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Nova Scotia Cancer Care Program

Yarmouth Area Cancer Services Review

September 6, 2018

Prepared by: **Yarmouth Area Cancer Services Review Steering Committee members**

Questions: Anyone who has questions about the methodology used in conducting the review or on the content included in the report may contact Dr. Drew Bethune's office at 902-719-8025.

Contents

Abbreviations

CPFN	Cancer Patient Family Network
CPQR	Canadian Partnership for Quality Radiotherapy
CWG	Comparator Working Group
CZ	Central Zone
DES	Deliberative Engagement Session
DHW	Department Health and Wellness
DWG	Data Working Group
EBRT	External Beam Radiotherapy
EEMWG	Equity-Enhancing Measures Working Group
GIS	Geographic Information System
HHR	Health Human Resource
IMRT	Intensity Modulated Radiation Therapy
IV	Intravenous
Linac	Linear Accelerator (radiotherapy machine)
LIM	Low Income Measure
NS	Nova Scotia
NSCCP	Nova Scotia Cancer Care Program
NSHA	Nova Scotia Health Authority
OPIS	Oncology Patient Information System
PFAC	Patient Family Advisory Council
QEII	Queen Elizabeth II
RT	Radiotherapy
SA	Yarmouth Service Area
SA+	Expanded Yarmouth Service Area
SBRT	Stereotactic Body Radiation Therapy
SC	Steering Committee
ST	Systemic Therapy

VMAT	Volumetric Arc Therapy
WZ	Western Zone
YRH	Yarmouth Regional Hospital

Executive Summary

History

There has been interest in establishing a radiation therapy facility in Yarmouth for many years. Cancer patients from the Yarmouth area are the largest group in the province who travel the greatest distance for radiation treatment.

Past reviews, including one conducted in 2014, examined the cost of building and operating a radiation treatment facility in Yarmouth. At the time, there was no formal process to guide decision making.

The concept of providing radiation treatment in Yarmouth re-emerged in the summer of 2016 and again in 2017. In the fall of 2017, with the endorsement of government and Nova Scotia Health Authority (NSHA) executive leadership, Dr. Drew Bethune, Medical Director, NSHA's Nova Scotia Cancer Care Program (NSCCP), established a Steering Committee (SC) to conduct a comprehensive review of the issue. The creation of the new NSCCP in 2016, which is responsible for the comprehensive delivery of cancer care throughout the province, made this approach possible.

Cancer program leaders believe that a full review of complex issues such as this is the best way to facilitate high-quality decision making regarding the use of limited health care resources. The mandate of the review was to consider all available data and expert opinion along with the personal toll on patients and their families who have to travel long distances for radiation treatment.

Process

In October 2017, a SC (p. 13) was established to lead a review of cancer services available in the Yarmouth area. Its objectives were: to revisit the feasibility and sustainability of adding radiation therapy services at Yarmouth Regional Hospital (YRH), and to consider other supports which could help improve access to care for patients when they need to travel for cancer services. SC members were committed to ensuring a rigorous and thorough examination of all of the issues. Engagement with the local advocacy groups and community in general was embedded in the design process.

The carefully-chosen 21-member SC included cancer program leadership from Halifax and Yarmouth, cancer health professionals, administrators, and patient and public representatives from Yarmouth. A senior medical ethicist from Dalhousie University joined the committee as a full member to ensure all components of the project were considered through an ethical lens. Early in the process a member of one of the three local advocacy groups was also added as a full member.

All SC members agreed an open and transparent process with a strong community and patient engagement component was important to the project's success. They also committed to keeping cancer program staff informed prior to any communication with the public or media. A project management approach kept the work focused and on time.

The addition of the ethicist added discipline and rigor to the process and supported benchmarks for a fair and ethical process. This prolonged the project slightly but the group unanimously agreed that this was essential.

A project charter (Appendix A) was developed and adopted. SC members agreed to use an ethical framework for discussions, and a deliberative engagement process at the end to consider all evidence and decide on a clear and unambiguous recommendation.

Working groups were established with specific expertise to gather, analyze and report to the SC in the following areas:

- Data including community characteristics; cancer statistics and treatment workload;
- Building and operational costs from 2014 were reviewed and revised;
- Equity-enhancing options for people who have to travel for specialty cancer services;
- Comparator options to enhance the cancer system; and
- A review of current and emerging trends in the delivery of radiation treatment.

Community Engagement

Staff, patient and community engagement formally began in January 2018 when Dr. Bethune and two committee members visited Yarmouth to meet with staff, community leaders, special interest groups, and media to share the process for the review, including staff, patient and community engagement opportunities and anticipated timelines. These meetings were followed by two focus groups in Yarmouth with 12 community members in each group, including a mix of patients, family members and concerned citizens. In early April, electronic and paper surveys were shared and promoted. More than 900 people responded.

All messages emphasized the SC’s commitment to a fair process with due consideration of all aspects to ensure a recommendation for a complex issue.

Final Deliberative Engagement Session

As feedback from the community engagement was being analyzed and working groups were gathering, analyzing and compiling data, SC members were planning for a day-long deliberative engagement session (DES) and considering who would participate as core stakeholders and relevant resource persons. Fifteen participants were invited to ensure inclusion of all perspectives. Participants included three patient/public advisors from Yarmouth, a cancer patient navigator, cancer program leadership from Halifax and

Yarmouth / Western Zone (WZ), experts in radiation oncology and medical physics, cancer population analytics, oncology nursing, representatives from the Yarmouth oncology clinic and medical and administrative leadership from WZ.

The DES took place at YRH on June 13, 2018. The six-hour session was facilitated by Dr. Jeff Kirby, a medical ethicist from Dalhousie University and a SC member. Cancer program leaders arrived a day earlier to update staff and community on the review, to provide information on the deliberative engagement process and next steps and to answer questions. Program leaders indicated that the outcome of the session would be a recommendation for inclusion in a report to government for its consideration, and that the recommendation and report would not be publicly shared by NSHA.

During the DES, participants listened to, considered, discussed and asked questions about information presented on many topics including: summarized results from community and public engagement activities; cancer data such as present and future cancer patterns in the community; anticipated design, implementation and operating costs for a radiation therapy suite; current trends in the delivery of radiation treatment technology, other equity-enhancing options and a review of other potential cancer system investment opportunities and their benefits (Appendix B).

Following presentations and discussion, there was conversation about the recommendations for consideration. The facilitator proposed three initial recommendations, as discussed and agreed at the SC meetings: 1) maintain the status quo, 2) build and operate a radiation therapy suite in Yarmouth, or 3) deliver a bundle of other equity-enhancing measures. Deliberators were also given the opportunity to suggest other recommendations for consideration. No other recommendations were suggested and there was unanimous agreement that the status quo should not be an option.

The next steps involved considering the benefits and burdens of each of the two remaining options separately, and then compared with each other using the selected substantive principles and values (Appendix C) outlined by the facilitator. Following this exercise, the facilitator provided deliberators with the opportunity to ask clarification questions, and/or to share additional thoughts on both options. After a brief period of personal reflection, deliberators voted for one of the two options by written ballot.

A high majority of deliberators (12:2) voted in favour of recommending the bundle of other equity-enhancing measures (pp. 40-41) which consists of four main components: travel support (e.g. lodging, meals); improved appointment coordination; enhanced use of technology/new treatment options; and enhanced psychosocial support.

The Yarmouth Area Cancer Services Review SC members strongly endorse this recommendation and propose the creation of a joint working group with representatives from DHW, NSHA, including cancer care program leadership from

Yarmouth and Halifax, patients/public advisors, and public interest groups and foundations from Yarmouth to fully explore, fine-tune and implement the bundle of equity-enhancing measures.

Chapter 1. Project Design

Purpose and Scope of Review

The review included full consideration of all relevant data and technical information along with the experience of the travel burden for patients who live long distances from radiation treatment services.

The purpose of the review was to gather, review and consider the evidence and information, together with meaningful patient and community input to determine the feasibility and sustainability of adding radiation therapy services at YRH to serve patients living in Yarmouth, Digby and Shelburne counties. The review also considered other supports to help improve access to care for patients when they need to travel for specialty cancer services.

Project Approach

The Yarmouth Area Cancer Services Review project was led by a SC, using a project management approach and assigning focused working groups to carry out the required project activities. The project management components included:

- Development of a project charter to outline the purpose, objectives and required activities (see Appendix A for full project charter)
- High level project phasing along with a more detailed initial project plan and projected timelines
- Role, membership and responsibilities of the SC, sponsors and Working Groups

The initial project management documents were intended to initiate the work, and thus remained quite static throughout the project lifecycle. Adjustments to the requirements were managed through the SC and individual working groups.

Objectives and Deliverables

1. Identify and develop recommendations to address concerns related to accessing quality cancer services, particularly radiation treatment, for residents in southwestern NS.

2. Develop a balanced decision/recommendation-making framework to evaluate various service delivery options (linear accelerator to provide radiation treatment in Yarmouth and others) with consideration to:
   - Cost
   - Feasibility
   - Utilization
   - Sustainability
   - Health Human Resources (HHR)

- Social justice
- Equity
- Patient and public values and preferences

3. Review the feasibility of delivering radiation treatment in Yarmouth in the context of cancer care delivery there:
    - Investment Cost
    - Feasibility and sustainability/viability of a single radiotherapy linear accelerator(Linac) in Yarmouth
    - Maintenance of service quality
    - Ongoing operating expenses
    - Sustainability of specialized HHR

4. Develop a comprehensive service programming proposal to evaluate options to improve access to quality cancer care for residents of the Yarmouth area.

5. Develop a comprehensive plan to ensure meaningful and effective communication and engagement with community members and health care providers.

The roles of the SC were established within the initial project charter. The roles and membership are as follows:

The SC actively supports the project leads, working groups and project manager by:

- Providing oversight and direction to the project leads, working groups and project manager, while not interfering with functional work activities and deliverables;
- Using their influence to ensure resources are made available as required throughout the project life cycle; and
- Using their influence to help the project leads, working groups and project manager overcome the many obstacles and conflicts that may occur throughout the project life cycle.

Steering Committee Membership

Name	Title / Affiliation
Dr. Drew Bethune	Medical Director, NSCCP (Co-Chair)
Erika Nicholson (until Feb. 2018)	Senior Director, NSCCP (Co-Chair)
Maureen MacIntyre	Director, Cancer System Integration, NSCCP Acting Senior Director, NSCCP (after Feb 2018)
Shelly Brown	Admin Assistant to Senior Director & Medical Director, NSCCP
Karen Jenkins	Interim NSHA Operations Executive Director, WZ
Wanda Matthews	Operation Executive Director, WZ
Dr. Alenia Kysela	NSHA Medical Executive Director, WZ

Janet Baker / Rob Zwicker	Acting Oncology Director, WZ (April - August 2017) Oncology Director, WZ (October 2017 – August 2018)
Debbie Wentzell	Oncology Manager, Yarmouth
Dr. Helmut Hollenhorst	Radiation Oncologist
Krista Rigby	Director, Community & Population Oncology, NSCCP
Dr. James Robar	Chief of Medical Physics
Christine Smith	Communications Manager, NSCCP
Nancy McLaughlin	Director, Pharmacy Services WZ
Dr. Jeff Kirby	Medical Ethicist, Dalhousie University Faculty of Medicine
Al Sullivan	Patient Rep from WZ
Maria Marshall	Patient Rep from WZ
Don Smith	Patient Rep from WZ
Sandy Dennis	Public Advisor and representative of advocacy groups from WZ
Liam Shannon	Management Engineer Quality and System Performance (PM)
Terry Boudreau	Management Engineer Quality and System Performance (PM)

Working Groups

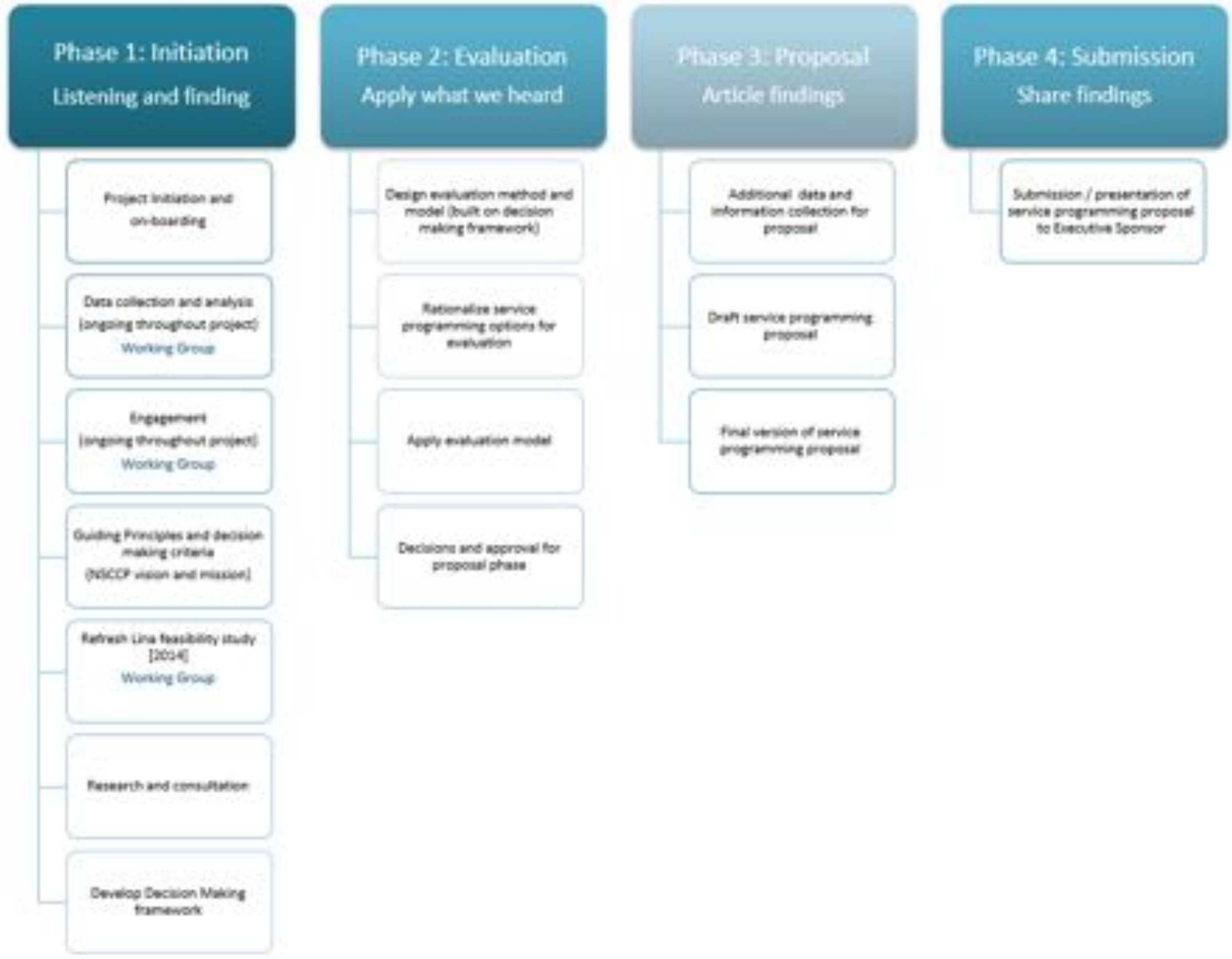
The specific purpose, objectives and membership of the individual working groups are highlighted later in the report, but the overall role of the working groups was established within the initial project charter, which states:

> *Project working groups are created to execute specific requirements of the project throughout the project life cycle. The nature of this activity was focused with well-defined deliverables and timelines from the project leadership and SC.*
>
> *Each of the work streams is managed as sub-projects, with a set of deliverables and timelines and an assigned group leader who is also a member of the SC.*

Working Group membership is based on the specific needs and includes the necessary mix of subject matter experts, resource persons and SC members. Five working groups gathered and analyzed information in areas including: cancer data, communications and engagement, cost estimates, equity-enhancing measures, and relevant comparators.

