in multidisciplinary cancer research. These centers put significant resources into developing research programs, faculty, and facilities that will lead to better approaches to prevention, diagnosis, and treatment of cancer.

Australia

- The costs of supportive services are born by the state/government within the healthcare system. However, the key informants noted that at least 50% of supports are provided by the private/not for profit sector.
- The Cancer Services Victoria defines supportive care as "an umbrella term used to refer to services which may be required by those affected by cancer. It includes self-help and support, information, psychological support, symptom control, social support, rehabilitation, spiritual support, palliative care and bereavement care. Supportive care in cancer refers to the following five domains: physical needs, psychological needs, social needs, information needs, and spiritual needs."⁶

New Zealand

• The New Zealand Midland Cancer Network defines "Supportive Services" as "The essential services required to meet a person's physical, social, cultural, emotional, nutritional, informational, psychological, spiritual and practical needs throughout their experience with cancer."⁷

⁶ <u>http://health.vic.gov.au/cancer/framework/supportive.htm</u>, Retrieved July 7, 2015

⁷ http://www.midlandcancernetwork.org.nz/page/pageid/2145862568, Retrieved July 7, 2015

- There is a public/private partnership for the provision of supportive cancer services offered in New Zealand. While there is a public database where each service is outlined, the entity that offers them can either be the public health system.
- Those in the public system supportive services are paid for by the state/government. However, key informants noted that most of these supports are provided are by the private and not for profit sector (such as the cancer society of New Zealand). Social workers, nurse coordinators, some psychologist are available at the hospital. The remainder of services fall within the public sector and is charity funded.

United Kingdom

• The United Kingdom has a nationally funded health system that contracts supportive care services out to large national charity organizations- MacMillan, and Cancer Coalitions, and the National Institute for Health Care Excellence (NICE) - that provide programming and services based on community needs.

Key Themes from the National and International Key Informant Interviews

Meeting Needs in Rural and Urban Areas

Many respondents provided insights into challenges and solutions for providing supportive care services to people outside urban centres.

- British Columbia offers a program to help with memory and cognition (e.g. chemo brain) that is offered by tele-health for people who live in the north.
- Health Sciences North, Cancer Centre in Sudbury offers a 'fighting cancer fatigue' via telemedicine.
- Most sites offer online supports groups to reach patients in their communities and in rural areas (CancerChat Canada).
- Building capacity in the community for oncology care is immensely useful so that care is closer to home, to care for vulnerable and underserved populations.
- Transportation can be a significant barrier to care.
- Cancer Care Nova Scotia provides cancer navigators in the community and a tele-health service with access to a general practitioner in oncology.
- Saskatchewan Cancer Agency provides navigation and palliative care in the community.
- Memorial Sloan-Kettering in New York City has created regional cancer centres that circle the Manhattan area to bring supportive services to other communities.

Diverse Populations, First Nations, Inuit, Metis in Supportive Cancer Care

Some centres and provinces provide special programs to address the complex and specialized needs of indigenous and diverse populations.

- At the Vancouver Cancer Centre special counsellors are hired to work with Mandarin and Chinese populations
- The Cancer Centre in Northern British Columbia has an aboriginal cancer care navigator
- Whitehorse general hospital offers a First Nations Healing Room and First Nation Health Program
- Nova Scotia Cancer Centre offers a smudging program
- A number of sites have aboriginal/First Nations programming including New Zealand and Cancer Care Ontario.

"We need to do everything possible to provide person-centered care. This means we need to pay attention to what is important to the person and have processes in place that ensure the person feels listened to. We need to attend to how we are identifying those individuals who may need additional help and put that help in place in ways that are mutually agreeable."

Meeting Complex and/or General Needs

The key informants offered suggestions for offering programs and services that could meet both complex and general needs of patients.

- Serve complex needs in consultation with teams of specialists, during active treatment to palliative care, and build the capacity of frontline staff to assess and address needs of lower complexity
- Identify patients who have complex needs and service them. The small percentages warrant extra help.
- Set exclusion and inclusion criteria for psychosocial and psychiatry care
- Apply funds to the patients who tend to be the most complex

What Should Be Considered When Choosing Programs

Most of the centres reported that programs and services were often determined by patient and/or clinical needs and resource availability. Considerations include:

- Address unmet patient and clinician needs*
- Have program champions*
- Availability of human resources in rural/urban communities*
- Start new programs as demonstration projects, before considering operational funding Consider the number of patients impacted
- Do data collection on supportive care services to document the benefits to patientstrack symptoms pre and post treatment

* These considerations were suggested by multiple key-informants

Funding Supportive Care Programs and Services

"Train people in the community so you have places to send patients"

Funding for supportive care programs and

services is primarily provided through the provincial health authorities but many Cancer Centres rely on additional foundation funding to offer services to the broader patient population, specifically health, wellness and survivorship programs.

- In Ontario, Cancer Care Ontario has mandated that all Cancer Centres provide palliative and psychosocial programs. The 14 Local Integrated Networks (LINs) provide funding to the regional cancer centres and they have discretion over the other supportive services provided
- At the Ottawa Hospital they use provincial funding to provide specialized programs and services to high needs patients
- At the Princess Margaret Cancer Centre, the survivorship centre programs and services are only partially funded by core funding and are funded by the hospital foundation
- In Manitoba, the Ministry of Health distributes funds to the community oncology programs and with stakeholder consultation they decide what to fund and then distributed directly to the regions
- In British Columbia the Ministry of Health distributes funding to the British Columbia Cancer Agency which allocates it to six regional cancer centres. Stakeholders were unaware as to how these funds were further distributed to supportive cancer care

Supportive Care Oncology Expertise

Supportive Care professionals providing services have mostly experience based training in oncology. However, a new program in British Columbia is training nurses to become oncology survivorship nurse practitioners.

- Most professionals providing dedicated care in cancer centres have experience training in oncology
- In some regions of the country, nurses and physicians are dedicated to oncology while occupational therapist and physiotherapist etc. are hospital wide and are generalists
- In many provinces, navigators are oncology specific and also tumour group specific,

Objectives for the Literature Search

Several of the key informants provided guidance on objectives for the literature search.

- Search the literature to see what kind of treatment patients need at each juncture and crisis intervention point and critical junctures*
- Search the literature to see how survivors are struggling and what the best interventions are. Clinicians and patients can validate because they are on the front line and they can tell you what they see
- Use patient reported outcomes evidence based on return to work impairment needs
- Search evidence based on what improves quality of life for patients
- Use screening data to track the "highest" patient-determined issues. This includes both in usage and patient driven need
- Search the literature for programs and services that have proven benefit to patients
- Assess cost and cost benefit factors.

*Recommended by multiple key-informants

Critical Programs/ Services for Quality Supportive Cancer Care

Key informants identified what they deemed as necessary supportive care services related to cancer care. * These services/programs were suggested by multiple key-informants, but the list is not in any particular order.

- Palliative Care/ Rehabilitation/Occupational Therapy/ Pain Management essential for survivorship*
- Patient and family counselling and psychiatry*
- Social work*
- Strong patient education some of the comments were:*
- Not just in pamphlets, we need to cater to various learning styles e.g. Provide cooking demonstrations to show patients how to prepare foods that are easy to swallow
- Pre-radiation, pre-chemo, pre-surgery education to alleviate anxiety and to prepare patients for treatment or transition to another treatment mode
- A comprehensive Patient and Family Library with specific disease information staffed with trained volunteers and a trained medical librarian.

- Expansion of group teaching classes drawing on different professions and offered in person and via tele-health
- Dietitian/ Malnutrition/ Obesity risk reduction*
- Relaxation program to deal with stress management meditation/ yoga/ tai chi*
- Financial navigator to help patients navigate through cancer treatment (drug costs, payper service costs, etc.)
- Coupling of inpatient and outpatient palliative care clinics is the key to continuity and support
- Interpreters
- Adult childhood cancer survivor program
- Medical reimbursement specialist
- Liaison with primary care / community cancer clinics
- Navigation program- that enables a number of services (OT/PT/RD) to be accessed through one role

Wish List

This is a list of supportive care services that the key informants wished they could provide to patients:

- A full supportive care program for cancer patients with advanced disease that applies not only to psychosocial but symptom control that involves dietician and physiotherapy
- Spiritual care*
- Self-management training*
- Increased staff levels for psychosocial staff and greater outpatient physiotherapy
- A sexual health clinic and program
- A list of supports that are available. This includes a full inventory, referral pathways outlined, a point person, and how to connect with the services, programs and initiatives
- Program for fear of reoccurrence
- This is a list of how key informants wished service could be improved:
- Expanded services to ensure access*
- Electronic health/Integrated records to ensure seamless transition of patients between regions and departments, and the community providing complementary therapy
- Improved integration of services
- Provincial funding, not foundation funding to provide services

*These services/programs were suggested by multiple key-informants

GAPS AND OPPORTUNITIES PROPOSED INTIATIVES

The value of supportive care services are an important factor for cancer treatment. This report sought to ensure that CancerContol Alberta's new framework was built on a strong stakeholder and engagement base. The engagement process seeks to improve how patients experience supportive cancer care within AHS. This report includes feedback from a wide range of stakeholders including patients, clinicians, and national and international experts.

There was strong consistency in the themes generated. Programs and services need to be coordinated and patients and clinicians need to be educated about the services offered and how to access them. This will require access to navigators and integrated service delivery model processes. Supportive care services need to be provided throughout the cancer journey, not just during treatment or end of treatment.

As the framework develops, the project team should consider these voices, ensure that patients are involved in the development of the services/initiatives, consider diverse populations, and work with community partners to fill the needs of a variety of people.