Project Phasing and Plan

An initial project plan was developed to highlight four major phases of work, along with some more detailed activities within the phases. A detailed project plan was also established to forecast project timelines. Specific activities and requirements were adjusted throughout the project work, however the overall phases remained consistent, with the vast majority of the work occurring in Phase 1. Phase 1 included collecting the necessary evidence/information from focus groups, surveys and data system sources to adequately inform participants in a planned DES. Phase 2 focused on executing the DES. Phase 3 was dedicated to drafting the report based on data findings, and Phase 4 involves finalizing and delivering the report with recommendation(s) to NSHA executive and the NS DHW. The high level plan is shown below:


Phase 1: Initiation
Listening and finding
Project Initiation and on-boarding
Data collection and analysis (ongoing throughout project)
Working Group
Engagement (ongoing throughout project)
Working Group
Guiding Principles and decision making criteria (NSCCP vision and mission)
Refresh Lina feasibility study [2014]
Working Group
Research and consultation
Develop Decision Making framework
Phase 2: Evaluation
Apply what we heard
Design evaluation method and model (built on decision making framework)
Rationalize service programming options for evaluation
Apply evaluation model
Decisions and approval for proposal phase
Phase 3: Proposal
Article findings
Additional data and information collection for proposal
Draft service programming proposal
Final version of service programming proposal
Phase 4: Submission
Share findings
Submission / presentation of service programming proposal to Executive Sponsor

Chapter 2. Communications and Engagement

Approach

A working group was established to discuss communication and engagement needs and opportunities to support the project. Members agreed that both communication and engagement strategies should focus on an open and transparent process with opportunities for early and ongoing input from patients, community members and cancer care program staff working in the Yarmouth area. A Communications Plan and accompanying Engagement Plan (Appendices D and E) were drafted for review by SC members and were finalized based on their input.

Communication and Engagement Working Group

Name	Title / Affiliation
Christine Smith	Communications Manager, NSCCP
Krista Rigby	Director, Community & Population Oncology, NSCCP
Leslie Hill	Coordinator Engagement, Diversity and Vulnerable Populations, NSCCP
Fraser Mooney	Senior Communications Advisor, WZ
Janet Baker	Interim Oncology Director, WZ

Communicating /Engaging with Stakeholders

The commitment to an open and transparent process, inclusive of all stakeholders, began with the establishment of the SC, whose members include cancer health professionals and administrators from Yarmouth and Halifax and three patient/public advisors from the Yarmouth area.

The NSCCP Coordinator, Engagement, Diversity and Vulnerable Populations recruited patient/public advisors for the SC by promoting the opportunity through: current public advisors on other cancer care committees, the NSCCP Cancer Patient Family Network, NSHA's Patient Family Advisory Council, and through oncology managers and navigators in the WZ. Two patient/public advisors from Yarmouth and one from Bridgewater joined the SC. A fourth advisor, an advocate selected by community leaders following an invitation from Dr. Bethune, joined the committee following the meetings with community leaders in January.

Town Hall Meetings – staff and community leaders – January 18, 2018

Dr. Bethune and two committee members visited Yarmouth on January 18th for separate meetings, first with WZ cancer care program staff, followed by meetings with board members from Yarmouth Hospital Foundation, municipal councilors, the organizer of the Facebook page who has more than 11,000 'friends/followers', and a journalist with the Yarmouth Vanguard. The purpose was to share the proposed approach for the review, listen to concerns, and answer questions. Following the meetings, a media release (Appendix F) summarizing the information shared was circulated to media. The meetings were both emotional and positive. Everyone was appreciative of the time Dr. Bethune and his team took to share information and to listen to and respond to concerns and questions. Members of each group shared experiences – their own and those of family, neighbours, and friends and the lived burden of traveling to and staying in Halifax for periods of time for radiation treatment. Each group shared stories with similar themes and expressed interest in providing financial support through local fundraising to help bring radiation treatment to YRH. They were pleased to learn of the patient and public representation on the SC and they welcomed the opportunity to nominate an advocate from their group to participate as a full member. They were also pleased to learn there would be opportunities for patient and community input through focus groups and surveys.

Focus Groups – February 20, 2018

Two focus groups, with 12 people registered in each group, were held on February 20th in Yarmouth. Participants included a mix of men and women of various ages and cancer experiences. Among them were patients, former patients/cancer survivors, family members and concerned citizens. Patient/Public Advisors on the SC attended and provided community support for the meetings, but were not involved as participants. The objective was to understand participants' experience of travelling for cancer services and to ask what supports could improve access to these services.

All participants had an opportunity to share their personal experiences as a patient or as a support person to someone who traveled to a distant cancer centre for treatment.

Survey – March 20 – April 6, 2018

Electronic and paper-based surveys (included in Appendix G), including three open-ended questions and nine structured questions with room for comments, were made available for a three-week period beginning on March 20, 2018. The opportunity to provide input was promoted with a Public Service Announcement (Appendix H), and through communication with stakeholders, including Yarmouth area community leaders, cancer health professionals, and community health boards for sharing with their contacts.

Individuals who were unable or uncomfortable in sharing their thoughts through a survey were invited to call the Cancer Care Program's toll-free line, 1-866-599-2267, or send their thoughts via email to cancercareinfo@nshealth.ca.

The NSCCP received a couple of phone calls and a handful of paper-based surveys. These responses were included in the total of 943 people who completed the survey.

Engagement Findings

The insights and themes shared by those who participated in community meetings, focus groups and/or completed surveys were similar.

Focus Groups

Focus group participants spoke of the challenges of being away from home and family for a period of time, noting the impact on family, children, work, lifestyle and emotional wellbeing.

They spoke of four main challenges (Appendix I):

- False assumption of some health providers that there is family support for patients traveling to another part of the province and/or for dependents who are left at home;
- Traveling long distances, particularly on bad roads in the winter and when a patient is sick;
- Additional financial stress on family, friends and patients; and
- Lack of coordination of care and appointments for rural patients to minimize travel whenever possible.

> "Cancer patients should be well taken care of, we are sick, we should be able to have treatments locally."
>
> -Focus Group Participant
>
> "I have to say that my comments are not intended to take away from the excellent services that are being provided but only to point out the shortfalls and hardships that are being encountered by rural patients."
>
> -Focus Group Participant
>
> "If you have never had to do it, you don't know the half of it. At a time when you need your family and friends most, you are all alone."
>
> -Focus Group Participant

Surveys

Of the 943 survey respondents (Appendix G), more than half (58%) were family members; 22% were patients, or former patients/cancer survivors; 9% were health professionals and the remaining 10% selected the 'other' category. A researcher and research assistant from Dalhousie University, were hired to analyze the data (Appendix G).

Almost all respondents found the travel to Halifax for treatment difficult, with a large percentage having to take time off work or school to accommodate the necessary travel. Approximately half of respondents had to delay or cancel appointments in Halifax for cancer treatment, usually due to poor weather.

They noted four key challenges in traveling to Halifax for cancer treatment:

- Travel (in poor weather and when someone is ill);
- Emotional toll of being away from home;
- Emotional toll of travel to, and being in Halifax for treatment; and
- Out-of-pocket expenses.

> “An elderly family friend actually had to decline treatment in Halifax because he just would not know how to manage alone in such a foreign place and no one could go and stay for the weeks needed.”
>
> -survey respondent
>
> “The loneliness of being away from family and friends at a time when you need them the most, fear of spending your limited time left alone and scared.”
>
> -survey respondent

Respondents indicated that NSHA should consider the circumstances and issues around travel, quality-of-care and cost while considering a recommendation on cancer services in Yarmouth. Fifty-three per cent of respondents indicated they would consider NOT having radiation treatment if they had to travel. Other than having radiation treatment available in Yarmouth, respondents indicated access to cancer services could be improved with:

- Greater access to cancer specialists;
- Enhanced access to relevant medical services;
- More psychosocial and informational supports; and by
- Addressing financial and logistical concerns

While 8% of respondents indicated they felt marginalized by the of lack of equity and fairness related to the delivery of cancer services in Yarmouth and the disparities created by their geography, there were many positive comments about existing cancer care services in Yarmouth.

“The services I received in Yarmouth were excellent; drug teaching, pharmacy consult, patient navigator was ‘top-notch’ (my best ‘go-to’ resource to help with everything). Lab work was easy and the results were provided by my oncology nurse even though my chemo was in Halifax.”

-survey respondent

“We have a good oncology unit with very good nurses. They are there for you when you have questions. If they don’t know the answers, they will find it. Also, the pharmacy/pharmacist are super knowledgeable about what drugs you are taking. Can’t say enough about that unit.”

-survey respondent

Chapter 3. Data Working Group Report

The SC identified evidence-based decision making as a fundamental element of its project approach. Within the project charter, “access to required data and evidence to support evaluation model” was recognized as a key success factor. A Data Working Group (DWG) was one of the sub-committees established as part of the project structure.

Data requirements were defined through an iterative process led by advice and direction from the SC and content knowledge provided by staff from the NSCCP’s Quality and System Performance portfolio. DWG membership included NSHA staff from the NSCCP Registry and Analytics team, Project Management and Decision Support.

Data Working Group

Name	Title / Affiliation
Maureen MacIntyre	Director, Cancer System Integration, NSCCP
Ron Dewar	Senior Epidemiologist, NSCCP
Devbani Raha	Staff Epidemiologist, NSCCP
Gordon Walsh	Manager Registry & Analytics, NSCCP
Ashley Boyce	Senior Decision Support Analyst, Decision Support, NSHA
Liam Shannon	Management Engineer Quality and System Performance (PM)
Terry Boudreau	Management Engineer Quality and System Performance (PM)

Process

The DWG met on many occasions from December 2017 through May 2018 to review data options, discuss analysis methods and results, and review the final presentation content. Data source options were examined with a focus on using existing, available, reliable and validated datasets that could be accessed to meet project timelines and were a best fit with the identified needs of the SC.

Data preparation and analysis tasks were assigned to specific members and outcomes were reviewed by the full DWG. Additional meetings were held with key stakeholders, as needed, to address data questions and to validate analysis results. For example, cancer program activity volumes for Yarmouth area residents were presented to local system managers, and radiation treatment utilization metrics were reviewed with radiation oncologist and physicist representatives from the SC. The DWG followed these steps to ensure confidence in the final data and statistics that would be used to inform the DES (see Appendix J, DES Presentation - Community, Demographics and Cancer Data).

Based on the direction provided from the SC and cancer program leadership the following three data areas were identified as key to an informed decision making process: community characteristics, cancer statistics, and cancer treatment services.

Community Characteristics – Early discussions at the SC raised questions about the geography and population to be included in the definition of 'Yarmouth Service Area'. There was strong consensus that Yarmouth, Digby and Shelburne counties were the primary focus for the project. There was recognition that the full scope of future service provision relative to geographic boundaries could reach beyond the three core counties mentioned above by considering drive time from other southwestern county locations to the Halifax radiation center. Travel time was identified by the WZ community as a significant challenge. Those with longer travel times indicated they experienced more difficulty accessing cancer services. The catchment scope definition outlined above was used to delineate a number of data analyses completed by the DWG.

In addition to understanding the spatial and population features of the Yarmouth catchment area, DWG members agreed that context was required around other community characteristics that could influence future cancer patient burden and/or service delivery. These features included: population trends, age distribution, and measures such as material and psychosocial deprivation for the Yarmouth area relative to other regions of the province.

A range of Statistics Canada datasets (e.g. Population Census) as well as NSHA analyses of drive time from various locations to cancer care facilities/services was used to complete this data section. The following community characteristic measures were included in the final deliberative engagement presentation and an explanation of each is provided in the results section below.

1.1 Catchment Area Map by County & Overall Population
1.2 Population Growth Trend
1.3 Population Proportion – Over 65 Years of Age
1.4 Population Vulnerability Measures
    1.4.1 Material Deprivation Index
    1.4.2 Psychosocial Deprivation Index
    1.4.3 Median Total Household Income
    1.4.4 Low Income Measure
1.5 Travel Time Consideration

Cancer Statistics – The need for cancer services is driven by the burden of cancer being experienced in the population. There are a variety of standardized measures that are commonly used to reflect this burden. In NS, cancer diagnosis and key outcome information is routinely collected through the provincial Cancer Registry operated by the NSCCP and this data is regularly used to produce provincial cancer statistics.

Registry data, both current and historical, was used to generate data on volumes of new cancer diagnoses (incidence), and cancer deaths (mortality). Registry data was then combined with Statistics Canada population data, and staff utilized standard projection methodologies to describe future expected cancer diagnosis volumes for the next 15 years (projections).

While new individuals are regularly diagnosed with cancer, at any given time there is an increasing number of people living in the community with and after a cancer diagnosis (prevalence). This growing segment of the population has a variety of cancer service needs which can include: ongoing active treatment for their cancer; active surveillance for evidence of recurrence; and, management of survivorship issues such as treatment side effects and psychosocial issues.

The following cancer burden measures were included in the final deliberative engagement presentation and an explanation of each is provided in the results section below.

2.1 Cancer Incidence and Mortality 2013-2015
2.2 Cancer Prevalence – 15 Year Limited Duration
2.3 Projections: New Cases & Deaths 2020, 2025, 2030 Compared to 2015

Cancer Treatment Services – The primary focus for the project was to examine the feasibility of establishing radiation treatment in Yarmouth and identifying other supports that could improve access to and quality of cancer services in general for persons living in the Yarmouth Area.

To assess feasibility around radiation treatment it was important to understand how this therapy is currently being used by persons in the Yarmouth area and throughout the province. At present, NS has two cancer centers located in Halifax and Sydney that offer this treatment and both are managed by the NSCCP. Radiation treatment data is scheduled in the Oncology Program Information System (OPIS) operated by NSHA in both centres. This information was available for analysis by the DWG.

Also under the auspices of the NSCCP are a range of other out-patient cancer services that are offered at the cancer centres where radiation treatment is delivered, as well as at a series of community and satellite clinics located across the province. A satellite cancer clinic location has operated at the YRH since 2007 when NS formally established this community-based approach to cancer service delivery across the province. Specialist cancer consultation and follow-up care as well as the delivery of cancer chemotherapy and supportive care are the major services offered at the satellite sites. The OPIS system also holds data related to these services. Additional out-patient cancer care is also provided at the Queen Elizabeth II Health Sciences Centre (QEII) Cancer Centre in the Medical Day Unit which cares for persons with hematology-based cancers. Data on this activity was obtained from NSHA's Central Zone Patient Booking system.

The final data set examined for the project was patient navigation. This program has been in place for over 15 years with community-based nurse navigators who provide cancer patients with navigation support as they deal with a cancer diagnosis and treatment. A navigator is based at the Yarmouth satellite clinic and routinely provides support for patients, including issues associated with receiving radiation treatment.

Data was examined from 2007 forward to ensure a clear understanding of care patterns and to coincide with any changes associated with the implementation of satellite clinics noted above. Patient as well as visit volumes were reported to gain a more accurate picture of cancer service use by the population.

The following cancer treatment service metrics were included in the final deliberative engagement presentation and an explanation of each is provided in the results section below.

3.1 Services in Yarmouth Clinic: Patient Counts by Fiscal Year
3.2 Services in Yarmouth Clinic: Visit Counts by Fiscal Year
3.3 Appointments to Medical Day Unit 2015-2017 (VG Hospital)
3.4 Number of Radiotherapy Patients by County, Fiscal Year
3.5 Number of Radiotherapy Visits by County, Fiscal Year
3.6 Summary of Radiation Patient and Visit Volumes by Fiscal Year for Yarmouth Catchment Area
3.7 Overall Use of Radiotherapy by Time Since Diagnosis and Specific Cancer Types
3.8 Patient Counts and Visits, Yarmouth Cancer Patient Navigator 2014-16
3.9 Patient Navigation Issues
    3.9.1 Practical and Financial Needs Issues

Results

All the metrics and statistics referred to in the following result sections were presented at the DES and is reported in Appendix I.

Community Characteristics

1.1 Catchment Area Map by County & Overall Population

The initial consideration for a radiation service catchment area operated out of Yarmouth was defined by the geographic region where travel time is equidistant to the Yarmouth site and Halifax site; this threshold equates to a drive time of approximately 1.5 hours. A Geographic Information System (GIS) was used to isolate the geographic catchment area, which included all of Yarmouth, Shelburne and Digby counties, as well as parts of Queens and Annapolis counties. The resulting catchment population is 71,782 residents, which is approximately 8% of the provincial population.

Two distinct catchment areas were defined to align with cancer statistics which are stratified at the county level:

- Yarmouth Service Area (SA): Yarmouth, Digby and Shelburne counties (46,736, 5.3% of NS pop.)
- Expanded Yarmouth Service Area (SA+): Yarmouth, Digby, Shelburne, Queens and Annapolis Counties (86,650, 9.4% NS pop.).

Practically speaking, any final catchment area used for service delivery will fall somewhere between the two areas above that were highlighted in the GIS calculation, however both catchment areas will be used when considering cancer statistics to ensure all options were examined.

1.2 Population Growth Trend

Statistics Canada data was used to highlight the 10-year population trend (growth or decline) across all NS counties. This consideration is intended to provide some context on population status to help understand the influence changing demographics may have on cancer patient volume which will in turn determine radiation and other cancer service requirements. Much like the majority of the rural counties in NS, the results indicate a population decline over the past 10 years in the Yarmouth area.

1.3 Population Proportion - Over 65 Years of Age

Statistics Canada data was also used to highlight the proportion of local population (county level) over 65 years of age. This consideration is intended to provide some context on the local vulnerability in relation to age demographics. Age is a significant risk factor for cancer with over 60% of all cancers in this province diagnosed in individuals over the age of 60. An aging population may also have increased challenges (e.g. medical co-morbidities; ability to travel; income disparities) that impact their ability to access and use cancer services. Much like the majority of the rural counties in NS, the proportion of the population over the age of 65 in the Yarmouth area is at least 23%, which is above the national average of 17%.

1.4 Population Vulnerability Measures

1.4.1. Material Deprivation Index

Material Deprivation Data from DHW Investment and Decision Support (Dr. M. Terashima, Dalhousie University, 2014) was used to highlight local Material Deprivation across the province. The Material Deprivation metric is a composite index, based on a number of factors which include: unemployment rate, adults with less than high school education and median household income. This measure was stratified at the local community count level and then rolled up to the county level. The Yarmouth Area counties are among the more deprived counties in NS based on this material deprivation factor which reflected census-based data from 2011.

1.4.2. Psychosocial Deprivation Index

Psychosocial Deprivation Data from DHW Investment and Decision Support (Dr. M. Terashima, Dalhousie University, 2014) was used to highlight local Psychosocial Deprivation across the province using census data from 2011. The Psychosocial Deprivation metric is also a composite index based on measures related to Single Parent Families, People Living Alone and Divorced / Separated / Widowed Adults. The Psychosocial Deprivation factor was stratified at the local community count level and then rolled up to the county level. The Yarmouth area counties are not particularly deprived counties based on the Psychosocial Deprivation factor, except for Shelburne which was identified as the most psychosocially deprived county in the province.

1.4.3 Median Total Household Income

Income is an important factor used to understand the economic capacity of an individual or community. Median household income is one standardized measure commonly used as starting point when examining this topic. Income variation may reflect community vulnerability which can impact a patient's ability to access care. The NS Government website's Economics and Statistics page was used to source the Median Household Income data. Queens, Digby and Annapolis counties report the three lowest Median Household Incomes in the province, while Shelburne and Yarmouth fall in the mid-range provincially.

1.4.4 Low Income Measure

Low Income Measure (LIM) was also included to further highlight community vulnerability across the province. The NS Government website's Economics and Statistics page was also used to source the LIM data.

The LIM provides more context than the previously reported median household income as it refers to the share of persons in households with incomes that are at least 50% lower than the Canadian median household income with adjustments made to account for household size. It is intended to assess prevalence of families that are more disadvantaged than others. Yarmouth, Digby, and Shelburne counties are in the top half of the LIM metric, indicating a higher number of families that are much worse off than others in these areas.

1.5 Travel Time Consideration

To examine travel time, Statistics Canada 2011 Census of Population data from NS Community Counts was used as it provides data at the local community level and can allow for more accurate travel distance calculations. The community counts travel distance analysis was then rolled up to the county level to highlight which counties have the most travel burden at various travel distance thresholds to the nearest cancer center where radiation treatment can be accessed. The results of the travel burden analysis highlight that both the Yarmouth Area and Guysborough County have more travel burden, particularly when using the 2.5 hour travel distance. Other counties also have some significant travel burden, but not at the 2.5 hour threshold. It should be noted that this drive time did not take into account any impacts associated with weather or other factors that could have additional negative effects on travel.

Cancer Statistics

2.1 Cancer Incidence and Mortality 2013-2015

Cancer diagnosis counts and associated death data from the provincial Cancer Registry Information System (OncoLog) for the most recent complete three calendar years were extracted by NSCCP epidemiology staff by county for the province. Standard diagnosis codes for invasive cancer diagnosis were used to select cases in accordance with Canadian Cancer Registry definitions. A three-year period was used to provide greater stability since there can be normal statistical variation from one year to the next. A yearly average was then computed for both new diagnoses (incidence) and deaths (mortality).

On average, 460 new cases were seen annually in Yarmouth, Shelburne and Digby counties combined. In the expanded service area, which also includes Queens and Annapolis counties, 740 new cases were seen annually. In terms of mortality, an average of 180 deaths were seen annually in the core Yarmouth Area, with an average of 305 occurring in the expanded service area.

2.2 Cancer Prevalence – 15 Year Limited Duration

Cancer prevalence measures are used to understand the number of persons who may be alive in the overall population after a cancer diagnosis. Prevalence was calculated using the same dataset noted above in 2.1 but it was expanded to cover a 15-year period of cases. The impact of cancer can last long after the initial diagnosis period and patient care needs can vary depending on where a patient is on the overall disease trajectory. At the time of diagnosis, the patient is in the midst of dealing with a new situation and managing the immediate demands of his/her treatment plan which can extend out for many months and even years depending on the specific diagnosis. After initial treatment ends patients may have ongoing treatment requirements or move into a monitoring and follow-up period. In later periods post-diagnosis, patients may experience delayed treatment effects, or may need to address long-term psychosocial impacts from their cancer experience, while others have moved on to a new normal in terms of their everyday life. Prevalence data in this report has been stratified by time since diagnosis to give a better appreciation of the potential population needs that may exist.

Overall, between 2,780 (Yarmouth Area) and 4,470 (Expanded Service Area) persons were identified as presently living with cancer. Sixty-six per cent of these individuals are over the age of 65 which is expected given that increasing age is a major risk factor for a cancer diagnosis. In both the Yarmouth Area and the Expanded Service Area, approximately 25% of individuals who are living with cancer were each within 1-2 years or 3-5 years since diagnosis. The remaining 50% of cases were diagnosed between 5 and 15 years earlier.

2.3 Projections – New Cases and Deaths 2020, 2025, 2030 Compared to 2015

Overall population counts and trends have been outlined earlier in this report. Expected changes in population (growth/decline) as well as trends in cancer rates over time can be used to project future cancer burden. Several factors can influence change in population size (e.g. immigration, death rates, aging). There are also many factors that impact cancer rates (e.g. screening programs, exposure to risk factors, aging). In NS, like the rest of Canada, some cancer rates have been decreasing over the last 15 years (e.g. breast, prostate, male lung). While decreasing cancer rates are positive news, the actual number of new cancer cases continues to increase. This increase in absolute numbers of new cancer diagnoses in Canada is largely due to population aging.

Using long-term cancer rate patterns calculated from the provincial Cancer Registry, in conjunction with Canadian population trend data, a 15-year projection model was created for NS cancer incidence and mortality using 2015 as the base year for comparison purposes. Projections were then reported for 2020, 2025 and 2030 relative to the 2015 experience.

Growth in the number of new cancer cases in NS is expected over the next 15-year period with increases of 10%, 19% and 25% respectively by 2020, 2025 and 2030. For the Yarmouth area this means 505 new cases annually in 2020, increasing to 550 in 2025 and 575 in 2030. In terms of future mortality counts, similar increases are expected (8% in 2020; 17% in 2025; 26% in 2030). A full table of the results for future incidence and mortality count projections is available in Appendix I.

Cancer Treatment Services

All appointments scheduled and seen in the Yarmouth Satellite Cancer Clinic located at the YRH along with unique patient identifiers and postal code data for each visit were extracted from the NSHA OPIS information system used to manage Cancer Centre and Satellite Cancer Clinic activity in the province. The time period examined covered the ten-year window from April 1, 2007 to March 31, 2017.

All appointments contributed to the visit counts based on the fiscal year in which they occurred. Appointments were assigned to a county of residence based on postal code recorded at the time of each visit. Visits were classified into two main groups: systemic therapy and clinic.

- Visits assigned to Systemic Therapy included patients who were seen in the chemotherapy unit. These visits include activity related to the delivery of cancer chemotherapy or other supportive care requirements. These requirements may have ranged from the administration of systemic agents other than chemotherapy (e.g. antibiotics, bisphosphonates), delivery of transfusions and line care.
- Visits and patients assigned to clinic included any consult or referral visit to a visiting medical or radiation oncologist or other physician covering in the clinic (e.g. General Practitioner in Oncology). In addition, visits assigned to clinic nurses were also counted, as were patients seen via tele-health.

Unique patient identifiers were used to define the total number of patients seen at least once each fiscal year. This analysis was also classified into the two activity groups.

3.1 Services in Yarmouth Clinic: Patient Counts by Fiscal Year

Variation in patient counts was seen across the ten-year period with increases each year until 2013 with a drop in 2014. It is likely that changes in availability of oncology physicians impacted volumes. A decision was made to examine the last three years because of alignment with current practice and community demand. One hundred and fifty-two unique patients were seen at least once in fiscal 2014/15 in systemic therapy; this increased to 190 in fiscal 2016/17. Yarmouth staff noted there may have been some additional increase in the most recent fiscal year 2017/18 but the data was not available for analysis in time for this report. New types of chemotherapy patients (hematology and gynecology) have recently been approved for care in satellite clinic locations in the province, including Yarmouth. For the clinic area, volumes were higher, with 453 unique patients seen at least once in fiscal 2014/15 and 471 in fiscal 2016/17.

3.2 Services in Yarmouth Clinic: Visit Counts by Fiscal Year

Volume patterns for the total number of visits parallels to a large degree the patient volume patterns outlined above in section 3.1. In the most recent fiscal years a significant increase in total visit volume was noted in systemic therapy, moving from 1092 visits in fiscal 2014/15 to 1761 visits in fiscal 2016/17. Clinic visits also increased in the same period (952 to 1276 visits) although not as significantly as those in systemic therapy.

3.3 Appointments to Medical Day Unit 2015-17 (VG Hospital)

Using a similar approach to defining patient and visit volumes outlined in 3.1 and 3.2 above, data was extracted from the NSHA Central Zone Registration/Booking System for appointments in the Medical Day Unit at the Victoria General Hospital. This data was examined to address workload activity for Yarmouth area patients with hematology cancer diagnoses since this workload was not captured in the OPIS data analysis. Overall, the volume of both patients and appointments was small. An average of 35 unique patients were seen each year for a total of 260 appointments from the Yarmouth Service Area. In the expanded Yarmouth service area, these numbers increased to 60 unique patients and 390 visits. Hematology patients can require complex management and it is unclear how much of this volume could be moved directly to the Yarmouth clinic.

3.4, 3.5 and 3.6 Radiotherapy Patient and Visit Volumes by County

Again, using the same approach outlined for earlier workload measures, scheduled visit activity for radiation treatment along with unique patient identifiers and postal codes was extracted from the OPIS module used for radiation treatment scheduling in both Halifax and Cape Breton.

For the purposes of this exercise, visits for both treatment preparation (e.g. simulation planning) as well as treatment were included.

In terms of the volume of patients receiving radiation treatment, the pattern varied by county in each of the last three fiscal years. The number of patients receiving treatment increased in Annapolis and Yarmouth counties and remained relatively stable in Digby and Queens Counties. Shelburne, however, has shown a decline from fiscal 2014/15 through fiscal 2016/17. This may not represent a trend as the overall numbers are small with the decrease moving from 54 to 47 patients over the three years.

For the radiation treatment visit volumes, outlined in 3.5, there are no consistent patterns across the five counties over the three fiscal years, although visit volumes did increase in the last fiscal year (2016/17) in Annapolis, Digby and Yarmouth. Overall visit volumes were similar in 2016/17 in these three counties at close to 1,200 for each.

In the radiation activity summary presented in item 3.6, the patient and visit counts for fiscal 2016/17 for the Yarmouth Service Area were 196 and 3,095 respectively. For the expanded service area in the same fiscal year, the volumes were 314 and 5,910 respectively.

3.7 Overall Use of Radiotherapy by Time since Diagnosis and Specific Cancer Types

During the analysis of radiation data, questions were raised about understanding overall radiation treatment use in the NS population. Epidemiology staff linked radiation treatment data (e.g. treatment start dates) from OPIS to diagnosis information (e.g. diagnosis date, cancer type) from the provincial Cancer Registry and carried out a series of analysis to examine overall utilization.

In examining all cancer diagnoses (excluding non-melanoma skin cancer) from the study period and use of radiation treatment within a year of the initial diagnosis date for each case, approximately 30% of all new cancer patients were identified as receiving treatment. When the time from diagnosis is extended out to 15 years post diagnosis, the proportion of cases receiving radiation increases to 40%. Radiation treatment can be used at various points in the treatment trajectory for any given patient. Because radiation treatment is not applicable for use in some cancer types, use proportions described above vary by diagnosis with ranges from 40 to 70% for rectum, lung, prostate, Hodgkin lymphoma, multiple myeloma and brain. In the case of breast, head and neck, esophagus and cervix diagnoses, these rates can exceed 70%.

3.8, 3.9 and 3.9.1 Patient Navigation Utilization in Yarmouth

Over 15 years ago a community-based Patient Navigation program was established for cancer patients in NS. This nurse-based role operated from selected facilities across the province including the YRH. The Yarmouth navigator generally provides service to residents from the three counties in the core Yarmouth Service Area. The navigator coordinates referral activity, provides education and psychosocial support, and organizes financial support. Data related to navigation was reviewed for the report as it represents objective information reflecting the challenges patients experience when diagnosed with cancer.

Navigators submit a summary navigation activity report for each case to the NSCCP and this data is entered into a specialized module in provincial Cancer Information System (OncoNav/OncoLog). Data was extracted for the province on cases entered for the 2014 to 2016 calendar years. Unique patient identifiers and postal code identifiers were used to count unique patients and to assign the case to a specific county for analysis.

Patient and visit volumes have been increasing in the last three years. There was a 25% increase in patients seen in 2016 as compared with 2014 with 501 patients in 2016, versus 402 patients two years earlier. Visits also increased by a similar amount from 656 in 2014 to 802 in 2016.

Navigation case reports outline the type of issues addressed by the navigator, which are classified into six main categories. In 2016 increases were seen in education, practical/financial needs, continuity of care needs and referral management (3.9). Practical and financial needs make up about 13% of all issues discussed with the Yarmouth navigator in 2016 (3.9.1). Within this 13%, transportation and parking accounted for half of the issues, while lodging needs represented an additional 14%.

The results provided in the navigation data analysis were in keeping with topics and issues reported by Yarmouth clinic staff as well as new information gleaned during the patient and community engagement opportunities through focus groups and the survey.

Chapter 4. Radiation Treatment Technology

The three pillars of cancer treatment are surgery, systemic therapy and radiation treatment.

The spectrum of radiation treatment applications includes External Beam Radiotherapy (EBRT), delivered by a linear accelerator, Brachytherapy Low Dose Rate (implant of radioactive resources directly into the tumour) or High Dose Rate Brachytherapy, a remote-controlled temporary position of radioactive material in preformed body cavities or other application processes, and lastly superficial KV x-ray for the treatment of early-stage skin cancer.