Summarized in the table below are the themes, evidence and suggested areas for further opportunity:

Gap	Evidence from the Surveys	Opportunity
Lack of awareness and	Clinicians & Physicians are not	To support physicians and clinicians in
knowledge of scope and	universally aware of or are	providing referrals to and information
availability of supportive	consistently referring to	on supportive care services.
care services (Patients and families and Clinicians) physicians are clinicians	supportive care services. Patients report they would like to be referred by and to learn about services through their healthcare provider. Key informant interviews indicated that programs and	To empower patients to seek out information on supportive care services that have been recommended by their health provider. To provide, maintain and have readily available an inventory of supportive care services and programs.
	services in Canada and internationally have been	

Gap	Evidence from the Surveys	Opportunity
	created on an ad hoc basis	
Access (physical and online)	Providers believe that access and ensuring equitable access is one of the main criteria to use to inform which supportive care services to offer.	To be able to inform all Albertans about the locations of services that they can access and the location of the nearest service to them using different technologies and modalities
	Patients & families also report that access is different and or limited in certain areas of Alberta creating a varying patient experience.	To describe a model of care that accounts for delivery of services across the province, including in regional and community centres.
	Key informant interviews provided a few examples of how to improve access to programs and services to patients living in remote and rural areas	
	Since the majority of patients seek information online the supportive care programs/initiatives should be readily, comprehensive and publically available online.	
Provider awareness of importance of Informational Supports to patients & families	Patient & family focus is on the importance of Informational Supports-specifically education about; treatment, after treatment and workshops.	To be able to offer and inform patients about person centred Informational Support Services that is reportedly important to them.
	Providers did not report the same level of awareness or referral to these services.	
	Key informants indicated that improving patient education is a critical program/service for cancer supportive care	

Gap	Evidence from the Surveys	Opportunity
Differing levels of reported referrals and reported use of services	Patients are reporting lower levels of use of some available services that providers are reporting they are referring to frequently such as social work and psychology services.	To be able to uncover barriers in the system and systemic reasons why patients are not following up on referrals.
	Key informants recommended tracking patient data to inform decision making about providing cancer supportive care programs and services	Track current needs/ use in rural vs. urban and along the cancer trajectory among cancer patients
Limited Resources	Physicians and clinicians are reporting a perceived lack of resources and funding to support supportive care services Key informants recommended looking at the literature to provide the most effective programs and services	Identify the optimal time in the cancer journey to provide program or services. Provision of programs and services is driven by patient needs and preferences. Programs and services are effective and evidence based. Develop effective, intentional partnerships with community agencies to enhance services provided and prevent duplication where this is appropriate

Service	Aware Of	Important	Used	Expect AHS to Pay	Expect to Pay Yourself
Psychology	Ø		Ø	Ø	
Social Worker	Ø			Ø	
Art Therapy					V
Psychiatry					
Spiritual Care	Ø				
Pastoral Care	Ø				
Mindfulness Meditation					
Support Groups at the Cancer Centre	V	V			
Support Groups in the Community			V		
Relaxation or Stress Reduction					
Yoga					M
Art Classes					V
Expressive Art Group					V
Physiotherap y	Ø	Ø	Ø	Ø	
Occupational Therapy			Ø	Ø	
Speech Language Pathology					

Service	Aware Of	Important	Used	Expect AHS to Pay	Expect to Pay Yourself
Clinical Nutrition (dietitian)	Ø	Ø	Ø	Ø	
Pharmacist Support	Ø		Ø	Ø	
Palliative Care Doctor or Nurse Practitioner				Ø	
Lymphedema					
Pain and Symptom Management	M	M		M	
Exercise		Ø	Ø		Ø
Help with Fatigue and Tiredness		V		Ø	
Sexuality, Intimacy, Survivorship (OASIS)					
Swallowing Therapy					
Special equipment loan or ordering					
Other physical symptom services (please specify)					

Service	Aware Of	Important	Used	Expect AHS to Pay	Expect to Pay Yourself
Transition nurses (arranging home care)		V	Ø	V	
Community Liaison nurses					
Drug Access Coordinators /help with drug costs				Ø	
Accommodati on and Transportati on	Q				Ø
Cancer Patient Navigator		V		Ø	
Social Workers (duplicate)	M				
Volunteer Driver Program	V				
Financial Counselling and Support					
Help with legal documents like personal directives					Ø
Language Translation Services					

Service	Aware Of	Important	Used	Expect AHS to Pay	Expect to Pay Yourself
Aboriginal Cancer Patient Navigator					
Patient and Family Education in cancer prevention		Ø			
Patient and Family Education about your cancer treatment	Ø	Ø	Ø	Ø	
Information about after your cancer treatment		Ø	V	Ø	
Workshops or conferences on cancer topics		Ø	Ø		
Classes on cancer subjects (eating well, fatigue, brain fog etc.)			Ø	Ø	

*Aware Of: a check mark was placed beside a service that received 42 responses or more.

Important: a check mark was placed beside a service that received 42 responses or more.

Used: a check mark was placed beside a service that received **20 responses or more**. This column was infrequently filled in so in order to display the results in a meaningful way the number was lowered from the other columns.

Expect AHS to Pay: a check mark was placed beside a service that received **42 responses or more**.

Expect to Pay Yourself: a check mark was placed beside a service that received **20 responses** or more. This column was infrequently filled in -so in order to display the results in a meaningful way the number was lowered from the other columns.

Table 2. Clinician and Physician Survey Responses

Service	Aware Of	Currently Recommend or Refer	Top 3 Services Recommended (Checkbox Question)	Top 3 Services Recommended (Qualitative Question)
Psychologist (counselling)	V	Ø		2
Social Worker (counselling)	V	Ø	1	1
Art Therapist				
Psychiatrist	V			
Spiritual Care Specialist (counselling)	M			
Mindfulness Meditation or Meditation				
Support Groups at the Cancer Centre	V			
Support Groups in the Community	V			
Relaxation or Stress Reduction				
Yoga				
Exercise				
Art Classes				
Expressive Art Group				
Physiotherapist	Ø	Ø		
Occupational Therapist	Ø			
Speech Language Pathologist	V			
Dietician (Clinical Nutrition)	V	Ø		3

Service	Aware Of	Currently Recommend or Refer	Top 3 Services Recommended (Checkbox Question)	Top 3 Services Recommended (Qualitative Question)
Pharmacist	Ø	Ø		
Palliative Care Doctor or Nurse Practitioner		Ø	3	
Lymphedema	$\mathbf{\nabla}$			
Pain and Symptom Management	M	M	2	
Exercise				
Help with Fatigue and Tiredness				
Sexuality, Intimacy, Survivorship (OASIS)				
Swallowing Therapy				
Special Equipment				
Transition nurses (arranging home care)	M	M		
Community Liaison Nurse				
Drug Access Coordinator				
Volunteer Driver Program				
Financial Counselling and Help	N	Ø		
Aboriginal Cancer Patient Navigator				
Language Translation Services	M			
Patient and Family Education in cancer prevention				

Service	Aware Of	Currently Recommend or Refer	Top 3 Services Recommended (Checkbox Question)	Top 3 Services Recommended (Qualitative Question)
Patient and Family Education about cancer treatment				
Information about after cancer treatment				
Workshops or conferences on cancer topics				
Classes on cancer subjects (eating well, fatigue, brain fog etc.)				

*Aware Of: a check mark was placed beside a service that received **50 responses or more**.

Currently Recommend or refer: a check mark was placed beside a service that received **38 responses or more**.

Top 3 Services Checkbox Question: a number was placed beside the services that ranked 1, 2 and 3 in the checkbox question.

Top 3 Services Qualitative Question: a number was placed beside the services that ranked 1, 2 and 3 in the qualitative question.

Table 3. List of Key Informants Interviewed

Canada	
Dr. Camilla Zimmerman	Scientist, Princess Margaret Cancer Centre, Ontario
Dr. Kristin Campbell	Associate Professor, Department of Physical Therapy, Faculty of Medicine, University of British Columbia
David Greenshields	Professional Practice Lead Social Work, BC Cancer Agency Centre for the Southern Interior- Kelowna
Deb Bulych	Provincial Leader for Supportive Care, Saskatchewan Cancer Agency
Dr. Deborah Dudgeon	W. Ford Connell Professor of Palliative Care Medicine, Director of Palliative Care Medicine; Professor, Departments of Medicine, Oncology and Family Medicine, Queen's University.
Dr. José Pereira	Professor and Head of the Division of Palliative Care at the University of Ottawa and Medical Chief of the Palliative Care Programs at Bruyère Continuing Care and The Ottawa Hospital in Ottawa, Canada
Dr. Margaret Fitch	Professor at the Bloomberg Faculty of Nursing, University of Toronto and Associate Researcher at the Sunnybrook Research Institute.
Dr. Pippa Hawley	Division Head of Palliative Care, Department of Medicine, University of British Columbia
Dr. Ryna Levy-Milne	Provincial Director of Clinical Operations and Practice Leader for Nutrition, BC Cancer Agency
Dr. Scott Ernst	H <i>ead, Division</i> of <i>Medical</i> Oncology, London Regional Cancer Program, Ontario
Dr. Manuel Borod	Assistant Professor, Department of Oncology, McGill University
Heather Rennie	Clinical Coordinator Provincial Psychosocial Oncology Program, Project Lead- Cancer Chat Canada, BC Cancer Agency
Dr. Jennifer Jones	Scientist, Princess Margaret Cancer Centre Affiliate Scientist, Toronto General Research Institute (TGRI)
Jill Taylor-Brown	Director, Patient and Family Support Services, Cancer Care Manitoba
Karen Blain	Provincial Director, Survivorship and Primary Care, BC Cancer

	Agency
Marianne Arab	Manager, Supportive Care, Cancer Care Nova Scotia
Ms. Paula Doering	Senior Vice-President, Clinical Programs for Peri-Operative
	Services, Cancer and Diagnostics Programs for Ottawa Hospital
Dr. Neil MacDonald	Professor, Departments of Medicine and Oncology, McGill University
Oren Cheifetz	Physiotherapist, Hematology/Oncology Program, , Hamilton Health Sciences
Robin Forbes	Oncology Social Worker, Princess Margaret Cancer Centre
Ruth Loewen	Program Director, Community Oncology Program, CancerCare Manitoba
Sheila Damore- Petingola	Coordinator Supportive Care Oncology Network, BC Cancer Agency
Stephanie Phan	<i>Stephanie Phan</i> , Acting Clinical Lead, <i>Cancer</i> Survivorship, Princess Margaret Cancer Centre
United Kingdom	
Professor/ Dr. Jane Maher	Chief Medical Officer, NHS Clinical Leader and Consultant Clinical Oncologist
Australia	
Dr. Haryana Dhillon	Research Fellow Survivorship Research Group, Deputy Director, CeMPED Central Clinical School, Centre for Medical Psychology, Sydney Australia
Jane Turner	Associate Professor, University of Queensland, Australia
New Zealand	
Dr. Humprey Pullon	Medical Director, Waikato Hospital, Midlands District Health, New Zealand
Jan Smith	Network Manager, Midland Cancer Network, Midlands District Health, New Zealand
Jo Anson	Project Manager - Supportive Care Framework project, Central Cancer Network, New Zealand