This review is limited to exploring the option of adding a linear accelerator at YRH to deliver EBRT only.

Radiation treatment in the management of cancer is used in a variety of formats, i.e., as primary radiation alone; in combination with concurrent chemotherapy; after other initial treatments such as surgery in an adjuvant setting; prior to definite surgery (neoadjuvant treatment); and in combination with surgery and chemotherapy on various protocols. About 50% of radiation treatments are given with a curative intent, and 50% are palliative with the intent to improve symptoms and quality of life and to prevent cancer-related complications in patients where a cure cannot be achieved.

Management of cancer requires a highly functional multidisciplinary team and skill set. The addition of a linear accelerator to existing cancer services does not, by itself, constitute a comprehensive cancer care program; this would require other services to further evolve or be newly-implemented in addition to existing services.

The Evolution of Radiation Treatment

Radiation treatment has undergone an evolution over time, which has come in waves of significant technical advances leading to a larger range of treatment indications and the enabling of delivery of higher doses with a fewer number of treatments and improved precision. The result is improved outcomes in cancer control with fewer side effects from the treatment.

In the 1970s and 1980s external anatomic marks were placed on the skin of the patient using fluoroscopy. This resulted in large volumes of normal tissue being unnecessarily exposed to radiation, in order to deliver the desired radiation dose to the tumour. Significant side effects meant the prescribed radiation dose had to be divided into as many as 40 sessions. In the 1990s and early 2000s, cross-sectional imaging and anatomy-based target definition, as well as advanced treatment planning and delivery techniques, were implemented. These provided higher precision of radiation treatment to the target cancer lesions and better sparing of organs at risk. Examples would be Intensity Modulated Radiation Therapy (IMRT) or Volumetric Arc Therapy (VMAT). This new technology provided opportunities for higher doses per treatment in order to achieve a better tumour control. However, large volumes of normal tissue were still exposed to radiation.

Current radiation therapy technology and protocols further optimize target definition and dose escalation allowing many patients diagnosed with cancer to be treated in 5 - 10 sessions within a week, as opposed to the usual 25 – 40 treatments over 5 – 8 weeks. Examples include Image Guided ultra-hypo-fractionated Volumetric Arc Therapy or Stereotactic Body Radiation Therapy (SBRT).

As radiation treatment planning, patient setup and treatment delivery become more complex, and radiation doses increase, there is an increased risk for missing the target or causing irreversible serious complications, both leading to undesired outcomes. The advances in technology require knowledge and skill that often can only be provided in a high volume centre of expertise, by a highly subspecialized, trained, multidisciplinary team.

Use of Radiation Therapy

A current estimate of the proportion of cancer patients who will require radiation treatment (which is based almost entirely on expert opinion) is approximately 50% over a patient's lifetime. There are large variations based on cancer type. Use also depends on other factors like travel distance to the cancer centre, a patient's age, awareness of services and degree of collaboration with centralized services.

In NS, overall radiation treatment use is about 8-10% below the national average for various reasons. (Canada Statistics - http://www.cancer.ca/en/cancer-information/cancer-101/canadian-cancer-statistics-publication/?region=ns)

Quality and Safety in Radiation Treatment

Radiation treatment in high income countries has a longstanding history of good quality and safety. In Canada, radiation treatment facilities are accountable to a number of local, provincial and national authorities, and the operation of these facilities follows the law and strict standards and guidelines.

The Canadian Partnership for Quality Radiotherapy (CPQR) was established in 2010 to support and promote the universal availability of high quality and safe radiation treatment for all Canadians through system performance plans aimed at improving quality and mitigating risk. CPQR is a collaboration of the Canadian Association of Radiation Oncology, the Canadian Organization of Medical Physics, the Canadian Association of Medical Radiation Technologists and the Canadian Partnership Against

Cancer. CPQR is focused on Quality Assurance Guidelines, Technical Quality Control Guidelines, Radiation Treatment Incidents, Patient Engagement and Patient Reported Outcomes. Together, member organizations define the framework for the implementation and delivery of high quality and safe radiation therapy in Canada. Every radiation therapy facility must follow these standards. (Quality Assurance Guidance for Canadian Radiation Treatment Programs, CPQR December 31, 2015 QRT.2015.12.03 - http://www.cpqr.ca/wp-content/uploads/2013/09/QRT2015-12-03.pdf)

The CPQR framework also places a strong emphasis on staff qualifications, standards and guidelines in radiation therapy, peer review of radiation treatment plans and outcome reporting. The NS Provincial Radiation Therapy Department as well as the Dalhousie Department of Radiation Oncology and the Atlantic Radiotherapy Alliance (under development) have been instrumental in developing and implementing these standards and guidelines. The regional multidisciplinary cancer site team in radiation treatment consists of 39 radiation oncologists, 32 medical physicists, 149 radiation therapists and 25 dosimetrists who have formed a community of practice, organized in cancer site-specific teams. They are responsible for developing and implementing standards and guidelines, a peer review process, incident reporting, learning teams and multiple collaborative multidisciplinary projects. These teams have the ability to provide strong support and access to skill and knowledge across the region. Any additional radiation therapy facility location must be firmly integrated and cannot operate as a stand-alone facility, as this would create a high risk for undesired outcomes.

Conclusion

Radiation treatment is an integral part of the multidisciplinary management of cancer. The rapid evolution of technology, along with improved convenience for patients, leads to better outcomes. Modern radiation therapy requires a highly subspecialist skill set and bears the risk for serious error.

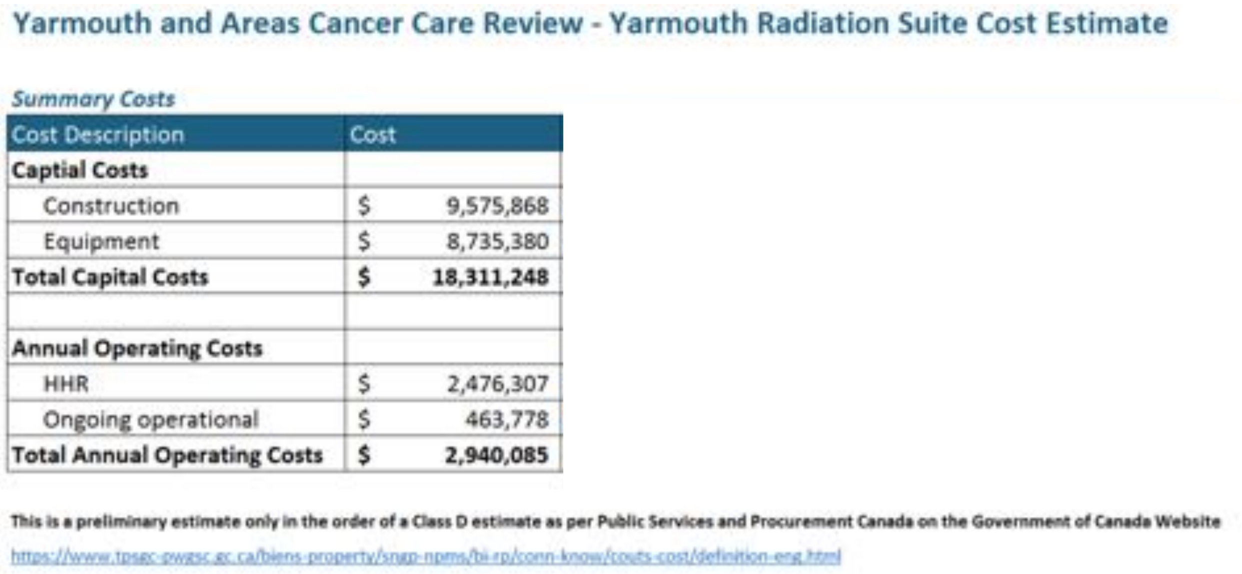
Smaller centres must be integrated with a larger program, and standards, guidelines, policies and procedures are essential for the delivery of high quality and safe radiation therapy.

There will always be a significant proportion of cancer patients who will not be able to receive their treatment in a smaller center, and will still have to travel to access the most appropriate services leading to best outcomes. All radiation treatment plans intended to cure the cancer and treatment plans with a high risk for undesired outcomes must undergo a mandatory peer review by a multidisciplinary team in order to streamline practices, prevent error and continuously improve outcomes. The reporting of outcomes has to confirm that expected benchmarks are met.

Chapter 5. Cost Estimates

The need for a thorough cost estimate for a radiation treatment suite in Yarmouth was identified early in the project to ensure the necessary due diligence was applied when considering the establishment of a complex and high cost service. Previous feasibility estimates and actual costs were available for radiation suites in Halifax and Cape Breton as well as a projection for Yarmouth. This provided a baseline and starting point for the cost estimate work activities. Because previous estimates were deemed to be out-of-date, and not scoped to the specific service requirements, a refreshed and appropriately scoped estimate was performed to inform the decision-making process.

Below is the resulting summary of the cost estimate submission to the SC which was included in the evidence and information set presented and supplied for the deliberative decision-making process.



Yarmouth and Areas Cancer Care Review - Yarmouth Radiation Suite Cost Estimate

Summary Costs

Cost Description	Cost
Captial Costs	
Construction	$ 9,575,868
Equipment	$ 8,735,380
Total Capital Costs	**$ 18,311,248**
Annual Operating Costs	
HHR	$ 2,476,307
Ongoing operational	$ 463,778
Total Annual Operating Costs	**$ 2,940,085**

This is a preliminary estimate only in the order of a Class D estimate as per Public Services and Procurement Canada on the Government of Canada Website

https://www.tpsgc-pwgsc.gc.ca/biens-property/sngp-npms/bi-rp/conn-know/couts-cost/definition-eng.html

Methodology

The method employed to develop the cost estimate relied on previous feasibility work, consultation with various subject matter experts (construction, Radiation Oncology and Medical Physics), as well as establishing a working group to finalize and approve the work for submission to the SC. Please see Appendix K - Radiation Suite Cost Estimate Summary PowerPoint for a summary and timeline of the consultation and working group activities.

Site plans and project costs for the QEII radiation suite project were used to inform space requirements and square foot construction estimates. Space estimates and equipment requirements were validated with Radiation Oncology, Medical Physics and construction. For a more detailed breakdown of the cost estimates please refer to Appendix K - Radiation Suite Cost Estimate Summary PowerPoint.

Linac Working Group

Name	Title / Affiliation
Liam Shannon	Management Engineer Quality and System Performance
Terry Boudreau	Management Engineer Quality and System Performance
Dr. Helmut Hollenhorst	Radiation Oncologist, QEII Cancer Care Program
Dr. James Robar	Medical Physics, QEII Cancer Care Program
Leo Lopez	Facilities Management and Support (FMS)
Doriano Sablone	Facilities Management and Support (FMS)
Peggy Green	Yarmouth/WZ Management/Operations Lead
John McKinnon	Space Planning, WZ
Bryan Darrell	Infrastructure Management, Transportation and Infrastructure Renewal, NS Government
Denis Pellichero	Transportation and Infrastructure Renewal, Building Services
Michael Joudrey	Procurement Manager, WZ
Debbie Wentzell	Oncology Manager, Yarmouth
James Bain	IM/IT, NSHA

Construction Cost Estimate

Previous estimates for a Yarmouth Radiation Service were scoped for a full service cancer center, as opposed to a focused radiation service. The first step in refreshing the construction cost was to revise the space requirements to align with the more realistic operating parameters. Revising the space requirements included consultation with Radiation Oncology and Medical Physics to better align the design with the true operational space needs for a single radiation treatment unit.

The construction costs were developed by replicating the methods and calculations applied in previous estimate work, and refreshing the construction factors and assumptions. Facilities experts from Government of NS, Transportation and Infrastructure Renewal and NSHA who were involved in previous work were consulted to inform the estimate. Various construction estimating factors were validated and revised, including building gross-up factor, escalation, standard design and project management fees, tax rate and project contingency. An estimating tool was designed to input the validated square footage estimates, and apply the required construction estimating factors to calculate overall construction costs. This resulted in a cost of **$9,575,868.**

Equipment Cost Estimate

A preliminary equipment cost list from previous cost estimate work (2014) was used as a starting point, and refined with consultation from Medical Physics experts. After the equipment line items were refined, escalation costs, taxes and contingency were applied. A purchasing representative participated on the working group to ensure costs were in-line with industry-based expectations. The overall equipment estimate calculation resulted in a cost estimate of **$8,735,380.**

Health Human Resources Cost Estimate

The required Human Health Resources (HHR) to adequately staff the proposed radiation suite was developed in a similar manner as the other estimate components, in that the previous estimate work was the foundation for the analysis. The HHR estimate was also refined, with consultation from radiation oncology and medical physics, to better align with service expectations. The result was some re-alignment to the previously estimated positions, with the understanding that a Yarmouth radiation service would need to be highly integrated with the QEII site as part of the provincial cancer program. This would enable a HHR design that could leverage the staffing capacity at the larger hub site and allow for slightly leaner staffing at the spoke site, while maintaining a safe level of redundancy. Refreshed position salaries were obtained, and an escalation factor was applied to reflect potential implementation date. The overall HHR estimate calculation resulted in an annual minimum cost of **$2,476,307**.

Annual Operating Costs Estimate

The annual operating cost estimate was again based on the previous estimate work, but relied heavily on the expert knowledge of medical physics and radiation oncology for validation. This component of the estimate was focused on accounting for the necessary supplies and expenses, maintenance contracts, repairs and software licensing. The overall operating cost estimate calculation resulted in an annual cost of **$463,778.**

Assumptions and Limitations

The nature of this type of estimate work is highly exploratory as many details are still unknown, but this is fully expected in feasibility analysis work. However, there are some notable assumptions and limitations to include in the scope of the work including:

- CT simulation will be performed at the proposed Yarmouth site as opposed to centralized in QEII; therefore, a new CT scanner will be required with simulation functionality.
- The proposed radiation treatment suite will be a new build as opposed to renovating the existing facility footprint.
- Areas are identified to locate related services within the hospital's existing cancer care area with minimal renovation cost (see construction slide).
- For practical purposes the 2011 QEII radiation construction project was used as precedence for ft^2 cost estimates (Cape Breton radiation project was a renovation of existing space).
- Planned construction timeline of 2020 (for consumer price index adjustment considerations).

- Operations of the proposed Yarmouth radiation treatment suite will rely on current HHR redundancy from the QEII site (hub and spoke model).
- The linear accelerator will need replacement approximately every 12-15 years at an estimated cost of $4 million. Additional facility upgrades ($500K-$1M) may also be needed to accommodate potential new equipment size, functionality and requirements.

Chapter 6. Equity-Enhancing Measures

An Equity-Enhancing Measures Working Group (EEMWG) was established to develop a package or "bundle" of relevant, equity enhancing measures to improve access to services for radiation therapy patients whose primary residence is located equal to or greater than an established travel time of 2.5 hours to the nearest radiation treatment centre. This group of patients includes those who live in Yarmouth, Digby, Shelburne and Guysborough counties. It also includes 20% of radiation therapy patients who live in Cape Breton who must travel to Halifax for specialized radiation treatment. The EEMWG was tasked with pricing these options and determining a total annual projected cost.

The equity-enhancing options were selected based on information provided by focus group participants, survey respondents as well as ongoing feedback from Yarmouth area staff and patients (see Chapter 2, Communications and Engagement).

The proposed bundle of equity-enhancing measures was approved by the SC and brought forward for collective consideration by participants as part of the DES held in Yarmouth on June 13th.

Equity-Enhancing Measures Working Group

Name	Title / Affiliation
Krista Rigby	Director, Community & Population Oncology, NSCCP
Christine Smith	Communications Manager, NSCCP
Dr. Jeff Kirby	Medical Ethicist, Dalhousie University Faculty of Medicine
Liam Shannon	Management Engineer Quality and System Performance (PM)
Terry Boudreau	Management Engineer Quality and System Performance (PM)

Assumptions

The EEMWG noted the following assumptions related to radiation therapy patients living in the Yarmouth area:

- There are, on average, 6,200 new cases of cancer per year in NS, 460 who live in the Yarmouth area; 70 live in Guysborough County.
- The total annual cost projection is for provision of the bundle of equity-enhancing measures to radiation therapy patients who reside equal to or greater than 2.5 hours from an existing radiation treatment centre (approximately 281 patients).
- If radiation therapy were available in Yarmouth, approximately 20% of cancer patients would still require radiation treatment in Halifax due to the complexity of care.