Susan Wragg	Project Coordinator - Supportive Care Framework project, Central Cancer Network, New Zealand
United States	
Dr. Lorenzo Cohen	Professor, University of Texas MD Anderson Cancer Centre, Division of Cancer medicine, department of General Oncology
Dr. Rob Sidlow	Head of Division of Supportive Care and survivorship, Memorial Sloan, Kettering Cancer Centre
Dr. Lillie Shockney,	Surgical Oncology Director, Breast Centre and Medical Oncology Cancer Survivorship Program, Johns Hopkins University
Dr. Thomas Lynch	Director of Yale Cancer Centre and Physician in Chief of Smillow Cancer Hospital at Yale-New Haven
Sarah Thirlwell	Nurse Director, Moffit Cancer Centre, Supportive Care Medicine
Vicki Evans	Associate Director of Supportive Care, Seattle Cancer Care Alliance, Supportive Care Services Division

Addendum A. Programs and Services in Canada

Site/ Agency	Appearance	Financial Support	Health, Wellness And Survivorship	Information And Patient Education	Language Services	Health Professional Services	Side Effect Management	Support Groups Programs
Vancouver centre, BC Cancer Agency*	Look Good Feel Better Program		Therapeutic Touch Clinic; Mindfulness Based Stress Reduction Program; Relaxation and Stress Management Program; Return to work program	Coping with cancer website	Chinese Peer Navigator	Counselling Services; Registered Dietitians; Speech Language Pathologist	Physiotherapist (inpatient only)	Brain Tumour Support; Cancer Support; Online Support; Lymphoma Network; Women Living with Metastatic Cancer; Chinese Cancer Support Group
Fraser Valley Centre, BC Cancer Agency*	Look Good Feel Better Program		Relaxation Program	Radiation Therapy Teaching; Chemo Teach Programs		Nutritional care; Counselling Services; Rehabilitation Counselling; Physiotherapy	Pain and symptom management	Online Support Group
Vancouver Island Centre, BC Cancer Agency*	Look Good Feel Better		Therapeutic Touch Clinic; Relaxation Program; Cancer transitions; Rehabilitation Counselling;	Education for Colorectal Cancer Patients; Pain Teach; education sessions ; Lay Navigation;		Nutritional care; Counselling Services; Rehabilitation Counselling	Pain and symptom management	Women with Metastatic Cancer Support Group; Prostate Cancer Support Association; Brain Tumour Group ;Lung Cancer Group;

RR*Programs and services confirmed by key informant Service/ program is unavailable (as confirmed by key informants) or unable to find record of service electronically

Site/ Agency	Appearance	Financial Support	Health, Wellness And Survivorship	Information And Patient Education	Language Services	Health Professional Services	Side Effect Management	Support Groups Programs
								Ovarian Cancer Support; Myeloma Support Group; Lymphoma/ Leukemia Support Group; Lung Cancer Support Group
Centre for the Southern Interior, BC Cancer Agency*	Look Good Feel Better		Mindfulness Based Stress Reduction	Radiation Therapy Teaching; Chemo Teach Programs Managing Life with Cancer		Nutritional care; Counselling services; Rehabilitation Therapy	Pain and symptom management	Brain Tumour Support Group; Online Support Groups
Centre for the North, BC Cancer Agency				Patient and community education in cancer prevention; patient multi- disciplinary consultation and care planning		Rehabilitation Therapy; Nutritional care; Patient and family counselling, and psychiatry services	Pain and symptom management	Cancer care support for northern Aboriginal communities

Engagement Report

Engagement Report

Saskatchewan	Look Good Feel	Personal	Relaxation and	A drop-in		Nutrition	Pain and	Women's
Cancer	Better;	and	Meditation;	education session		Support;	symptom	Metastatic
Agency*		Financial	Creativity for	on cancer-related		Counselling;	management;	Cancer Support;
		Services;	Health; Cancer	fatigue		Advanced care		Brain Tumour
		Accommod	Transitions:			directions ;		Support Group;
		ation and				Rehabilitation		CANCOPE,
		Transporta				Therapy;		Cancer Support
		tion				Patient and		Group; Ovarian
						Family Support		Cancer Canada
						Counsellor;		Support Group;
						Social		Saskatoon
						Workers;		Ovarian Cancer
						Psychology and		Support ;
						Psychiatry;		Saskatoon
						Spiritual Care;		Prostate Cancer
						Navigation;		Support
						Lodge services		Caregiver
								Support Group:
								Caring for the
								Caregiver - a
								drop in;
								education
								session on
								caregiver stress,
								burnout, coping
								and community
					T			
Cancer Care			Brain Fog;	Patient and Family	Language	Clinical	Pain and	Head and Neck
Manitoba*			Pilates and	Resource Centres;	interpretation	Dietitians;	symptom	Laryngectomy
			Cancer; Yoga;	Spiritual and	and	Speech	management	Support Group
			relaxation	cultural care	translation	Language		Lung or
			techniques,	Community liaison		Pathologists;		Esophagus
			guided			Psycho Social		Lymphoma
			visualization,			Counsellors;		Support Group
			meaningful			Spiritual		Melanoma
			relationships,			Health		Support Group
			Mindfulness			Specialist;		Women Living

SS*Programs and services confirmed by key informant

Engagement Report

		Practice (modeled on Mindfulness Based Stress Reduction Stress Management Programs; Expressive Art Group		Patient Navigation		with Recurrent/Meta static Gyne Cancer Women with Metastatic Breast Cancer Young Adult Cancer Survivors (18 - 30) Younger Women with Breast Cancer Women over 50 with Breast Cancer Multiple Myeloma Support Group Peer support;
Ministere de la sante et des service sociaux			nurse oncology passport book; nurse oncology pivot (IPO) in the early 2000s. Role: evaluate the identified needs; teach and inform; coordinate care and services; hold up;			
the Jewish General Hospital (JGH),	Wigs, scarves, turbans, Look Good.Feel Better (cosmetic	Providing complementary approaches (a wide range of	Guiding patient navigation; Providing information on	Dietitian; physiotherapis t; social workers,	Pain clinic	Accessing peer support. Support groups

TT*Programs and services confirmed by key informant

Montreal	*********		a attiviti a t th		navahal	
Montreal	worksnopj		activities at the	cancer care.	psychologist;	
			јын норе &	Patient education	Psychiatry;	
			Cope Wellness	lectures,	Pastoral	
			Centre)	workshops and	Services	
			Wellness	information kits		
			Centre: a free-			
			standing facility			
			offering a			
			nutrition			
			program, a fully			
			equipped			
			exercise room			
			and physical			
			activities			
			program, and			
			complementary			
			therapies such			
			as yoga,			
			relaxation			
			Complementary			
			therapy			
			sessions are			
			available:	Information and		
Hôpital		Special	guided imagery	sharing		
Maisonneuve-		special	(visualization),	workshops for		
Rosemont,		parking	therapeutic	persons with		
Montreal		fees	group (Mieux	cancer and their		
			vivre ses	loved ones		
			relations),			
			relaxation and			
			auto-hypnosis.			
			J F J			
CSSSL - Hôpital				Solely dedicated to		
Cité de la Santé				French		
de Laval Centre				information for		
de				patients- includes		

UU*Programs and services confirmed by key informant

Documention Pour Les Personnes Atteintes De Cancer, Laval				books, CDs, website, and access to the internet			
Hôpital du Saint- Sacrement, St. Foy					social worker; a psychologist		
l'Université de Montréal Integrated Cancer Centre CHUM , Montreal			stress management interventions		Nutrition; rehabilitation; Therapists; psychological assessment; psychiatric assessment and treatment; spiritual care		
CHUQ - Hôtel- Dieu de Québec , Quebec City	Look Good Feel better			Library, Information on Cancer referral system for information (ICC)			Anxiety Management Group
McGill University Health Centre*	Resource centres with wigs and turbans	Financial assistance	Survivorship Program	Information and resource centres; Public lectures on key issues in oncology	oncology pivot nurse; psychologists, psychiatrists, social workers and nurses; spiritual care specialist; nutrition and cancer	Palliative care; pain clinic; rehabilitation clinic	Peer support from cancer survivors; Professionally led support groups and workshops

Engagement Report

Whitehorse must cancer (clinical must information lines; must information				rehabilitation		
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XX*Programs and services confirmed by key informant
Engagement Report

	conditions, to cover prescriptio ns, equipment and some treatments, though Alberta Blue Cross.						
Stanton Territorial Health Authority		Aboriginal wellness	Saskatoon Multiple Myeloma	Language services	Registered Dietitian; Physiotherapis t, Occupational Therapist, Speech and Language Pathologist and Recreation Therapists		NWT Breast health/breast cancer action group: Find resources on this website, check us on Facebook, or phone 867-873- 8089 in Yellowknife.
Cancer Care Nova Scotia*		Music Therapy; Survivorship program	Publications and videos provided; Medical resource specialist		Physiotherapis t; Recreational Therapist; Psychology; Clergy; Social Worker; Psychiatrists; Psychologists; Clinical Nurse Specialists; Cancer Patient Navigators; Occupational Therapists	Pain and symptom management services	The Cancer Patient Family Network (CPFN); Smudging ceremonies

YY*Programs and services confirmed by key informant

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Vitalité Health Network, New Brunswick	Skin care during radiation therapy	Th	he Mgr. Henri- Cormier Lodge (FREE)	what to expect during radiation therapy	Nurses and physicians	Palliative Oncology Clinic	Skin care during radiation therapy
PEI Cancer Treatment Program	Look Goo Feel Better		Moving Forward: cancer Transition Program	Cancer Patient Navigator Program. Lodging Information.	Radiation Clerical Navigator; Social Worker; Dietitian; Spiritual Care; Nurse Practitioner; Oncology Nurses; Clinical Trial Nurse		The Cancer Patient Advocate Program. Local Support Groups
Eastern Health, Newfoundland	Look Good Feel Better			Library; The Elaine Deluney Patient and Family Resource Library is located on the first floor of the Dr. H. Bliss Murphy Cancer Centre. It has books, pamphlets and video/audio tapes covering a wide range of cancer-related topics. There is also a computer with internet access. Library materials are also available in each of the regional	specially trained oncology (cancer) nurses act as compassionate and effective guides.	Lymphedema Program	

ZZ*Programs and services confirmed by key informant

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				cancer centres in Corner Brook, Grand Falls- Windsor and Gander			
South-eastern Cancer Centre, Ontario					medicine doctors, nurses, social workers, physiotherapis ts, spiritual care workers, psychiatrists, pharmacists, dietitians, and dedicated volunteers.	Pain management	
Carlo Fidani Peel Regional Cancer Centre, Peel, Ontario	Look Good Feel Better	Financial Clinic	Nutrition and Radiation Therapy; Cancer and Women's Sexual Health; Next Steps: Life After Cancer; Living Well Beyond Cancer	Resources for Your Cancer Journey	Oncology Nurse; Clinical Trials Nurse; Advance Practice Nurse; Medication Access Specialists; Dietitians; Psychosocial Oncology Team; Chaplain; Psychology and Social Work	The Coping Clinic; The Breathing Wellness Clinic	Support groups
Durham Regional					Social Worker; Dietitian		Support groups; Patient advisory

AAA*Programs and services confirmed by key informant

Cancer Centre,						team
Ontario						
Simcoe- Muskoka Regional Cancer Centre, Muskoka				Aboriginal Patient Navigator; Psychosocial Oncology		Support Groups
Windsor Regional Hospital	Look Good Feel Better			Counsellors and Dietitians		
Grand River Regional Cancer Center, Serving Waterloo Region, Ontario			Patient Orientation Sessions	Physiotherapis t (PT): Registered Dietitians; Spiritual care provider; Social worker (SW); music therapist	Pain and symptom management	
Health Science North, Sudbury, Ontario*		Return to Work; Cognitive Rehabilitation Program; Expressive Arts and Play Therapy: Transitions to Survivorship program	Information sessions on Eating Well and Living Well After Cancer Treatment; Breast Cancer Information Session; Caregiver Information Session; Fighting cancer fatigue	Dietitians; Physiotherapis t; Our Speech Language Pathologists ; Psychosocial Services; Social Workers ; Aboriginal navigators; Neuropsycholo gist		Laryngectomy Information and Support Group: CancerChat Canada; Group; Cancer Transitions; Return to work group

Engagement Report

Appendix 2

Engagement Report

Thunder Bay Regional Health Sciences Centre, Ontario	Income replacemen ts assistance; secure drug coverage			Dietitian; Counsellors		
Ottawa Hospital, Ontario*		The Wellness Beyond Cancer Program	tools and resources	Psychosocial Oncology; Social Worker; Occupational therapy; Speech Language Therapist; Psychology; Psychiatry	The Palliative Rehabilitation Program	
South Lake Regional Health Centre, Newmarket, Ontario		Transitions program for those completing their treatment		Individual counselling appointments; Psychosocial Oncology Assessment Clinic; Spiritual Care Chaplains; Social Workers	Pain and Symptom Management Clinic	
The Juravinski Cancer Centre, Hamilton, Ontario*		Survivorship Clinic	The Aboriginal Patient Navigator	Registered Dietitians; Social Workers; Clinical Nurse Specialist and Psychiatrist; chaplain	The Pain and Symptom Management Team. Community Exercise Program	

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London Health Science Centre*	wigs and hair coverings vendors; breast prosthesis vendors	patient assistance program; financial assistance	Chemo education; radiation education; patient information about side effects	Dietitian; Geneticist; Medical Physicist; Nurses; Occupational Therapists; Pharmacists; Physiotherapis ts; Social Workers; Spiritual Care Specialists	
Odette Cancer Centre, Toronto, Ontario	Look Good/ Feel Better; Canadian Cancer Society			Registered Dietitians; Speech language pathologists; Physiotherapy; Psycho- oncology ; Spiritual Counselling; Social workers; Occupational therapists	Wellspring Cancer Support Network

Engagement Report

The Princess Margaret Cancer Centre*	Look Good/ Feel Better; Wig Salon & Accessories Boutique	Medication Reimburse ment Specialists; Income Assistance	relaxation therapy; Wellness and Exercise for Cancer Survivors; Survivorship centre; survivorship consults; exercise classes; cooking demonstrations	patient and family library; cancer centre lodge; education classes; lunch and learn	document translation; interpreters	ethical guidance; genetic counselling; occupational therapy; physiotherapy; psychology; social work; spiritual care; dental oncology; nutrition therapy; pharmacy; psycho-social oncology; Speech language therapy; enterostomal therapy; Familial Breast & Ovarian Cancer Clinic	Fatigue Clinic; Lymphedema; Neurocognitive Clinic; Prostate Cancer Rehabilitation Clinic; Function and Mobility Clinic; Fertility preservation; pain clinic	Brain Tumour Support Groups; Individual relaxation therapy Prostate Support Group ;The Magic Castle is a free child-care service; MedsCheck; Prostate Centre's Psychosocial Support Program
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Appendix 3. AOPSS Supportive Care

Alberta Oncology Patient Experience Survey 2014 Results

Analyses and Results of the Ambulatory Oncology Patient Satisfaction Survey (AOPSS) National Research Corporation Canada (NRCC)

- Formerly NRC Picker Canada -

<u>Provincial Results, Supportive Care Specific</u> <u>Information, & Diagnosis Time Cohort Results</u>

March 2016

Linda Watson, Ph.D. & Rie Tamagawa, Ph.D.

Alberta Health Services

Introduction

This report summarizes analyses and results of the Alberta Ambulatory Oncology Patient Satisfaction Survey (AOPSS) 2014 survey data. This survey (AOPSS) was launched in 2002, developed and validated nationally by NRCC (formerly NRC Picker) in 2003 and has been adopted by many of the cancer jurisdictions in Canada. The former Alberta Cancer Board and the current CancerControl Alberta (CCA), within Alberta Health Services (AHS) have conducted the survey in 2004, 2006, 2008, 2012 and the most recent in 2014.

NRCC AOPSS uses a standardized tool with validated questions related to six dimensions of care that contribute to patient satisfaction. They are: Physical Comfort; Information, Communication & Education; Coordination & Continuity of Care; Respect for Patient Preferences; Emotional Support; and Access to Care. The survey results reveal areas of concern where patient satisfaction is low, and identify areas for quality improvement.

The Satisfaction Survey (AOPSS) was conducted across CCA care delivery sites between February and May, 2014. The sample was drawn from patients who were receiving or had received ambulatory cancer care in the past 6 months. Over 3700 surveys were sent out with 2074 patients returning completed questionnaires. The response rate was 56.0%.

This report addresses patients' satisfaction with the six dimensions of person-centred care and overall impression of their cancer care in Alberta in 2014. The following aspects are included in this report:

- 1. Provincial Overview Results
 - Patient characteristics
 - Overall impression of cancer care
 - o Strengths and weaknesses of Alberta oncology care as reported by patients
 - Satisfaction with six dimensions of person-centred care
 - The top ten areas for quality improvement provincially
 - o Strategies to improve quality of care and patient satisfaction
- 2. Supportive Care Specific Information
 - o Patient responses to Supportive Care specific items
- 3. Diagnosis Time Cohort Analyses
 - Identifying three cohorts
 - o Comparisons of demographic and medical characteristics across cohorts
 - Differential needs of three cohorts

1. Provincial Overview Results

Patient Characteristics

The sample selection of Alberta cancer patients who are or had received cancer treatments in the last 6 months was retrieved from the Alberta Cancer Registry., A total of 3701 surveys were sent out and of them, 2074 were returned (response rate of 56.0%). Table 1 shows distributions of patients from each care facility.

Table 1 Patients' survey locations

Facility	Facility name	n	Percentages (%)	0
Tertiary	Cross Cancer Institute	468	22.6	a
Tertiary	Tom Baker and Richmond Road Cancer Centre	487	23.5	g
RCC	Central Alberta Cancer Centre	364	17.5	0
RCC	Grande Prairie Cancer Centre	95	4.6	p
RCC	Jack Ady Cancer Centre	328	15.8	iρ
RCC	Margery E. Yuill Cancer Centre	121	5.8	s
CCC	Barrhead - Aspen Community Cancer Centre	34	1.6	w
CCC	Bonnyville Community Cancer Centre	20	1.0	6
CCC	Camrose Community Cancer Centre	35	1.7	v
CCC	Canmore - Bow Valley Cancer Centre	13	0.6	
CCC	Drayton Valley Community Cancer Centre	6	0.3	2
CCC	Drumheller - RHA5 Community Cancer Centre	15	0.7	- a
CCC	Ft. McMurray -Northern Lights Cancer Centre	13	0.6	d L
CCC	High River-Headwaters Cancer Centre	39	1.9	tr
CCC	Hinton Community Cancer Centre	15	0.7	n
CCC	Lloydminster Community Cancer Centre	17	0.8	ri
CCC	Peace River Community Cancer Centre	4	0.2	w
Total		2074	100	0
				5

years of age (85%). The majority of respondents had been living with their cancer diagnosis for over 3.5 years. Breast, Genitourinary, and Hematology cancers were the most common cancer types in the people who responded. About half of patients were receiving treatment for a first time cancer diagnosis.

Table 2 - Patients' demographic and medical characteristics

	n	Percentages (%)
Age M (SD)	66.0 (12.1)	
Age groups		
18-34	31	1.5
35-44	67	3.2
45-55	224	10.8
55-64	580	28.0
65 and over	1172	56.5
Gender		
Female	1061	51.2
Male	1013	48.8
Tumor groups		
Breast	560	27.0
CNS	18	0.9
Endocrine	4	0.2
Gastrointestinal	299	14.4
Genitourinary	426	20.5
Gynecology	102	4.9
Head and Neck	37	1.8
Hematology	411	19.8
Intrathoracic	150	7.2
Melanoma	11	0.5
Non melanoma skin	22	1.1
Other Malignant	3	0.1
Sarcoma	31	1.5
Months since diagnosis <i>M</i> (SD)	44.3 (57.4)	
Treatment was for		
First time cancer diagnosis	1311	63.2
Repeated cancer diagnosis	584	28.2
Not answered	179	8.6

Quality of Care and Services

"Overall, how would you rate the quality of all of your care in the past 6 months?"

The majority of respondents (97.4%), rated their overall experience positively, with the positive responses distributed between Good (10.6%), Very good (34.0%), or Excellent (52.8%). These data are comparable to the national average (See Figure 1).