- The average number of round-trips to Halifax for a patient residing in Yarmouth is six (1-day initial consultation, 1-day CT simulation, 4 weeks of radiation treatment), assuming patients staying overnight through the week to receive daily treatments.
- The majority of Yarmouth patients and their support persons can be accommodated at The Lodge That Gives in Halifax.

Bundle of Equity-enhancing Measures

Careful consideration was given to the abundant information obtained from surveys and interviews to craft an equity enhancing package. With this consideration the following four areas were determined to help in alleviating the hardship experienced by cancer patients having to travel and spend considerable time in Halifax for their treatment:

1. Transportation, lodging, meals and home support
2. Enhanced appointment logistics
3. Enhanced use of technology and new treatment options
4. Enhanced psychosocial oncology support

Please review Appendix L - Equity Enhancers Workbook for more detail on the methodology.

1. Transportation, lodging, meals and home support – Estimated Cost = $1,935,000

This includes:

- Transportation to and from Halifax for radiation treatment appointments at no out-of-pocket cost to the patient; during SC and working group discussions, the use of a high-quality shuttle service emerged as the recommended best transportation enhancement option. This includes the contracting of an existing reputable or new shuttle service by NSHA to provide comfortable travel for patients with local pick-up and drop-off in a convenient location. Priority seating would be offered to patients travelling for radiation treatment; however unfilled seats would be offered to other cancer patients from the designated area who are traveling to Halifax for cancer appointments/ treatment. For patients who prefer to use their own vehicle, and those Cape Breton radiation treatment patients who must travel to Halifax, coverage for alternative transportation costs could be considered (e.g. per/km rate reimbursement and parking). Estimated cost = $750,000.
- Comfortable, quality lodging for the patient and one support person for required overnight stays in Halifax at no cost to the patient. Accommodations may include The Lodge That Gives without the requirement to share a room with a stranger or a hotel in close proximity to the cancer centre. Associated costs based on approximately 80% of Yarmouth area patients (including one support person) staying at The Lodge That Gives and 20% requiring hotel

accommodations are $337,000 and $184,000 respectively. Estimated cost = $521,000.

- Meal provision for the patient and one support person ($50/ day each) based on approximately 281 patients. Estimated cost = $618,000.
- Subsidized home care for dependents who remain at home ($50/ day). This includes support for remaining-at-home children and elderly parents of the patient and is based on an estimate that 15% of travelling cancer patients could benefit from such support. Estimated cost = $46,000.

2. Enhanced appointment logistics – Estimated Cost = $50,000
   - Funding for a 1.0 FTE coordinator position to support logistics and optimize the booking of appointments to minimize travel back and forth to Halifax. Attention would be given to the coordination of multiple specialist/ diagnostic/treatment appointments for the same visit to reduce the need for travel as well as the scheduling of appointments to allow for same-day travel when appropriate (e.g. late morning).

3. Enhanced use of technology and new treatment options – Estimated Cost = $93,000
   - Enhanced tele-oncology service delivery for Yarmouth area and Guysborough County patients. This includes funding for a 1.0 FTE administrative support position ($50,000) to assist with coordination and logistics. This position would be located at the cancer centre in Halifax and could also support tele-oncology at other sites across the province with priority being given to Yarmouth area and Guysborough County patients. An additional 0.5 FTE RN ($43,000) would also be required in Yarmouth to support an expanded tele-oncology clinic. Commitment would need to be established from relevant NSCCP and Dalhousie Division Heads to ensure optimal engagement and training of clinical faculty members in the use of tele-oncology.

   - Commitment to explore the use of innovative/ novel treatment approaches to cancer care that have the potential to reduce the requirement for patient travel (e.g. hypo-fractionated radiation treatment protocols).

4. Enhanced psychosocial oncology support – Estimated Cost = $130,000
   - Funding for a 1.0 FTE psychosocial oncology professional for the Yarmouth area (e.g. a Clinical Psychologist or Social Worker with oncology training).

Total Estimated Annual Cost of the Equity Enhancing Bundle = $2,208,000

Chapter 7. Comparators

Costs are an important element for consideration in any new project work within the health care system. Outlining proposed infrastructure and operating costs was identified as a critical component of the material necessary for decision making when considering the establishment of radiation treatment services in Yarmouth. In addition, because some of the SC members do not routinely deal with project costs, there was agreement about the added value of establishing 'comparator' project costs. This information helps SC members and DES participants assess the cost of the radiation treatment request in comparison with other cancer care system needs. SC members recognize there are finite resources available to support the health care system, with the majority of funding for both infrastructure and operating costs provided by government. Any decision made to invest in a specific project has an associated 'opportunity cost' given the assigned funding is no longer available to support other health care activities.

Following discussions, SC members agreed that the most relevant comparator cases for this project would be examples from recent cancer program experience in NS. Members of the NSCCP leadership team were asked to provide appropriate business cases for presentation to participants of the DES.

A small Comparator Working Group (CWG) was formed to prepare the comparator case material.

NSCCP Comparators Working Group

Name	Title / Affiliation
Maureen MacIntyre	Director, Cancer System Integration, NSCCP
Krista Rigby	Director, Community & Population Oncology, NSCCP
Christine Smith	Communications Manager, NSCCP
Dr. Jeff Kirby	Medical Ethicist, Dalhousie University Faculty of Medicine

Process

The CWG met on two occasions in April 2018 to identify appropriate comparator examples from the NSCCP. Budget submissions from the past two fiscal years were examined and three examples were identified where the business case had sufficient depth of information, including costs that would be relevant for this project. Cases were selected that had been submitted for funding, but had not yet been approved for implementation. All examples are still under consideration as future initiatives for the NSCCP, thus representing 'real' life program experience. These examples were reviewed and approved by the memberships of the CWG and the SC. A template consisting of three sections (case description, benefits, and costs) was developed for the content of each comparator case example. An outline of the three examples is provided below.

Comparator Case Examples

Example 1: Lung Cancer Screening

Description – Over the last several years, many provincial cancer programs including the NSCCP have been closely examining the value of establishing a formal, population-based lung cancer screening program.

This program proposal focuses on developing an organized, population based, high-risk lung cancer screening program for NS.

Benefits - Currently in NS, approximately 1,000 persons are diagnosed each year with lung cancer, most with late stage incurable disease. NS has among the highest incidence and mortality rates from lung cancer in Canada. An organized, population-based lung cancer screening program for those at high risk for the disease (using a low-dose CT scan) is expected to reduce mortality (death) by about 20%, one of the highest benefits observed from any screening program.

Costs - An organized program will ensure that routine evaluation and benefit measures are identified as part of standard operations. For example: standard screening criteria would be established and communicated to physicians and the public, screening would occur using a defined procedure, with qualified individuals providing the testing, and standardized data collection in place, and patients would receive standardized follow-up care based on their screening results.

Cost estimates in the proposed budget submission were as follows:

Year One – Program development (project management, meetings, consultation, staffing model, data model/registry, identification of key performance indicators high-risk criteria and pathway development, education planning; physician compensation model)	**$175,000**
Year Two – Initiate phased implementation by Zone **(350,000 new, plus 75,000 from year one)**	**$425,000**
Year Three & Ongoing – Full implementation by Zone (**25,000 new, plus 425,000 from year two**)	**$475,000**
Cumulative cost over 3 Years:	**$1,075,000**

Example 2: Psychosocial Oncology

Description – Providing adequate psychosocial oncology support for cancer patients and families has been a strong NSCCP focus for many years. Existing programming levels are barely adequate to meet current levels of demand.

Psychosocial oncology health service standards for persons with cancer and their families were approved by NSHA in 2016, shortly after the NSCCP was established. There is a growing body of evidence showing that appropriate psychosocial interventions reduce distress and improve the quality of life in cancer patients. The NSCCP Manager for the Provincial Oncology Program, Palliative & Spiritual Care has worked over the last several years with a wide range of stakeholders across NSHA and communities to assess current needs and to identify existing resources. The NSCCP database of cancer patients routinely screened for psychosocial distress identifies about 50% of patients experiencing moderate to severe distress.

This assessment indicates that the psychological needs of patients with cancer have not been adequately met across our cancer system with expected avoidable poor outcomes for patients undergoing cancer treatments and follow-up.

Benefits – We have been screening patients for years for psychosocial distress as this is an accreditation requirement and is part of any well-run cancer program. We have a gap however in resources to manage patients experiencing significant levels of distress. This funding would help to fill this gap, greatly enhancing patients and families' ability to manage the very real psychological consequences of a cancer diagnosis.

This program enhancement would ensure that all Nova Scotians diagnosed with cancer would have access to similar standards of psychosocial oncology support and most importantly they would have improved quality of life from timely and appropriate distress management.

Costs – To achieve the benefits noted above the following costs associated with program development and coordination were identified for a three-year period.

Year One – Hiring 7.5 positions (e.g. social work, psychology, navigator, resource coordinator)	**$ 712,000**
Year Two – Additional 3.0 positions (e.g. psychiatry, spiritual care) **(350,000 addition to & 712,000)**	**$1,062,000**
Year Three & Ongoing – Additional 1.0 position (e.g. psychology **(100,000 addition to 1,062,000)**	**$1,162,000**
Cumulative cost over 3 Years:	**$2,836,000**

Example 3: Oral Systemic Therapy Management

Description – Systemic therapy (ST) is a major treatment modality for managing a wide-range of cancer diagnoses. ST includes intravenous (IV) chemotherapy, injections and oral medications. Historically, the bulk of ST has been administered in hospital-based outpatient IV chemotherapy units. In recent years and moving forward, an increasing number of chemotherapy agents will be taken orally by patients in the home setting and they will be dispensed via prescription through a community pharmacy – not the hospital pharmacy.

Many of the new oral agents have significant risks (e.g., side effects, interactions with other medications) that need to be routinely assessed and managed in a timely manner. Despite being highly toxic biological agents, oral systemic therapy is not currently subject to the same level of supervision as IV therapy.

A recent review in our province shows considerable risks of dose mismanagement, drug interactions, and suboptimal supervision of side effects in the current practice. The best resources to manage oral systemic therapy are the hospital-based pharmacists, nurses and clinicians who specialize in cancer care. The cancer care system needs appropriate processes in place to manage and support home-based oral systemic therapy and to educate and support community-based pharmacists who are now dealing with multiple oral cancer systemic therapies.

This proposal focuses on developing and implementing the resources necessary to manage the safe delivery of oral systemic therapy in NS.

Benefits –An organized oral systemic therapy management approach provides a number of benefits:

- Standardized processes for oral systemic therapy ordering, dispensing, administration and monitoring. This will address a range of issues including patient assessment protocols; patient and provider education; maintenance of current drug profiles; drug interactions, and adverse reaction management.
- Improved patient safety and more efficient patient care (e.g., timely reordering of prescriptions and addressing financial coverage).
- Cost savings from appropriate prescription management (e.g., no refill by pharmacy before patient assessment is completed).

Cost – This new program could be implemented over a two-year period.

Year One – Program planning (e.g. job descriptions, procedure/process development, space, data collection tools) and initiate hiring processes.	**$228,000**
Year Two & Ongoing – Additional staffing across zones, program evaluation/monitoring **(450,000 addition to 228,000)**	**$678,000**
Cumulative cost over 2 Years:	**$906,000**

Chapter 8 – Ethical Considerations and Methodology

The NSCCP and NSHA recognize there is an existing health-related inequity involving access to radiation treatment for cancer patients who live at a significantly greater distance from a radiation treatment centre than most other patients in the province. This unfair disparity in access to radiation treatment particularly affects those who live equal to, or greater than 2.5 hours travel time, by car, from an existing radiation treatment centre. This includes people who live in Yarmouth area and Guysborough County, and about 20% of radiation treatment patients who live in Cape Breton, but must travel to Halifax for specialized radiation treatment.

Although all who live in the Yarmouth area and Guysborough County are at a relative disadvantage regarding access to provincial cancer care services, those who could potentially benefit from radiation treatment are particularly disadvantaged because of the high number of treatment visits and extended periods of time away from home that are necessary. The Yarmouth Area Cancer Services Review was initiated to explore and examine, in detail, this identified health-related inequity, and to provide a recommendation to the NS DHW about how to potentially address and mitigate it in a practical way.

Deliberative Engagement Recommendation-making Methodology

A *deliberative engagement recommendation-making methodology* was used to structure and guide the decision making during the DES on June 13th, 2018. This methodology also informed the planning and oversight activities of the SC.

Influenced by the work of liberal, deliberative democracy and social justice theorists, this methodology aims to create and maintain a moral-reflective space where participants collaboratively deliberate to reach decisions/recommendations that can be justified (and defended) in understandable terms. The optimal dynamics of such a deliberative space are captured in the following quote by Tineke Abma, Bert Molewijk and Guy Widdershoven:

> *"Deliberation refers to the interaction and dialogue between participants. They do not just accept each other's beliefs and persuasions, but will explore these. Listening, probing and dialogue characterize this process, rather than confronting, attacking and defending. Central features of dialogue are openness, respect, inclusion and engagement … [and] conditions for dialogue are the willingness of stakeholders to participate, to share power and to change in the process."*

(Abma, T. A., Molewijk, B., and G. A. M. Widdershoven. 2009. Good Care in Ongoing Dialogue: Improving the quality of care through moral deliberation and responsive evaluation. *Health Care Analysis* 17, 217-235.)

The **key elements** of a deliberative engagement recommendation-making methodology are:

1. Identification, and gathering, of the ‘right’ deliberators, i.e., participants from core stakeholder groups and relevant resource persons, who together form a manageably-sized recommendation-making working group; working group members from historically-marginalized or otherwise disadvantaged sociocultural groups may benefit from pragmatic support to enable their participation in the working group, such as the provision of child care services.

2. Use of a targeted recommendation-making framework that has been developed by the SC with the assistance of relevant experts; such a framework aims to facilitate the balanced application of multiple, relevant lenses to the decision- and recommendation-making.

3. Expert facilitation of the deliberations by a facilitator(s) who, ideally, has a working knowledge of provincial/territorial health care systems and no particular, vested interest(s) in the recommendation outcome(s); the roles of the facilitator include: the enabling of all ‘voices’; the paying of careful attention to the effective management of relevant power dynamics (including the use of intentional power-leveling strategies); and the mitigation of non-constructive conflict, ‘group-think’ and circular reasoning.

4. Development, and agreement on the use, of a set of Terms of Deliberative Engagement (see Appendix L: Terms of Deliberative Engagement for the DES); one of these terms of engagement is highlighted here, i.e., the adoption of an *engaged participation* role by working group members – in the role of *engaged participation*, deliberators are encouraged and supported by the facilitator and fellow participants to constructively bring their individual, personal and professional perspectives, values and attitudes to the deliberations (in contrast to a traditional representational role in which a deliberator may feel an obligation to protect and further the interests of the particular vocational, patient or sociocultural group that she/he is representing).

5. Collaborative development, and applied use during the DE Session, of a set of relevant, task-specific Substantive Principles and Values (see Appendix B: Substantive Principles and Values for the DE Session); these substantive principles and values inform and ground the deliberations by acting as: 1) lenses for normative framing and interpretation, and 2) criteria for decision- and recommendation-making, including the weighing and ranking of recommendation options that are collectively considered during the deliberations; the seven substantive principles and values (and sub-principles) that were collaboratively developed by the Steering

Group for the Yarmouth Area Cancer Services Review are as follows (see Appendix M for their descriptions in accessible/understandable language):

   a. Equity
   b. Individual Autonomy
   c. Patient Welfare Principles
      i. Beneficence and Duty-of-Care
      ii. Nonmaleficence
   d. Justice
      i. Traditional distributive justice
      ii. Formal justice
      iii. Social justice
      iv. Procedural justice
   e. Utility
   f. Efficiency
   g. Sustainability

<u>Note</u>: It is important to appreciate that these substantive principles and values are not lexically-ordered, i.e., no one principle or value is intended to take precedence over another or others in all health-related decision/recommendation-making. As such, they can be, and often are, in some tension/conflict, and consideration of these principles and values during the DE Session frequently leads to the emergence of competing obligations/responsibilities that require careful weighing and balancing by the engaged deliberators.