Positive Responses to Quality of Alberta Oncology Care

Figure 1. Percentage Positive Response to Overall Satisfaction with Alberta Oncology Care

Strength and Challenges

Beyond their positive response to the overall quality of care, patients were most pleased with the opportunities created in their care for the involvement of family and friends, that they were treated with dignity and respect, and that they could trust their providers with confidential information. On the other hand, they reported low levels of satisfaction with the amount of information they received in relation to possible changes in relationships, having their wait for initial consultation explained, and receiving support to deal with difficult emotions such as anxiety and fear.

Table 3 represents the top 5 areas provincially where patient satisfaction scores were the highest and the bottom 5 areas provincially where the patient satisfaction scores were the lowest.

Table 3 - 1	Top 5 areas	of strength	and challenges
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	Strength					
	Question	Positive				
		score				
1	How much opportunity did your care providers give your family and	93.9%				
	friends to be involved in your care and treatment?	(response: right amount)				
2	Did your care providers treat you with dignity and respect?	93.3%				
		(response: yes, completely)				
3	Did you feel you could trust your care providers with confidential	90.5%				

	information?	(response: yes, completely)
4	If you had to wait for IV chemotherapy, do you think your care	83.5%
	providers did everything they could to make you feel comfortable?	(response yes, completely)
5	Do you think the care providers knew enough about the therapies for	83.4%
	treating cancer?	(response yes, completely)
	Challenges	
1	Did you get enough information about possible changes in your	35.9%
	relationships with your spouse or partner?	(response: yes, completely)
2	If you had to wait for your first consultation appointment with your	38.2%
	care providers, did someone explain why?	(response: yes, completely)
3	In the last 6 months, has someone at your cancer care clinic put you in	39.4%
	touch with other care providers who could help you with anxieties and	(response: yes)
	fears?	
4	Did you get enough information about possible changes in your	44.4%
	emotions?	(response: yes, completely)
5	Did you get enough information about possible changes in your sexual	47.6%
	activity?	(response: yes, completely)

Satisfaction with Six Dimensions of Person-Centred Care

Patients gave high ratings for some, but not all aspects of quality of care

The AOPSS survey contains behavioral based questions developed through research with patient and families to identify what was most important to them and how to measure those aspects of care. While the industry's most common tools focus on issues that providers believe drive satisfaction, the AOPSS survey addresses performance from the patient's perspective. Core questions in the survey fall into one of the following six dimensions of Person-centred care. The domain scores are the average of responses to all questions which roll up into each domain. *Please see Appendix 1 questions included in each domain.*

Emotional support: This dimension assesses patient perceptions of how they have been emotionally supported during their cancer treatment. Various aspects addressed include manners in which they were told of their cancer diagnosis, being provided services for their anxiety and fears, and information for emotional, sexual, and relationship changes due to cancer treatment.

Information Communication & Education: This dimension assesses patients' perception in regards to communications around tests, physical changes, daily activities, nutrition needs and cancer treatments.

Coordination and continuity of care: This dimension assesses patients' perception regarding the ability to receive clear, unambiguous information regarding their illness and treatment. It also measures how patients perceived the coordination of care across time and systems.

Access to care: This dimension assesses patient perception in relation to access to medical care, such as wait times for treatment as well as the extent to which care providers supported patients' through challenging situations related to waiting for care.

Respect for patient preferences: This dimension measures patient perception in relation to a holistic approach in cancer care. It measures how comfortable patients were in regards to trusting care providers, and talking about alternative therapies.

Physical comfort: This dimension assesses patient perception in regards to managing and controlling side effects of treatment and cancer-related symptoms.

Figure 2 represents 2014 percentage positive response for each of the 6 dimensions of person-centred care, in comparison with results from previous years (Figure 2a) and in comparison of this year's national average benchmark (Figure 2b).



Patients' Satisfaction with Six Dimensions of Quality of Care Since 2006 to 2014

Figure 2a

Levels of satisfaction & trends over the years: Patients indicated the highest level of satisfaction in the domain of Respect for Patient Preferences, Physical Comfort, and Access to Care. Patients gave the lowest satisfaction scores to questions in the domains of Coordination and Integration of Care, Information, Education & Communication and Emotional Support. These varied levels of satisfaction have been a common pattern since 2006.



Alberta Patients' Satisfaction with Six Dimensions of Quality of Care in 2014 & National Average

Figure 2b

<u>Alberta 2014 results relative to 2014 national benchmarks</u>: Patients in Alberta showed significantly lower satisfaction with Physical Comfort, Coordination and Integration of Care, and Information, Communication & Education relative to the national average ratings. Satisfaction with Emotional support and Respect for Patient Preferences were on par with the national average. On the other hand, patients in Alberta rated significantly higher on Access to Care relative to the National average ratings.

Improving the Quality of Care and Patient Satisfaction

A novel aspect of the AOPSS survey analytics is the ability to identify the top areas for quality improvement. The priority matrix displays items ranked in order of percentage satisfied and how strongly that question is correlated to overall satisfaction. The following table shows the top 10 questions from the provincial priority matrix where Alberta patients reported low levels of satisfactions and the items were highly correlated with the overall satisfaction with care experiences. Overall, the top domain for quality improvement was Information, Education and Communication.

Importance	Domain	Question	Positive	Correlation
				satisfaction
1	Emotional	Did you get enough information about possible changes in your emotions?	44.4	.361
2	Information	Did you get enough information about possible changes in your work/activities?	50.5	.381
3	Emotional	Did you get as much help as you wanted in figuring out how to pay for any extra cost for your cancer care?	50.6	.375
4	Coordination	How often were your care providers aware of your medical history?	52.6	.410
5	Respect	Did you feel comfortable talking with your care providers about complementary, alternative, or non-traditional therapies?	54.2	.363
6	Information	Did you get enough information about your nutritional needs?	55.5	.383
7	Information	Did you get enough information about possible changes in your energy/fatigue level?	55.6	.388
8	Coordination	How often did you know what the next step in your care would be?	56.8	.446
9	Coordination	How often did you know who to ask when you had questions about your health problems?	59.1	.367
10	Information	Did you get enough information about possible changes in your physical appearance?	62.9	.391

Table 4 – Specific areas of priority for improving overall patient satisfaction

Priority area for improvement:

1) Enabling easy access to cancer-related information for patients, in particular how they can deal with emotions and physical changes, changes in activities, fatigue, nutrition and financial cost;

2) Build capacity at point of care to identify patients' individual interests and needs, and connect them to the appropriate resources/supports such as complementary and alternative therapies, help with practical issues, or symptom management resources

3) Improve access to patients' medical history and individualized information, so that tailored and informed care responses can be delivered across the care continuum, ensuring patients are always aware of next steps in care, and know who to ask when they have questions about their health problems.

Conclusions

Alberta patients showed high levels of satisfaction (97%) for "overall quality of care". This level of satisfaction was similar to the national average. Patients were pleased with the involvement of family and friends, and that they were treated with dignity and respect. Patients expressed low satisfaction with the amount of information communicated in relation to changes in relationships, dealing with difficult emotions, sexual activity, and understanding the reasons for a long wait for their first consultation. In terms of person-centred care, patients reported high levels of satisfaction in the Respect for Patient Preferences Domain. However, their satisfaction with three domains; Physical Comfort, Coordination and Integration of Care, and Information, Communication & Education were below the national average, while their satisfaction with Access to Care was above the national average. Patients also reported low levels of satisfaction in the Domain of Emotional Support, which was on par with the national average. This report highlighted areas for improvement, which are closely related to overall patient satisfaction. Provision of efficient information and services regarding possible changes in emotional health, work/activities, nutritional needs as well as dealing with financial costs were all areas identified as areas for improvement. Care teams must be able to effortlessly access patients' medical history and individualized information, so that tailored and informed care responses can be delivered based on the needs, preferences, and concerns of the individual.

2. Supportive Care and Symptom Management Specific Information

The AOPSS includes questions that are specifically related with Surgery, Systemic Therapy, Radiation Therapy and Supportive Care. The following section shows the distribution of patients' responses to questions in areas of Symptom Management and Supportive Care.

Symptom Management Questions				
Q47	In the past 6 months, if you had pain, on a scale of 1-10, was it usually severe, moderate or mild?			
Q48	Do you think your care providers did everything they could to control your pain or discomfort?			
Q49	Did you get enough information about possible changes in your physical appearance?			
Q50	Did you get enough information about possible changes in your sexual activity?			
Q51	Did you get enough information about possible changes in your emotions?			
Q52	Did you get enough information about your nutritional needs?			
Q53	Did you get enough information about possible changes in your relationship with your spouse or partner?			
Q54	Did you get enough information about possible changes in your work or usual activities?			
Q55	Did you get enough information about possible changes in your energy/fatigue level?			
Q57	Did you feel comfortable talking with your care providers about complementary, alternative, or nontraditional therapies?			
Q77	If you had a visit with your family doctor in the past 6 months, did you feel your family doctor knew enough about your cancer care?			
Supportive Care Questions				
Q58	If you had any worries or concerns before beginning your treatment, did your care provider discuss them with you?			
Q59	If you had worries or concerns during your treatment, did your care provider discuss them with you?			
Q60	Do you feel your doctor(s) listened carefully to you?			
Q61	Do you feel your other care provider(s) listened carefully to you?			
Q62	Did you get the help you wanted to cope with.? (Please mark the type(s) of help you have received)			
Q63	Did your care providers give your family or someone close to you all the information they needed to support you in your care and recovery?			
Q64	In general, how would you rate your emotional health?			