6. Collective exploration and critical analysis of the subject matter(s) or issue(s) under consideration in a facilitated, deliberative-dialogical format.

7. As derived from the *principle of charity* in philosophical discourse, collaborative development of 'best/optimal arguments' on all sides of relevant matters/issues being considered in the deliberations.

8. Collective development of potential recommendation options and a subsequent, formal comparative analysis of their anticipated benefits and burdens (and to whom).

9. The making of a recommendation(s) is achieved through a consensus-seeking and/or democratic decision-making approach. As possible, a consensus is reached in the recommendation-making deliberations that 'all (working group members) can live with' and support outside of the deliberative forum. In circumstances where the development of such a consensus is not achievable (or this outcome is anticipated in

advance due the nature of the matter(s)/issue(s) under consideration), the final recommendation, or ranking of recommendations, is determined by (democratic) majority vote.

10. A Report with Recommendation(s) is developed by the SC. It describes the process/methodology of the project/initiative and its DE Session, provides a descriptive synopsis of the content of the deliberations, and documents the recommendation outcome(s) of the DE Session. This report is provided to the leadership of the organizational entity, e.g., the DHW of a provincial/territorial government that is in a position to take pragmatic action on the recommendation(s). Typically, the relevant organizational entity will make this report accessible to members of the public.

Comparative Analyses of a Set of Recommendation Options

Members/deliberators of the DE Session Working Group (with pre-session assistance from Steering Group members and external resource persons) collaboratively developed the following set of three potential recommendation options for possible consideration during the active deliberative-engagement component of the DE Session:

I. Maintenance of the status quo
II. Establishment and maintenance of radiation treatment capacity in Yarmouth with an on-site Linac and support (see Chapter 5, Cost Estimates)
III. Implementation of a bundle of other equity-enhancing measures (see Chapter 6, Equity-Enhancing Measures)

At the beginning of the afternoon sessions, the facilitator asked working group members to consider whether Recommendation Option I should be kept on the list of potential options given the mandate/purpose of the Yarmouth Area Cancer Services Review and the decisional outcomes of prior SC discussions. Members/deliberators expressed their view that maintenance of the status quo would not meaningfully address the important health-related inequity described in Chapter 2, Communications and Engagement. It was therefore unanimously agreed that Recommendation Option I should be eliminated from further formal consideration.

The facilitator suggested, and the deliberative engagement participants agreed, that the following comparisons should be collaboratively performed through the use of the deliberative engagement recommendation-making methodology described in this chapter:

I. Identification and comparison of the benefits and burdens of Recommendation II (and to whom)

II. Identification and comparison of the benefits and burdens of Recommendation III (and to whom)
III. Direct, head-to-head comparison of Recommendations II and III

I. Identification and Comparison of the Benefits and Burdens of Recommendation II

(Establishment and maintenance of radiation treatment capacity in Yarmouth)

Benefits	Burdens
Significant enhancement of access to radiation treatment (RT) for 80% of RT patients in the Yarmouth Area with an associated, significant mitigation of the identified, unfair disparity for this particular patient group (an equity-enhancing consideration) Reduced travel-related burdens for 80% of Yarmouth Area RT patients and their support persons Reduced financial burdens for 80% of Yarmouth Area RT patients and their families	Significant use of publicly-funded, health resources including financial, staffing, capital-construction and equipment expenses plus related education, administration, oversight and integration-related costs; given the reality of a current 'fixed pot of limited health resources' in the province, a choice to use this level of resources to meet the particular health needs of a subpopulation would necessarily preclude the use of this level of resources to meet other, legitimate cancer care related needs; see NSCCP Comparators (Section 7) for examples; an additional example that emerged during the deliberations is the possibility of a delay in the implementation of 'cutting edge' radiation oncology technologies in the Central Zone because of the RT directed funding being spent elsewhere (a traditional, distributive justice consideration)
Possibility that more Yarmouth Area patients who could benefit from RT receive this form of cancer treatment given that, currently, some patients in this position are not availing themselves of recommended, Halifax-based RT because of the current access barriers (particularly so for patients who may benefit from palliative radiation treatment)	
Enabling of as much quality 'family time at home' as possible for 80% of Yarmouth Area RT patients and their families	
Potentially less travel-time for Halifax-based radiation oncologists who currently commute to Yarmouth	

Provision of, respect for, and promotion of, social justice in the sense that particular, practical attention would be paid to addressing the health needs of a disadvantaged subpopulation of the province, i.e., residents of Yarmouth, Digby and Shelburne Counties who, on average as a social group, are disadvantaged on a socioeconomic axis relative to other groups of residents in the province	From a social justice perspective, no provision of additional, practical attention to addressing the health needs of another, similarly disadvantaged subpopulation in the province, i.e., the residents of Guysborough County; in addition, no mitigation of travel-related and financial burdens for the 20% of radiation treatment patients from Cape Breton who must travel to Halifax for specialty radiation treatment.
From a formal justice perspective, pragmatic recognition of the *relevant* difference between the health care delivery circumstances of Yarmouth Area RT patients and the health care delivery circumstances of RT patients from most other areas of the province	From a formal justice perspective, this option does not constructively address the *relevant* difference between the health care delivery circumstances of Guysborough County RT patients (and 20% of radiation treatment patients from Cape Breton) and the health care delivery circumstances of RT patients from most other areas of the province
Possibility of a reduction in wait times for radiation treatment for cancer patients who reside in all areas of the province	
Potential enhancement of opportunities for collaboration between locally-based medical oncology and radiation oncology teams in the far-Western end of the province should a satellite RT unit be established in Yarmouth	
The built-structure of a satellite radiation oncology satellite could provide a tangible, local focal point with regard to the future encouragement of private donations/contributions to cancer care in the Yarmouth Area	
The provision of tangible, meaningful health-related benefits to an area of the province that has been strongly advocating for it, i.e. It provides a constructive response to the existing inequity that has been recognized and experienced by the local population.	

II. Identification and comparison of the benefits and burdens of Recommendation III

(Implementation of the bundle of other, equity-enhancing measures)

Benefits	Burdens
Enhancement of practical access to RT for cancer patients in the Yarmouth Area and Guysborough County with an associated mitigation of the identified unfair disparity for these particular patient groups (an equity-enhancing consideration) Reduced travel-related burden for Yarmouth Area and Guysborough County RT patients and their support persons Reduced financial burdens for Yarmouth Area and Guysborough County RT patients and their families	Use of some publicly-funded, health resources; given the reality of a current 'fixed pot of limited health resources', a choice to use these resources to meet the health care needs of cancer patients in the designated, geographic areas would preclude the use of this relatively low level of resources to meet other legitimate cancer care needs (a traditional, distributive justice consideration)
Enhanced access to medical oncology services for Yarmouth Area and Guysborough County cancer patients through enhancement of telehealth consultation service delivery, and the use of non-priority seats in the to-be-established, proposed high-quality shuttle service	
Provision of respect for, and promotion of, social justice in the sense that particular, practical attention is paid to addressing the health needs of disadvantaged subpopulations of the province, i.e., the residents of Yarmouth, Digby, Shelburne and Guysborough Counties	
From a formal justice perspective, recognition of a *relevant* difference between the health care delivery circumstances of Yarmouth Area and Guysborough County RT patients and the health care delivery circumstances of RT patients in other areas of the province	
The content of the proposed bundle of equity-enhancing measures is scalable, it can be constructively modified/adapted over time to accommodate changes and emerging evidence in such factors as population demographics and the introduction of innovative methodologies and technological advancements in radiation oncology.	

The provision of timely, tangible, meaningful, health-related benefits to an area of the province that has been strongly advocating for it, i.e., Yarmouth, Digby and Shelburne counties, that has been strongly advocating for it provides a constructive response to the existing inequity that has been recognized and negatively experienced by the local population.	

III. Direct, head-to-head comparison of Recommendations II and III

Axis of Analysis	**Yarmouth Area Radiation Treatment Option**	**Bundle of Equity-Enhancing Measures Option**
Equity enhancement	Overall: ++ for 80% of Yarmouth Area RT patients Reduction in travel burden: ++ for 80% of Yarmouth Area RT patients and their support persons Reduction in financial burden: ++ for 80% of Yarmouth Area RT patients and their families	Overall: + for 100% of Yarmouth Area and Guysborough County RT patients Reduction in travel burden: + for 100% of Yarmouth Area and Guysborough County RT patients and their support persons Reduction in financial burden: + for 100% of Yarmouth Area and Guysborough County RT patients and their families Reduction in travel-related and financial burdens for approximately 20% of radiation therapy patients from Cape Breton
Traditional distributive justice	Significant utilization of limited, publicly-funded health resources	Considerably less utilization of publicly-funded health resources
Social justice	Practical attention is paid to addressing a particular RT related, health need of a disadvantaged NS subpopulation, i.e., Yarmouth Area residents	Practical attention is paid to addressing particular RT and medical oncology related needs of two disadvantaged NS subpopulations, i.e., Yarmouth Area and Guysborough County residents
Utility	The distribution of proposed benefits is limited to one subpopulation group and one type of patient group	There is a greater distribution of proposed benefits both geographically and by patient-group types, i.e., access to cancer treatment is enhanced for medical oncology and radiation oncology patients in these areas of the province

Efficiency	This option presents some vulnerability related to legitimate concerns about the recruitment and retention of required, highly-specialized professionals including radiation oncologists, radiation physicists and radiation oncology nurses and radiation therapy technicians Some operational inefficiency is anticipated as it is currently projected that the satellite radiation oncology suite/unit would operate at approx. 70% capacity	There is no new requirement for the recruitment and retention of highly specialized radiation oncology professionals Operational efficiencies can be maximized in the implementation of the bundle Given the enhancement of telehealth services for both medical oncology and radiation oncology patients and the stated commitment to the phased-in introduction of innovative, evidence-based RT methods and technologies that have the potential to reduce the need for patient, support person and professional travel, implementation of the proposed bundle of measures could facilitate the development of a supportable, comprehensive and efficient cancer care program in the Yarmouth Area Some vulnerability is presented by the possibility of funding-fragmentation of the various component measures contained in the proposed bundle, i.e., the possibility of receiving approval of some but not all of the measures
Sustainability	There is some vulnerability in this sphere/domain because of the amount of health resource utilization, the evolving field of radiation oncology, and anticipated challenges with recruiting and retaining highly-specialized professionals in the Yarmouth Area	Possible enhanced sustainability of the NSCCP and the provincial health care system because of use of a significantly smaller amount of publicly-funded health resources
Scalability	Limited scalability once the option is implemented	The content of the bundle is scalable, i.e., it can be constructively modified/adapted over time to accommodate changes in emerging evidence in such domains/factors as population demographics and introduction of innovative, methodological and

		technological advancements in the radiation oncology field.
Other considerations	Implementation would address the local, strong, existing advocacy for establishment of RT capacity in Yarmouth Area; however it is possible there would be negative, across-province public reaction to the use of the initial, significant amount of publicly-funded resources; this response from the provincial public could be exacerbated by reporting of the anticipated, suboptimal operational efficiency, i.e., the satellite radiation oncology suite/unit is anticipated to operate at approx. 70% capacity If approved, there is the possibility of some uncertainty/ fragility of the funding commitment given the anticipated, several year planning/start-up time between approval and full implementation	Implementation would address the local, strong, existing advocacy for enhancement in Yarmouth area cancer care service delivery in a (likely) satisfactory way, given the relatively low level of initial health resource utilization, a negative, across-province public response to government approval of this recommendation is not anticipated

Process for determining the recommendation

As part of the planning for the DES, SC members discussed the process of how participants would ultimately decide on the recommendation(s) for government to consider. They compared the benefits and challenges using a consensus-seeking versus a democratic decision-making approach.

Committee members anticipated that there would be challenges in reaching consensus on the way forward. They were aware of unavoidable power differentials in the deliberative forum as deliberators included: administrators, cancer specialists, patients and public. The SC was committed to ensuring a fair process in which every deliberator would feel comfortable and not coerced in contributing to the final recommendation. For these reasons, a decision was made to use a democratic decision-making approach and to ask deliberators to vote on their recommendation of choice using a written ballot.

Recommendation

A high majority of deliberators (12-2) voted in favour of Recommendation II, the proposed bundle of other equity enhancing measures (see Chapter 6, Equity Enhancing Measures) which consisted of four main components: travel support (e.g. lodging, meals, home support); improved appointment coordination; enhanced use of technology and new treatment options; and enhanced psychosocial support.

The Yarmouth Area Cancer Services Review SC members strongly endorse this recommendation and propose the creation of a joint working group with representatives from DHW, NSHA’s cancer care program from Halifax and Yarmouth and patients/public advisors from Yarmouth to fine-tune and implement the proposed bundle of other equity enhancing measures.

Chapter 9. Conclusion

This review was undertaken with great care to include expert opinion, a full body of data and also to address the real human hardships experienced by this group of Yarmouth Area cancer patients. Patients from this part of the province have felt particularly disadvantaged since the creation of the Cape Breton Cancer Center and indeed, they are the largest group in the province who travel a great distance for radiation treatment.

The DES participants considered the two options carefully and decided by a large majority on the option to enhance care delivery using a multipronged approach rather than building a radiation treatment facility.

It is important to carefully review the recommended equity-enhancing options. Many of the suggested enhancements will benefit all NS cancer patients, e.g., improved telemedicine services, new technology reducing the duration of radiation treatment courses. The SC recognizes that implementation of the enhancement package will require further collaboration – perhaps in the form of a working group - including representatives from government, NSCCP and patients/families to finalize the details.

Cancer patients from the Yarmouth Area (and Guysborough County) have unique challenges in accessing radiation treatment services and need special consideration. Benefits, including practical travel assistance and the engagement of a support person, can make a significant difference for these patients during their cancer care journey. The SC believes that, short of building a very expensive facility to address the inequity experienced by these patients, special consideration in the form of implementation of the recommended package of other equity-promoting measures is reasonable, and would ensure relatively equal access to radiation treatment for the whole population of Nova Scotia.

Appendices

Appendix A. Project Charter

Appendix B. DES Presentation, Sample Bundle of Other Equity-Enhancing Options

Appendix C. Guiding/Substantive Principles and Values

Appendix D. Communications Plan

Appendix E. Engagement Plan

Appendix F. Media Release/Advisory, January 18, 2018

Appendix G. Survey Response Report – Care Close to Home

Appendix H. Public Service Announcement, March 16, 2018

Appendix I. Focus Group Report

Appendix J. DES Presentation, Community, Demographics and Cancer Data

Appendix K. DES Presentation, Radiation Cost Suite Estimate

Appendix L. Equity Enhancer Workbook Summary

Appendix M. Terms of Deliberative Engagement

Appendix N. Other Supporting Documents

i. Public Service Announcement, February 7, 2018
ii. Media Release, June 11, 2018
iii. DES Presentation, A Brief Primer on Deliberative Engagement
iv. DES Presentation, Communications and Engagement
v. DES Presentation, Relevant Radiation Oncology Primer, Linear Accelerator Radiation Treatment Facts
vi. DES Presentation, Comparator Cases
vii. DES Participants

Appendix A. Project Charter

PROJECT CHARTER: YARMOUTH AREA CANCER CARE REVIEW

ABSTRACT

Carry out an open and transparent review of Cancer Care services in the Yarmouth area. Access to care must consider, and reconcile to a comprehensive set of quality dimensions.