Q47: In the past 6 months, if you had pain, on a scale of 1-10, was it usually severe, moderate or mild?

	n	%
Severe (7-10)	194	10.3
Moderate (4-6)	438	23.2
Mild (1-3)	503	26.7
Didn't have pain in the past 6 months	751	39.8

Q48: Do you think your care providers did everything they could to control your pain or discomfort?

	n	%
Yes, completely	758	68.9
Yes, somewhat	289	26.3
No	53	4.8
Didn't have pain	12	n/a

Q49: Did you get enough information about possible changes in your physical appearance?

	n	%
Yes, completely	964	62.9
Yes, somewhat	398	26.0
No	170	11.1

Q50: Did you get enough information about possible changes in your sexual activity?

	n	%
Yes, completely	611	47.6
Yes, somewhat	340	26.5
No	333	25.9

Q51: Did you get enough information about possible changes in your emotions?

	n	%
Yes, completely	731	44.5
Yes, somewhat	596	36.2
No	318	19.3

Q52: Did you get enough information about your nutritional needs?

	n	%
Yes, completely	971	55.5
Yes, somewhat	525	30.1
No	252	14.4

Q53: Did you get enough information about possible changes in your relationship with your spouse or partner?

	n	%
Yes, completely	445	35.9
Yes, somewhat	365	29.4
No	431	34.7

Q54: Did you get enough information about possible changes in your work or usual activities?

	n	%
Yes, completely	715	50.5
Yes, somewhat	467	33.0
No	233	16.5

Q55: Did you get enough information about possible changes in your energy/fatigue level?

	n	%
Yes, completely	1016	55.6
Yes, somewhat	609	33.3
No	202	11.1

Q56: Did you want but NOT receive information about any of the following services? (mark all that apply)

	n	%
Counseling/support (social worker, psychologists, psychiatrist)	110	5.3
Spiritual support	60	2.9
Dietitian	132	6.4
Speech therapist	24	1.2
Occupational therapist	37	1.8
Physiotherapist	55	2.7
Support groups	100	4.8
Palliative care	46	2.2
Other	48	2.3
I didn't want or need information	368	17.7
I received all the information that was wanted	1261	60.8

Q57: Did you feel comfortable talking with your care providers about complementary, alternative, or nontraditional therapies?

	n	%
Yes, completely	560	54.2
Yes, somewhat	282	27.3
No	191	18.5
I don't use complementary	866	n/a
therapies		

Q58: If you had any worries or concerns before beginning your treatment, did your care provider discuss them with you?

	n	%
Yes, completely	873	58.2
Yes, somewhat	515	34.3
No	113	7.5
I had no worries or concerns	425	n/a

Q59: If you had worries or concerns during your treatment, did your care provider discuss them with you?

	n	%
Never	49	3.3
Sometimes	237	15.9
Usually	342	23.0
Always	859	57.8
I had no worries or concerns	433	n/a

Q60: Do you feel your doctor(s) listened carefully to you?

	n	%
Never	19	1.0
Sometimes	188	9.8
Usually	489	25.5
Always	1223	63.7

Q61: Do you feel your other care provider(s) listened carefully to you?

	n	%
Never	18	1.0
Sometimes	160	8.4
Usually	589	30.9
Always	1137	59.7

Q62: Did you get the help you wanted to cope with.? (Please mark the type(s) of help you have received)

Issues endorsed	n	%
Practical	393	18.9
Financial	301	14.5
Social/family	194	9.3
Emotional	396	19.1
Spiritual	122	5.9
Informational	1094	52.7
Physical	876	42.2
Other	138	6.7

Q63: Did your care providers give your family or someone close to you all the information they needed to support you in your care and recovery?

	n	%
Yes, completely	1089	63.7
Yes, somewhat	450	26.3
No	169	10.0
I did not want them to be involved	111	n/a
I did not have family or support persons to be involved	83	n/a

Q64: In general, how would you rate your emotional health?

	n	%
Poor	39	2.0
Fair	260	13.5
Good	706	36.8
Very Good	619	32.3
Excellent	296	15.4

Q77: If you had a visit with your family doctor in the past 6 months, did you feel your family doctor knew enough about your cancer care?

	n	%
Yes, completely	989	58.2
Yes, somewhat	532	31.3
No	178	10.5
Does not apply	217	n/a

Summary

About one-third of patients reported they had experienced moderate to severe levels of pain in the last 6 months, and 70% of them feel that their care providers did everything to control the pain. About 60% of patients reported they were well-informed about possible changes in their physical appearances. Fifty-five percent of patients reported they were well-informed about possible changes in their energy levels and nutrition needs. About 50% of patients were satisfied with the information given for possible changes in usual activities or work and fewer patients (47%) were satisfied with the information given for possible changes in sexual activity and emotions. The worst level of satisfaction (35%) was found for the information given for possible changes in the relationship with partner/spouse. About 20% of patients reported they wanted but did not receive the help from various supportive care providers, including psychologists, social workers or Dietitians. About a half of patients reported they were comfortable talking about complementary and alternative therapies with their care providers, and about 60% reported that they felt completely satisfied that their family doctor knew about their cancer care. Overall, this area of care showed consistently low levels of patient satisfaction. The highest was seen for the extent to which care providers' effort to control pain or discomfort. About 50% or more patients were not well-satisfied with the information received in relation to energy levels/fatigue, nutrition needs, usual activities/work, sexual activities, emotions, relationships, and complementary and alternative therapies, indicating unmet informational needs for a significant proportion of patients.

About a half of patients reported that they could discuss about their worries and concerns with their care providers before and during the treatment, and about 60% of patients agreed that their care providers always listened carefully to them. Given that the majority of patients (about 80%) have some worries and concerns, provision of supportive care through patient-provider interactions needs to improve. The most common issues patients received the help with were informational and physical issues, followed by emotional and practical issues, indicating high levels of support demand for these areas. About 60% of patients were highly satisfied with the amount of information their family and friends received in regards to cancer treatment and recovery from treatment. The majority of patients (over 80%) rated their general emotional heath as good, very good or excellent. Overall, these results identified room for improvement in provision of supportive care through patient-provider interactions, and high levels of support sought by patients for coping with informational and physical issues. Also, patients in general, rate their emotional health at satisfactory levels.

3. Diagnosis Time Cohort Analyses

The AOPSS survey included patients who received their cancer treatment in the last 6 months. However, there was a large variability in the duration of time since these patients were diagnosed with cancer (9 months to 784 months), suggesting that some patients are in their early phase of cancer journey, while others are being treated for a repeat diagnosis or chronic cancer. This part of the analyses demonstrates patient experiences and needs are different depending on how long they have been living with cancer and receiving cancer treatment. In this analysis patients were divided into Early, Middle and Late groups based on their time since diagnosis, and comparisons were made for their background characteristics, types of needs, and priority areas of care for improvement.

<u>Three diagnosis cohorts</u>: Table 1 shows the distributions of patients in the three cohorts, and Figure 1 shows average time since diagnosis for the three cohorts.

Cohort	Early	Middle	Late
Criteria:	Being diagnosed less than	Being diagnosed	Being diagnosed more
	18 months ago	between 18 and 37	than 37months ago
		months ago	
n	678	696	700
% of total sample	32.7	33.6	33.8

Table 1 - Distributions of three diagnosis cohorts



Average Months Since Diagnosis

Figure 1. Average time since diagnosis across three cohorts

About one-third of patients were diagnosed with cancer more than three years ago, and patients in Late group had been diagnosed with cancer significantly longer (8.5 years) than those in Early (14 months) and

Middle (2 years) groups. Patients in Middle group had been diagnosed with cancer significantly longer than those in Early group. Table 2 shows demographic characteristics of the three cohorts.

Table 2 – Demographic	characteristics	of three	cohorts.
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	Early (n = 678)	Middle (n = 696)	Late (n = 700)	Differences
Age M (SD)	64.27(12.62)	64.38 (11.67)	69.47 (11.67)	<.001
Gender N (%)				
Female	382 (56.3)	394 (56.6)	285 (40.7)	<.001
Male	296 (43.7)	302 (43.4)	415 (59.3)	
Diagnosis N (%)				
Gynecology	49 (7.2)	32 (4.5)	21 (3.1)	<.001
Gastrointestinal	115 (17.0)	120 (17.2)	64 (9.1)	
Genitourinary	89 (13.1)	122 (17.5)	215 (30.7)	
CNS	8 (1.2)	4 (0.6)	6 (0.9)	
Breast	194 (28.6)	220 (31.6)	146 (20.9)	
Endocrine	1 (0.1)	1 (0.1)	2 (0.3)	
Hematology	105 (15.5)	130 (18.7)	176 (25.1)	
Intrathoracic	71 (10.5)	54 (7.8)	25 (3.6)	
Head and neck	28 (4.1)	3 (0.4)	6 (0.9)	
Melanoma	1 (0.1)	2 (0.3)	8 (1.1)	
Non-melanoma skin	4 (0.6)	4 (0.6)	14 (2.0)	
Sarcoma	11 (1.6)	5 (0.7)	15 (2.1)	
Other malignant	2 (0.3)	1 (0.1)	0 (0)	
Treatment was for, N (%)				
First time cancer diagnosis	590 (91.3)	521 (81.0)	200 (33.0)	<.001
Repeat cancer diagnosis	56 (8.7)	122 (19.0)	406 (67.0)	
Treatment received (currently or in the last 6 months), N (%)				
IV chemotherapy	276 (40.7)	245 (35.2)	157 (22.4)	<.001
Oral chemotherapy	51 (7.5)	83 (11.9)	145 (20.7)	
Radiation therapy	258 (38.1)	170 (24.4)	92 (13.1)	
Systemic (immunotherapy,	93 (13.7)	198 (28.4)	306 (43.7)	
biotherapy) therapy				

The three cohorts were significantly different in their average age, distributions of gender, tumour groups, first time or repeat cancer diagnosis, and types of treatment received.

<u>Age</u>: Patients in Early and Middle groups were significantly younger than those in Late group.

<u>Gender</u>: Early and Middle groups included significantly more females than males, while Late group included more males than females.

<u>Tumour groups</u>: The proportions of Breast and GI patients were significantly greater in Early and Middle groups relative to Late group. The proportions of Hematology and Genitourinary patients were significantly greater in Late group relative to Early and Middle groups. The proportions of Gynecology, Intrathoracic, Head and neck patients were significantly greater in Early group relative to the other two groups.

<u>First vs repeated diagnosis</u>: There were significantly more patients with first time diagnosis and significantly fewer patients with repeated diagnosis in Early group relative to Middle group. Similarly, there were significantly more patients with first time diagnosis and significantly fewer patients with repeated diagnosis in Middle group relative to Late group.

<u>Treatment received</u>: There were significantly more patients who received IV chemotherapy and RT and significantly fewer patients who received Oral chemotherapy and Systemic therapy in Early group relative to Middle group. Similarly, there were significantly more patients who received IV chemotherapy and RT and significantly fewer patients who received Oral chemotherapy and Systemic therapy in Middle group relative to Late group.