An initial evaluation phase will focus on refreshing a previous assessment of the potential service expansion of a single Linac (Linear Accelerator) for radiation treatment in Yarmouth, acting as a satellite service of the provincial Radiation Oncology Program. Appropriate due diligence must be applied for such a highly complex and intensive service option. Alternative service programming options will also be evaluated with the objective of improving access to quality cancer care and services. The final deliverable of this project is to produce a report with recommendation options by late summer 2018.

1.0 Project Identification	
Name	Yarmouth Area Cancer Care Review
Description	Carry out an open and transparent review of Cancer Care services in the Yarmouth area. Access to care must consider, and reconcile to a comprehensive set of quality dimensions. An initial evaluation phase will focus on refreshing a previous assessment of the potential service expansion of a single Linac (Linear Accelerator) for radiation treatment in Yarmouth, acting as a satellite service of the provincial Radiation Oncology Program. Appropriate due diligence must be applied for such a highly complex and intensive service option. Alternative service programming options will also be evaluated with the objective of improving access to quality cancer care and services. The final deliverable of this project is to produce a report with recommendation options by late Spring 2018.
Executive Sponsor	Paula Bond, VP Integrated Health Services Program Care 1
Sponsor	Erika Nicholson, Senior Director Nova Scotia Cancer Care Program Dr. Drew Bethune, Medical Director Nova Scotia Cancer Care Program
Project Manager	Liam Shannon + Terry Boudreau, Management Engineers Quality and System Performance

2.0 Steering Committee	
Role:	▪ The Steering Committee is responsible for setting the project objectives and priorities and the application of organizational assets. ▪ The Committee will develop a robust project plan inclusive of key deliverables, milestones, timelines, decision points, risks and mitigation strategies required to accomplish the project. ▪ The Committee will ensure that focus is maintained on the strategic objectives of the project. ▪ Based on the information gathered during the review, the Steering Committee will issue a recommendation(s) to the Executive Sponsor. ▪ The opinions and priorities of Steering Committee members may not always be aligned, but they do share a common purpose of accomplishing the objectives of the project. ▪ Decision-making authority of the Steering Committee will be limited to those decisions related to facilitating the project plan and meeting project deliverables. ▪ Regular reporting (via meeting or email) will provide Steering Committee members with timely information.
Membership:	▪ Karen Jenkins, NSHA Operations Executive Director, Western Zone ▪ Dr. Alenia Kysela, NSHA Medical Executive Director, Western Zone ▪ Erika Nicholson, Senior Director Nova Scotia Cancer Care Program (Co-Chair) ▪ Dr. Drew Bethune, Medical Director Nova Scotia Cancer Care Program (Co-Chair) ▪ Janet Baker / Rob Zwicker, Western Zone Oncology Director ▪ Debbie Wentzell, Oncology Manager, Yarmouth ▪ Dr. Helmut Hollenhorst, Radiation Oncologist ▪ Medical Oncology/General Practitioner in Oncology Representative from Western Zone: (Dr. Julia Merryweather, Dr. Heather Robertson) ▪ Krista Rigby, Director of Community and Population Oncology, NSCCP ▪ Dr. James Robar, Chief of Medical Physics ▪ Christine Smith, Communications Manager, NSCCP

	- Maureen MacIntyre - Director Cancer System Integration, NSCCP - Nancy McLaughlin, WZ Pharmacy Director - Jeff Kirby, Medical Ethicist - Al Sullivan, Patient Rep from WZ - Sandy Dennis, Advocacy Group Patient Rep - Maria Marshall, Patient Rep from WZ - Don Smith, Patient Rep from WZ - Liam Shannon, Management Engineer Quality and System Performance - Terry Boudreau, Management Engineer Quality and System Performance - BIAM Representative
What does the Steering Committee do?	The Steering Committee will actively support the Project Leads, working groups and project manager by: - Providing oversight and direction to the Project Leads, working groups and project manager, while not interfering with the functional work activities and deliverables. - Using their influence to ensure resources are made available as required throughout the project life cycle. - Using their influence to help the Project Leads, working groups and project manager overcome the many obstacles and conflicts that present themselves throughout the project life cycle.

2.1 PROJECT WORKING GROUPS	
General:	Project working groups will be created to execute specific requirements of the project throughout the project life cycle. The nature of these requirements will be activity focused with well-defined deliverables and timelines from the project leadership and steering committee. Each of the work streams will be managed as sub-projects, with an agreed upon set of deliverables and timelines with an assigned group leader who will also be a member of the Steering Committee. Members of each Project Working Group will be determined based on the specific needs and likely include a mix of subject matter experts, facilitators and steering committee members.
1.0 Data Working Group	Members: - Maureen MacIntyre - Director Cancer System Integration, NSCCP - Devbani Raha, Staff Epidemiologist NSCCP - Ron Dewar, Senior Epidemiologist NSCCP - Liam Shannon, System Performance - Terry Boudreau, System Performance - Ashley Boyce, Senior Decision Support Analyst System Performance Deliverables + Timelines:
2.0 Communication and Engagement	Members: - Krista Rigby, Director, Community & Population Oncology, NSCCP - Christine Smith, Communications Manager, NSCCP - Leslie Hill, Coordinator Engagement, Diversity and Vulnerable Populations, NSCCP

	- Fraser Mooney, Communications and Public Relations, WZ Deliverables + Timelines:
3.0 Cost Estimate Working Group	Members: - Liam Shannon, Management Engineer Quality and System Performance - Terry Boudreau, Management Engineer Quality and System Performance - Dr. Helmut Hollenhorst, Radiation Oncologist - Dr. James Robar, Chief of Medical Physics - Debbie Wentzell, Oncology Manager, Yarmouth - Leo Lopez, Facilities Management and Support (FMS) - Doriano Sablone, Facilities Management and Support (FMS) - Peggy Green, Yarmouth / WZ Management / Operations Lead - John McKinnon, Space Planning WZ - Bryan Darrell, Infrastructure Management NS Government - Denis Pellichero, Transportation and Infrastructure Renewal, Building Services - Michael Joudrey, WZ Procurement Manager - James Bain, IM / IT
4.0 Equity Enhancers Working Group	Members: - Krista Rigby, Director, Community & Population Oncology, NSCCP - Christine Smith, Communications Manager, NSCCP - Jeff Kirby, Medical Ethicist - Liam Shannon, Management Engineer Quality and System Performance - Terry Boudreau, Management Engineer Quality and System Performance
5.0 Nova Scotia Cancer Care Relevant Comparators Working Group	Members: - Maureen MacIntyre, Director, Cancer System Integration, NSCCP - Krista Rigby, Director, Community & Population Oncology, NSCCP - Christine Smith, Communications Manager, NSCCP - Jeff Kirby, Medical Ethicist

3.0 Project OBJECTIVES (purpose)

6. Identify and develop recommendations to address concerns related to access to quality cancer services for residents in south western Nova Scotia.

7. Develop a balanced decision making framework to evaluate various service delivery options (Linac and others) with consideration to:
   - Cost
   - Feasibility
   - Utilization
   - Sustainability
   - HHR
   - Social justice
   - Equity
   - Patient and public values and preferences

8. Review the feasibility of delivering radiation therapy treatment in the context of cancer care delivery in the Yarmouth Area
   - Investment Cost
   - Feasibility and sustainability/viability of a single linac in Yarmouth

- Maintenance of quality service
- Ongoing operating expenses
- Sustainability of specialized Health Human Resources

9. Develop a comprehensive service programming proposal to evaluate options to improve access to quality cancer care provided to residents in the Yarmouth area.

10. Develop a comprehensive plan which ensures meaningful and effective communication and engagement with community members and health care providers.

4.0 Project Scope

- Although evaluation data and evidence may expand to a provincial lens, service programming considerations will focus on the Yarmouth area, with some further consideration expanding to the broader western zone.

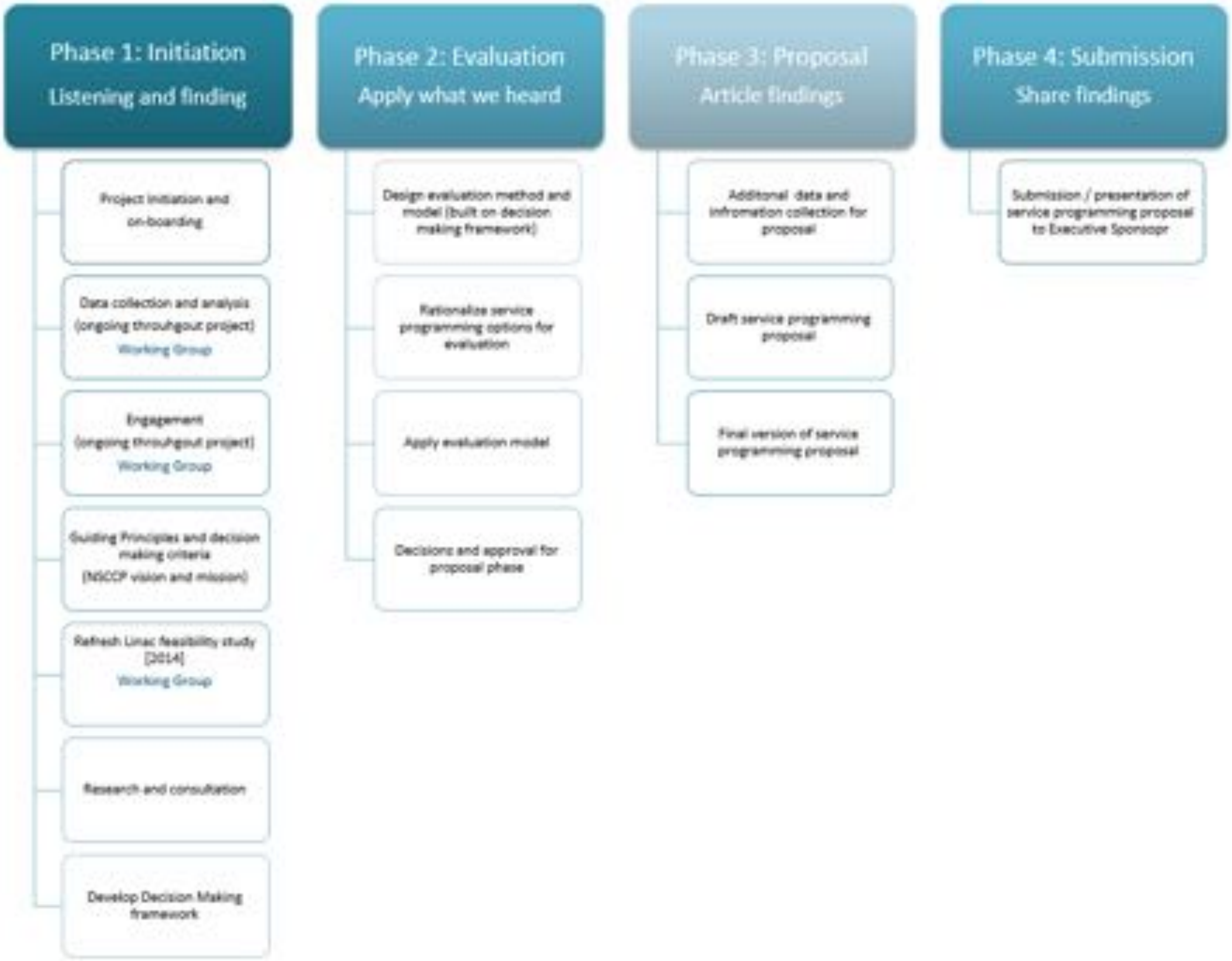
- Linac evaluation will rely on an approved planning framework and model which will guide the decision making process.

- Alternative service programming options will focus on principles and opportunities, all functional details required for implementation may not be fully rationalized in this phase of the planning. Should any of the recommendations be accepted further work would be required relating to impact analysis, implementation planning and operations.

5.0 Key Project deliverables

Item	Deliverable	Target Dates (to be updated)
1.	Draft Project Charter	Sept.2017
2.	Draft Action Item Log	Sept.2017
3.	Draft Risk Register	Sept.2017
4.	Draft Project Communication Plan	Sept.2017
5.	Draft Project Plan	Sept.2017
6.	Phase 1	October.2017 – April.2018
7.	Phase 2	April.2018 – May.2018
8.	Phase 3	May.2018 – June.2018
9.	Phase 4	July.2018

5.0 Key Project deliverables



6.0 Communication PLan

Communication	Audience	Responsible	Method	Frequency
Steering Committee Update	Project steering committee, Executive Sponsor	Project Manager	Group meeting if deemed necessary, or formal email update if more appropriate	Twice a month in early stages, and monthly once project is established
Project Leads meeting	Projects Leads + PM when required	Project Leads	In person / online meeting	As required in early stages and weekly once project tis established
Working group updates	Steering Committee	Working group lead	During steering committee update unless otherwise specified	In line with steering committee

7.0 Project's criteria for success (must be measurable)

Any and all service program options, Linac option included, must demonstrate an improvement to the quality of patient care, accounting for a broad set of quality dimensions with a patient and family lens, as well as a system feasibility lens. The dimensions must be comprehensive, well rounded and measurable, the following dimensions highlight the required evaluation parameters:

- **Safe**: Avoiding harm to patients from the care that is intended to help them.
- **Effective**: Providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit (avoiding underuse and misuse, respectively).
- **Patient-centered**: Providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.
- **Timely**: Reducing waits and sometimes harmful delays for both those who receive and those who give care and ensuring a high level of patient access to services.
- **Efficient**: Adequate numbers of patents benefitting from investment, Avoiding waste, including waste of equipment, supplies, ideas, and energy, and minimizing the duplication of services wherever possible.
- **Equitable**: Providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status.
- **Sustainable**: Feasibility over time ensuring adequate scarce resources can be supplied to ensure a reliable system can be maintained.