Differential needs of three cohorts: Figure 2 shows different levels of needs across the three cohorts.



Did you get the help you wanted to cope with ...?

Figure 2. Various levels of needs across the three cohorts

Patients' needs in all except spiritual aspects were significantly different depending on how long they have been living with cancer and receiving cancer treatment. Significantly fewer patients in Late group reported they got the help they wanted to cope with practical, financial, social/family, emotional, informational, and physical issues relative to those in Early and Middle groups.

Improving the quality of care and patient satisfaction for each time cohort: As reported in the provincial overview results, the priority matrix displays items ranked in order of percentage satisfied and how strongly that question is correlated to overall satisfaction. Table 3 shows the top 10 questions from the provincial priority matrix where Alberta patients reported low levels of satisfactions and the items were highly correlated with the overall satisfaction. It also includes positive response scores of the three cohorts to show how the priority areas for improvement are similar or different across the three cohorts.

Importance	Domain	Question	Correlation to overall satisfaction	Provincial positive score	Early	Middle	Late
1	Emotional	Did you get enough information about possible changes in your emotions?	.361	44.4	48.5	49.4	33.8*
2	Information	Did you get enough information about possible changes in your work/activities?	.381	50.5	54.3	54.5	40.5*
3	Emotional	Did you get as much help as you wanted in figuring out how to pay for any extra cost for your cancer care?	.375	50.6	54.2	52.4	43.7
4	Coordination	How often were your care providers aware of your medical history?	.410	52.6	49.1	55.9	53.0
5	Respect	Did you feel comfortable talking with your care providers about complementary, alternative, or non-traditional therapies?	.363	54.2	56.1	55.4	51.1
6	Information	Did you get enough information about your nutritional needs?	.383	55.5	61.3	60.0	43.8 *
7	Information	Did you get enough information about possible changes in your energy/fatigue level?	.388	55.6	61.5	60.8	43.1*
8	Coordination	How often did you know what the next step in your care would be?	.446	56.8	58.4	59.9	51.9
9	Coordination	How often did you know who to ask when you had questions about your health problems?	.367	59.1	60.0	59.9	57.3
10	Information	Did you get enough information about possible changes in your physical appearance?	.391	62.9	65.7	68.1	52.6*

Table 3 – Specific areas of priority for improving overall patient satisfaction for three cohorts

*Indicates significantly different levels in the positive response score for the cohort relative to other cohorts

Satisfaction levels in 5 out of the 10 priority areas were significantly different across the three cohorts. Relative to patients in Early and Middle groups, patients in Late group expressed significantly lower satisfaction in relation to the information given for possible changes in emotions and work/usual activities, nutrition needs, fatigue/energy levels, and physical appearance. These emotional and informational aspects

of care need to be tailored to accommodate the needs of patients who have been living with cancer and on treatment for a long time.

Summary

There is a large variability in the duration of time since patients have been diagnosed with cancer, and currently little is understood in regards to the potential influence of this variability on aspects of care and patient satisfaction. The results highlighted that a significant proportion of patients (one-third) have been living with cancer for a very long time (more than 3 years, on average 8.5 years), and recently received cancer treatment, suggesting the existence of a large patient group who are chronically under cancer treatment or have returned to the cancer system with a repeat diagnosis and associated treatments. The results indicated that the three cohorts are different in their demographics, cancer types, treatment received, and frequencies of repeated cancer diagnosis. Importantly, patients in Late group reported distinctive patterns and levels of needs in the majority of aspects and fewer patients in this group reported their needs were met relative to other patients. Taken together, the results highlighted that the same model of care may not be equally effective for all patients because patient characteristics, treatment experiences, needs, priority for improvements are all different depending on how long patients have been living with cancer and receiving cancer treatment. Of the 10 priority areas for quality improvement, five areas are influenced by the time since diagnosis. Patients who have been living with cancer and been receiving treatment for a long time reported consistently poorer satisfactions in those area relative to other patients. Therefore, more targeted quality improvements are important in the informational and emotional care domains.

Appendix 1: Question items used for calculations of positive responses

1. Emotional support: % positive responses = Mean of the positive response for Qs 4, 5, 50, 51, 53, 67, 75, & 76.

2. Information Communication & Education: % positive responses = Mean of the positive response for Qs 7, 8, 13, 15, 17, 18, 49, 52, 54 & 55

3. Coordination and continuity of care: % positive responses = Mean of the positive response for Qs 12, 66, 68, 69, 70, 71, 72, 77

4. Access to care: % positive responses = Mean of the positive response for Qs 14, 16, 36, 37, 43, 44 & 86

5. Respect for patient preferences: % positive responses = Mean of the positive response for Qs 9, 10, 11, 57, 73, 74

6. Physical comfort: % positive responses = Mean of the positive response for Qs 38, 39, 45, 46, 48

Appendix 4. Consultation Rubric

Consultation	Meeting/Group	People Involved	Purpose
Dates	Dolliotive and End of Life	Auroralaang	Determine work
	Care Framework	Michelle Peterson Fracer	Underway and approach
	Care Framework	Max Jaiszcazk	to developing a
			framework that was
			used
November 13.	Knowledge Management	Mark Moland	Determine the support
2014	Practice Support and	Obianuju Mollel	that could be offered by
	Education	,	Knowledge
			Management Services
December 2, 2014	BC Cancer Agency	G Macken	Information gathering
		V Mattimo	
		Core Committee	
January 27, 2015	Clinical Engagement	Lisa Petermann	Work out Engagement
February 3, 10, 17,		Core Committee	approach
24, 2015		Anna Fabbroni	
March 3, 10, 17,		Obianuju Mollel	
24, 31, 2015		Sarah Singh	
		Maria Ian	
January 29, 2015	Engagement and Patient	Jennifer Dotchin	
February 5, 2015	Experience	Krista Marsden	
		Sarah Singh	
		Frin Fani	
March 16.2015	CCA Systemic Treatment	Council members	Consultation
	Council	Lisa Peterman	
		Debora Allatt	
March 27, 2015	CCA Radiation Treatment	Council Members	Consultation
	Council	Lisa Peterman	
April 16, 2015	Engagement	Erin Quaale	Review work on
April 30, 2015		Jennifer Dotchin	Engagement
		Lisa Petermann	
May 21, 2015	Communication and	Kira Kulicki	Communication
	Clinical Engagement	Melody Morin	Strategy possibilities
June 8, 2015	Rehabilitation Working	Janice Yurick	
June 17, 2015	Group		
August 0, 2013 October 7 th 2015		Anna Sytsanko	
		Susanne Lesniak	
		Kelsey Waisanen	
		Chester Ho	
		David Langelier	
		Sarah Singh	
		Debora Allatt	

Consultation Dates	Meeting/Group	People Involved	Purpose
May 25, 2015	Psychosocial working	Debora Allatt	
June 15, 2015	group	Barry Bultz	
August 10, 2015		Jill Turner	
October 19, 2015		Vivian Collacutt	
		Laura Labelle	
		Lisa Lamont	
		Tricia Hutchison	
		Melissa Wilde,	
		Bejoy Thomas	
		Michael Speca	
		Ceinwen Cumming	
		Sarah Singh	
		Paula Germann	
May 4, 2015	Spiritual Care working	Wilson Miranda	
May 26, 2015	group	Zinia Pritchard	
September 14,		Margaret VanGinhoven	
2015		Vivian Collacutt	
September 21,		Jill Turner	
2015		Sarah Singh	
		Debora Allatt	
May 13, 2015	Art Therapy working group	Haley Toll	
June 8, 2015		Jill Turner	
August 14, 2015		Marie Butler	
September 30,		Allan Rosales	
2015		Krista Marsden	
		Debora Allatt	
		Vivian Collacutt	
		Sarah Singh	
May 26, 2015	Patient navigation working	Jennifer Anderson	
June 3, 2015	group	Linda Watson	
August 24, 2015		Tricia Hutchison	
September 15,		Debbie Benoit	
2015		Robbi Allen	
		Linda Knapp	
		Leanne Eshleman	
		Janice Petruk	
		Wendy Council	
		Saran Singn	
May 15 2015	Detient and Family		
IVIAY 15, 2015	Education working group	Liysa Mekinnen	
June 24, 2015	Eulealion working group		
August 17, 2015			
OCIODEI 20, 2015		Allison Courlow	
		Karov McCana	

Consultation	Meeting/Group	People Involved	Purpose
		Deborah McTaggart-Baird Maurice Paul Carol Craig Debora Allatt Amanda Jacques Shelley Currie	
July 27, 2015	Cancer SCN leadership	Janice Yurick Debora Allatt Angie Estey Barbara O'Neill	Create awareness, identify areas of overlap and discuss presentation
September 16, 2015	Primary Care/Chronic Disease Management	Soraya Haynes Judith Britten Margaret Sills Maerox Shahnaz Davachi Donna Rose Janice Yurick Debora Allatt	
September 17, 2015	Planning meeting for presentation to Core Cancer SCN Committee	Janice Yurick Debora Allatt Angie Estey Chris Normandeau	
September 25, 2015	CCA Provincial Tumour Group Council	Tumour Group leads Janice Yurick	Present and consult on overview of framework to date
September 30 2015	Presentation to Strategic Clinical Network	SCN Committee members (full list available on request)	Focus groups with Core Cancer SCN Committee
February 1, 2016	Community Agencies and Partnerships Discussion with AHS legal	AHS legal – Matthew Ferg Janice Yurick Brenda Hubley	Discussion of partnership parameters, AHS requirements
January 28, 2016	Community Agencies and Partnerships – consultation with Alberta Survivorship Network	Committee Members (membership available on request) Debora Allatt Janice Yurick	Consultation on CCA working with Community Agencies
January 29, 2016 March 3, 2016	Community Agencies and Partnerships – Working Group	Patti Morris (Wellspring)and Joanne Stewart (CCS) Janice Yurick	Draft parameters for CCA work with Community Agencies
February 24, 2016	Patient and Family Advisory Council (Calgary)	Council Membership Debora Allatt	Consultation on identified Gaps and Opportunities
February 29, 2016	AHS Communications and Community Engagement	Janice Yurick Kristin Bernhard	Consultation on CCA working with

Consultation Dates	Meeting/Group	People Involved	Purpose
		Kathryn Ward	Community Agencies, AHS policy and guidance.
March 8, 2016	Community Oncology – community engagement perspective	Janice Yurick Tricia Hutchison Janice Petruk	Build understanding around the unique needs of rural communities regarding community partnership and information sharing.
March 11, 2016	Wellspring Edmonton	Janice Yurick Marilyn Hundleby	Discussion to build understanding as to potential Wellspring Edmonton programming and partnership with CCA.

Appendix 5. Putting Patients First



Patient Label

Talking About What Matters To You Putting Patients First

Your answers will help us understand how you have felt since your last visit, and how you feel today. Knowing this will help us care for you. If you cannot or do not wish to fill out this form for any reason please let us know.

Note: Please make sure to fill out both sides of the form

A member of your healthcare team will go over the form with you and talk to you about what concerns you the most today. If we are not able to talk about all of your concerns today, we will decide the next steps together.

Date (yyyy-Mon-dd) Completed	by:	Fam	ily		Ass	iste	d by	far	nily/	hea	lth p	rofessional
Please answer the yes/no questions:												
1. Have you been to Emergency and/or been admitted to hospital since your last visit?												
2. Have your medications changed since your last visit?(e.g. stopped, started, dose change) 🛛 🗆 Yes 🗆 No												
3. Have you had a fall since your last visit? □ Yes □ No												
4. Would you like information	on (Goal	ls of	Ca	re o	r ad	van	ce d	are	pla	nnin	g (green sleeve)? □ Yes □ No
5. Are you receiving home car	e se	ervio	es?	>								🗆 Yes 🗆 No
6. Have you used tobacco in t	he p	past	yea	ar?		ΟY	'es		No	In	the	past 30 days? □ Yes □ No
Please circle the number that best describes how you feel NOW												
0 means you do not have that s	0 means you do not have that symptom, 10 means it is at its worst											
No pain	0	1	2	3	4	5	6	7	8	9	10	Worst possible pain
No tiredness (Tiredness=lack of energy)	0	1	2	3	4	5	6	7	8	9	10	Worst possible tiredness
No drowsiness (Drowsiness=feeling sleepy)	0	1	2	3	4	5	6	7	8	9	10	Worst possible drowsiness
No nausea	0	1	2	3	4	5	6	7	8	9	10	Worst possible nausea
No lack of appetite	0	1	2	3	4	5	6	7	8	9	10	Worst possible lack of appetite
No shortness of breath	0	1	2	3	4	5	6	7	8	9	10	Worst possible shortness of breath
No depression (Depression=feeling sad)	0	1	2	3	4	5	6	7	8	9	10	Worst possible depression
No anxiety (Anxiety=feeling nervous)	0	1	2	3	4	5	6	7	8	9	10	Worst possible anxiety
Best well-being (Well-being=how you feel overall)	0	1	2	3	4	5	6	7	8	9	10	Worst possible wellbeing
No Other problem (e.g. constipation)	0	1	2	3	4	5	6	7	8	9	10	Worst possible

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What concerns have you had since your last visit? Check any boxes that have concerned you.								
Emotional Fears/Worries Sadness Frustration/Anger Changes in appearance Intimacy/Sexuality Thoughts of ending my life Social/Family/Spiritual Feeling alone Feeling like a burden to others Worry about friends/family Support with children/partner Meaning/Purpose of life Faith	Physical Fever/Chills Bleeding/Bruising Cough Headaches Concentration/Memory Vision or hearing changes Numbness/Tingling Sensitivity to cold Changes to skin/nails Bladder problems Lymphedema/Swelling Range of motion Strength	Nutrition Weight gain (amount) Weight loss (amount) Special diet Difficulty swallowing Mouth sores Taste changes Heartburn/Indigestion Vomiting Diarrhea Constipation Informational Understanding my illness and/or treatment						
Practical	□ Speech difficulties □ Sleep							
Work/School Finances Getting to and from appointments Home Care	Boop Mobility Dizziness Walking/Mobility Trouble with daily activities (e.g. bathing, dressing)	 Making treatment decisions Knowing about available resources Taking medications as prescribed 						
	Other Concerns:							
Containing to bacco Drug costs Health insurance How much alcohol you drink	Thank you for filling out the form. The rest of the form will be completed by your healthcare professional							
To be filled out by a health care pr	ofessional only - Screening Intervent	on Documentation						
Review of Form:								
Review of Form: Patient declined to fill out form Language barrier Other Form reviewed through conversation with patient If form not reviewed why: Patient declined discussion Is patient at falls risk? Yes No Patient Priority Concern Identified Patient indicated no concerns Specify ONE priority concern (either ESAS or CPC); ESAS: Pain Drowsiness Appetite Depression Well-being Tiredness Nausea Shortness of breath Anxiety Other CPC: Emotional Practical Mobility Social/Family /Spiritual Nutrition Physical Informational Other Specific area indicated under the CPC domain:								
Provided information/Education Offered Tobacco Cessation Advice Prescription provided								
Provided emotional support Referral suggested but patient declined No further action required								
Referrals: Social Work Palliative Care Tobacco Clinic Dyspnea/Respiratory Psychology Nutrition Home Care OT/Physio/Speech CO Navigation Spiritual Care Pharmacy Pain Clinic Other Further details on action taken:								
See progress notes/nursing docu	umentation for further information							
Reviewed By (Name of Health Care Profes	ssional) Signature (of Health Ca	re Professional) Date (yyyy-Mon-dd)						
L	I	1						

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Appendix 6. Criteria for Partnership: Community-Based Organizations and AHS CancerControl Alberta

For Discussion

Principle #1: The Partnership is developed based on an identified need and there is a shared interest in meeting that need.

Partners who have shared interests and goals (such as patient-centered vision and collaborative intent) often discover that their individual expertise can be magnified toward resolving issues when the two work in partnership. Exploring opportunities to work in synergy, rather than duplication through partnership, can provide new answers to shared issues and opportunities.

Principle #2: The Partnership forms to serve a specific purpose and may take on new goals over time.

The purpose and goals should be specified and included in any memoranda the partnership develops. Overtime, the original goals may need to be revised and/or augmented.

Principle #3: The Partnership agrees upon mission, values, goals, measurable outcomes and processes for accountability.

The first step towards agreement in these areas is to discover the questions each partner has. Both parties may have questions of each other regarding mission, values, goals, anticipated outcomes, and processes for accountability. Once perspectives and agendas are better understood, a negotiation and priority setting process should be used to distill the areas of mutual agreement that can be used as the beginnings of a working relationship.

Principle #4: The relationship between partners in the Partnership is characterized by mutual trust, respect, genuineness, and commitment

These elements will become stronger over the passage of time, but it is critical to highlight their importance at the very beginning stages of relationship-building. Each partner must have as a basis for working together, genuine respect for the other in terms of the value and importance of the resources, perspectives, knowledge, and time each side devotes to the partnership.

Principle #5: The Partnership builds upon identified strengths and assets, but also works to address needs and increase capacity of all partners.

High quality assessment can be productive at all stages of a partnership, even the beginning. Discussions around the first three partnership principles should provide a base upon which to maximize each partner's assets while also uncovering needs that can be addressed effectively through the partnership. Establishing a pattern of mutual assessment also paves the way for rigorous and meaningful evaluation as the partnership evolves.
Principle #6: The Partnership balances power among partners and enables resources among partners to be shared.

Many institutions assume that their community partners hold limited power and that it's necessary for the institutions to "build them up." While possibly well-intentioned, this is an unproductive and potentially dangerous assumption. Partners should both openly discuss and assess the partnership's power dynamics; then, if necessary, methods of power redistribution should be considered. Once a more equitable balance of power is in place, resources can be shared more effectively. Partners should also be creative regarding how resources are defined. Resources are not just financial; they also often include people, supplies, space, or knowledge. Moreover, appreciation and energy can be seen as resources that partners can and should share and celebrate.

Principle #7: Partners make clear and open communication an ongoing priority in the Partnership.

Establish communication expectations as well as the best communication mechanisms for all partners and then honor them. Schedule times for regular in-person meetings possibly alternating between partner sites, as possible. Addressing the issue of communication processes to follow when misunderstandings and disagreements arise can strengthen the partnership and ensure that the partnership's goals remain paramount, reducing the likelihood that participants will be diverted by issues that turn out to have been misunderstandings.

Principle #8: Principles and processes for the Partnership are established with the input and agreement of all partners, especially for decision-making and conflict resolution.

Many partnerships begin with the discussion of roles and procedures. If values and goals aren't aligned, however, and if mutual trust and effective means of communication have not been established, the process design phase is unlikely to go smoothly or to have successful, lasting results. Thus, it is strongly recommended that parties address the first six principles before embarking on the course of designing processes and defining roles.

Principle #9: There is feedback among all stakeholders in the Partnership, with the goal of continuously improving the Partnership and its outcomes

Gathering feedback is an effective way to show respect for partners; incorporating that feedback into evaluation outputs and program design reflects a true appreciation of each partner's perspective.

Principle #10: Partners share the benefits of the Partnership's accomplishments.

Benefits of accomplishments can be defined as growth and an increase in resources as well as appreciation; appreciation can be shown in numerous ways. It is important that each partner share credit and show appreciation for the other partners. At a minimum, this could be through recognition in reports, newsletters, or journal articles, celebrations, formal presentations and public acknowledgement.

Principle #11: Partnerships can dissolve, and when they do, need to plan a process for closure.

Effective partnerships must have the capacity and patience to consider and embrace change as they develop. Partnerships can be viewed as living organisms that must be nurtured over time. Those nurturing activities can proceed indefinitely, or in some cases, the partnership can recognize that formal partnering must come to a close. In these cases, establishing an agreed upon process for closure is critical so that partners retain the strength and growth developed through having been part of an authentic partnership. In instances where the partnership elects not to close but to morph into something entirely different, members may elect to close the initial partnership formally before structuring the new entity or it may decide that a simple change in the Memorandum of Understanding is sufficient.

Principle #12: Partnerships agree upon evaluation, measurable outcomes and processes for accountability.

Partnerships develop through organizations and individuals coming together to achieve what they could not have achieved working alone. In coming together, participants must recognize not only how the environment and culture in which they function affects their views and approaches but also how they affect their partnering organizations' approaches to initiative design, evaluation, and sustainability. Honesty and openness required to develop authentic partnerships mean that partners will be cognizant of the multiple ways in which their environments restrict and/or free them to shape the partnership and its work.

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