7.1 critical success factors

- Buy-in and support from senior leadership
- Buy-in and trust with local community and stakeholders for the process and methods
- Effective communication and change management planning
- Access to required data and evidence to support evaluation model
- Approval of evaluation model and methods from team, leadership and stakeholders

8.0 PROJECT COST CONSIDERATIONS

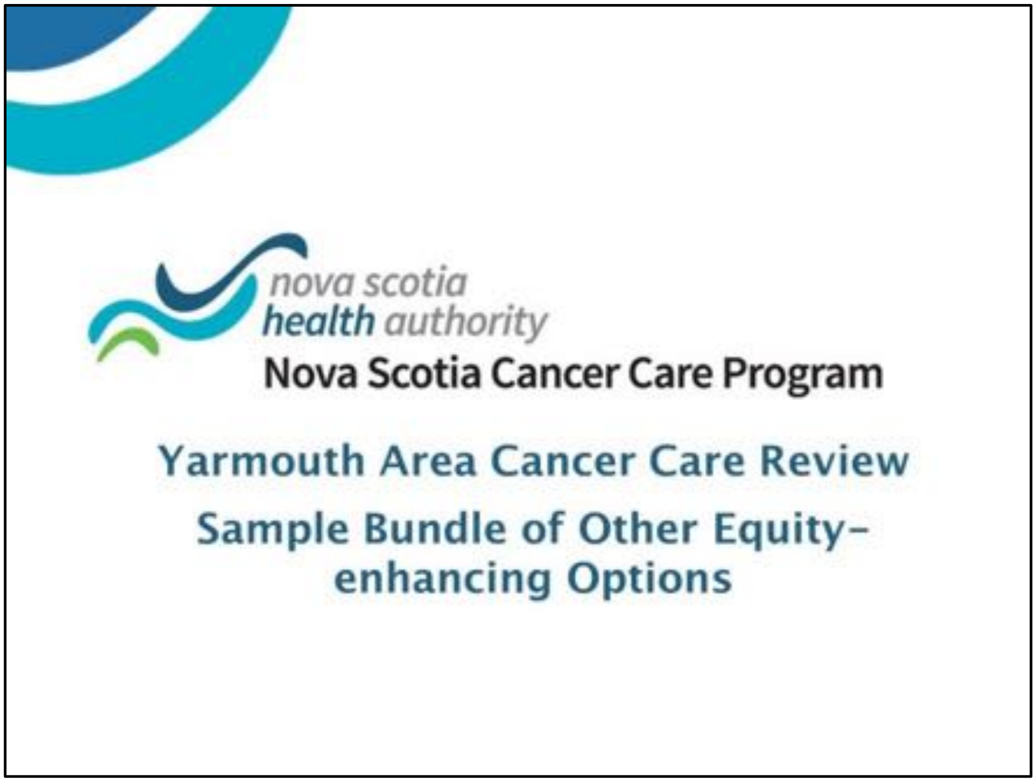
Requirement	Description	Estimate	Approval	Actual
Engagement Facilitation and Expertise	Focus groups with community members and health care providers may likely be required at various stages throughout the work	TBD		

9.0 Sign-Off

Project Sponsor:

Date:

Appendix B. DES Presentation - Sample Bundle of Other Equity-Enhancing Options



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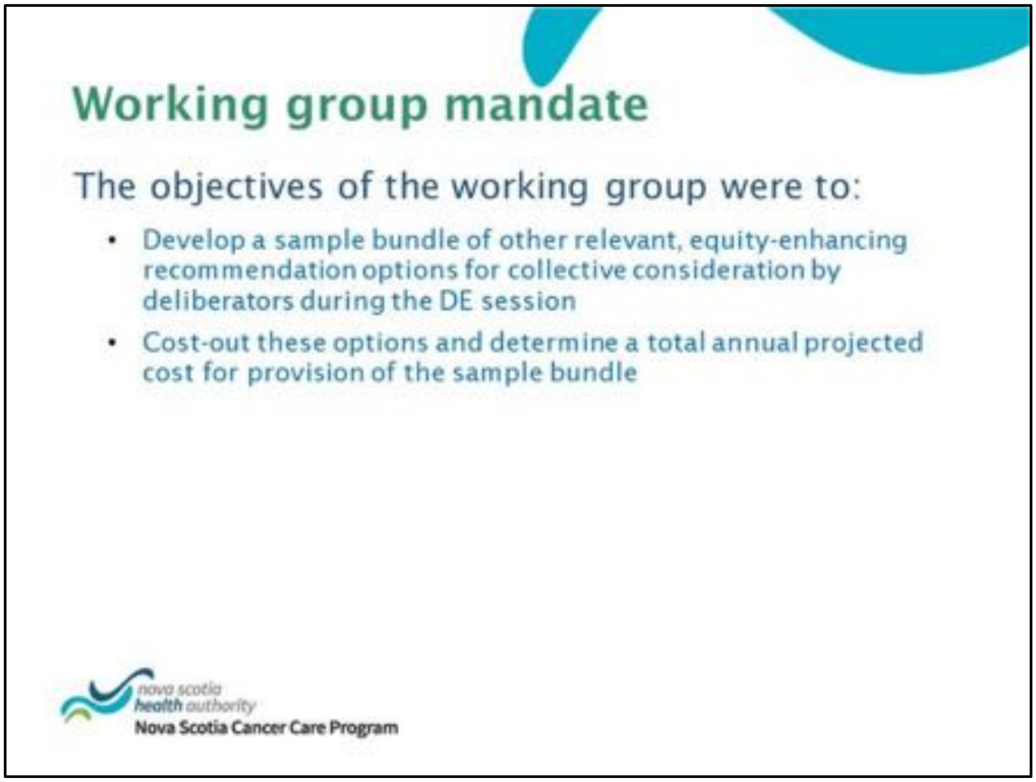
Yarmouth Area Cancer Care Review

Sample Bundle of Other Equity–enhancing Options



Working group mandate

The objectives of the working group were to:

- Develop a sample bundle of other relevant, equity-enhancing recommendation options for collective consideration by deliberators during the DE session
- Cost-out these options and determine a total annual projected cost for provision of the sample bundle

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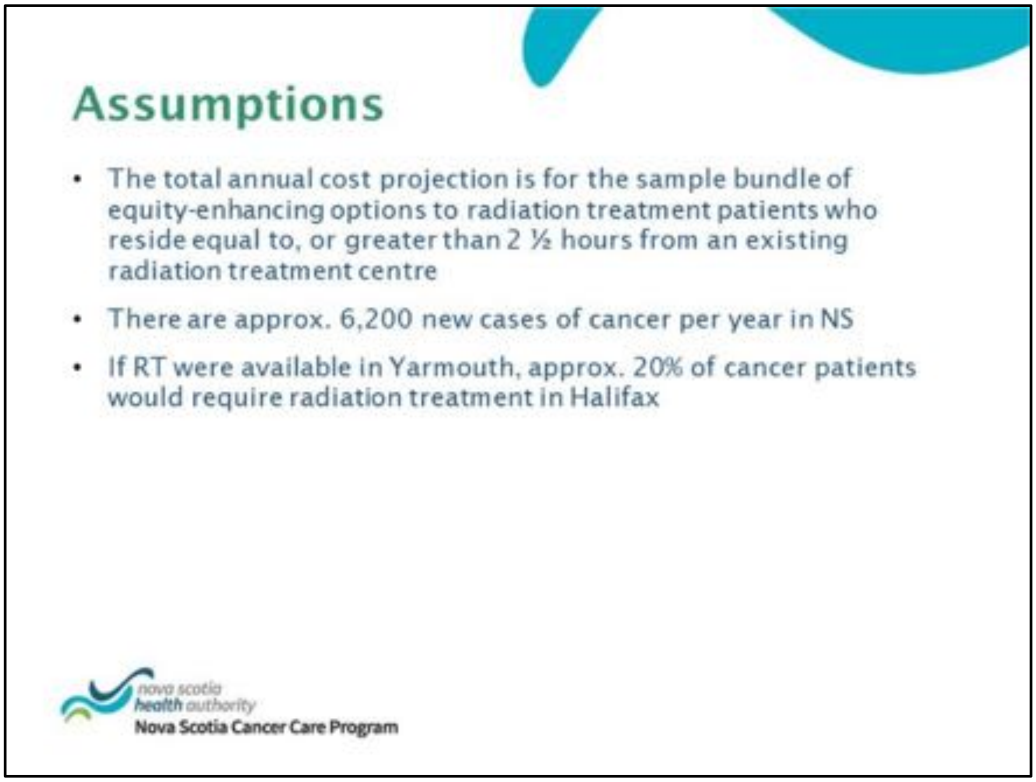

Assumptions

- The total annual cost projection is for the sample bundle of equity-enhancing options to radiation treatment patients who reside equal to, or greater than 2 ½ hours from an existing radiation treatment centre
- There are approx. 6,200 new cases of cancer per year in NS
- If RT were available in Yarmouth, approx. 20% of cancer patients would require radiation treatment in Halifax

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Assumptions cont'd

- The average number of round-trips to Halifax for a patient residing in Yarmouth is 6 (1-day initial consultation, 1-day simulation, 4 weeks of radiotherapy)
- The majority of Yarmouth patients and their support persons can be accommodated at the Lodge That Gives in Halifax

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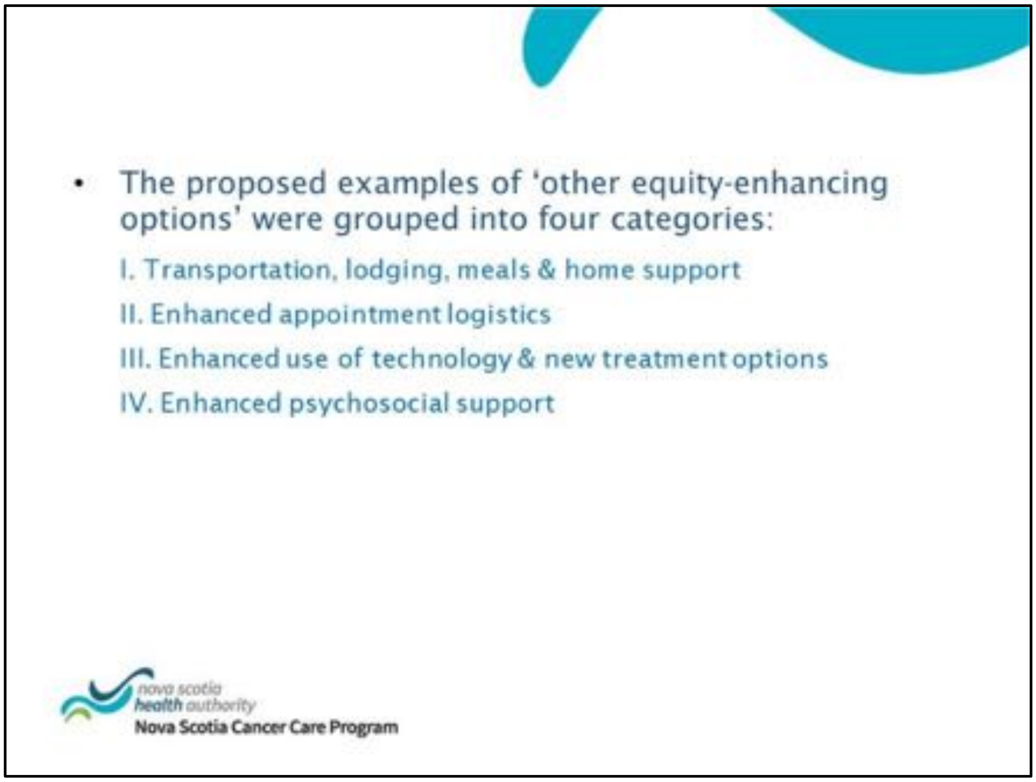

- The proposed examples of 'other equity-enhancing options' were grouped into four categories:

  I. Transportation, lodging, meals & home support

  II. Enhanced appointment logistics

  III. Enhanced use of technology & new treatment options

  IV. Enhanced psychosocial support

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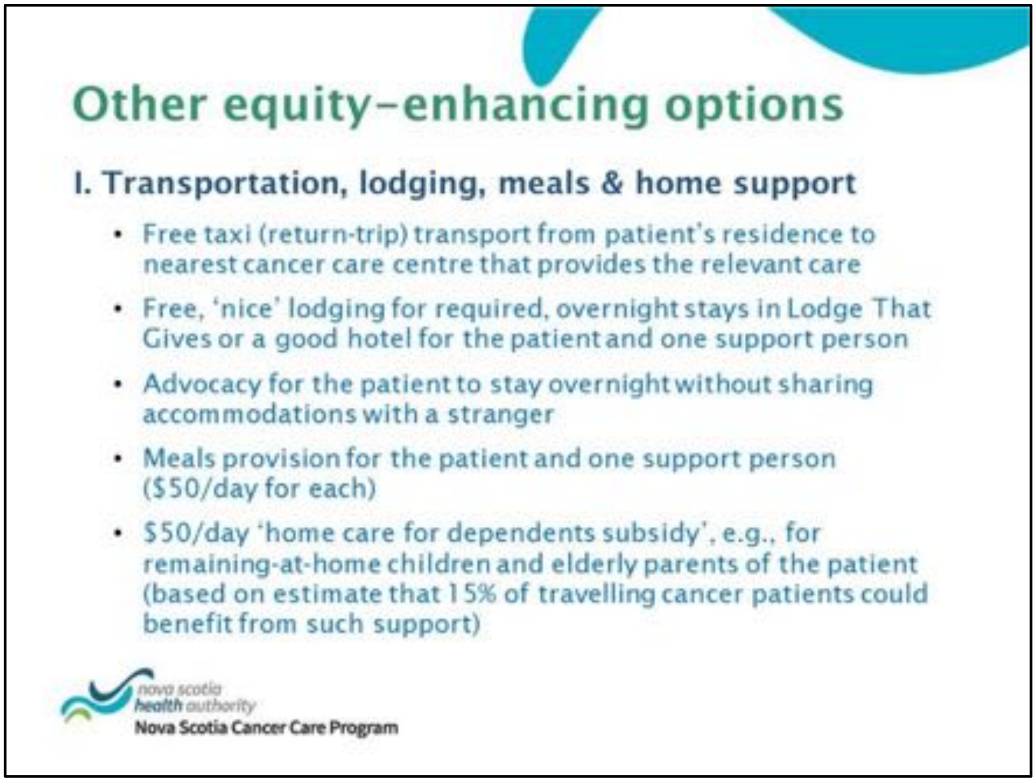

Other equity-enhancing options

I. Transportation, lodging, meals & home support

- Free taxi (return-trip) transport from patient's residence to nearest cancer care centre that provides the relevant care
- Free, 'nice' lodging for required, overnight stays in Lodge That Gives or a good hotel for the patient and one support person
- Advocacy for the patient to stay overnight without sharing accommodations with a stranger
- Meals provision for the patient and one support person ($50/day for each)
- $50/day 'home care for dependents subsidy', e.g., for remaining-at-home children and elderly parents of the patient (based on estimate that 15% of travelling cancer patients could benefit from such support)

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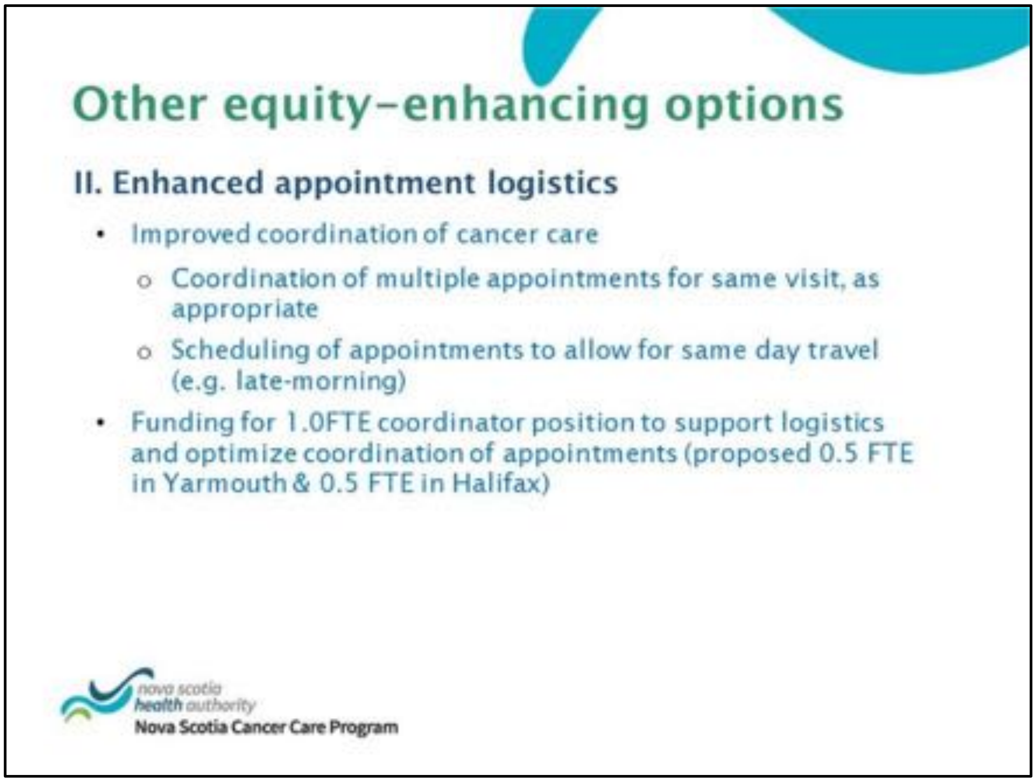

Other equity–enhancing options

II. Enhanced appointment logistics

- Improved coordination of cancer care
    - Coordination of multiple appointments for same visit, as appropriate
    - Scheduling of appointments to allow for same day travel (e.g. late-morning)
- Funding for 1.0FTE coordinator position to support logistics and optimize coordination of appointments (proposed 0.5 FTE in Yarmouth & 0.5 FTE in Halifax)

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Other equity–enhancing options

III. Enhanced use of technology & new treatment options

- Enhanced tele-oncology service delivery
    - funding for a 1.0 FTE telehealth technical support position
    - commitment from relevant NSCCP/Dalhousie leadership to support physician use of tele-oncology
- Commitment to explore the use of innovative/novel treatment approaches to cancer care that reduce the requirement for travel

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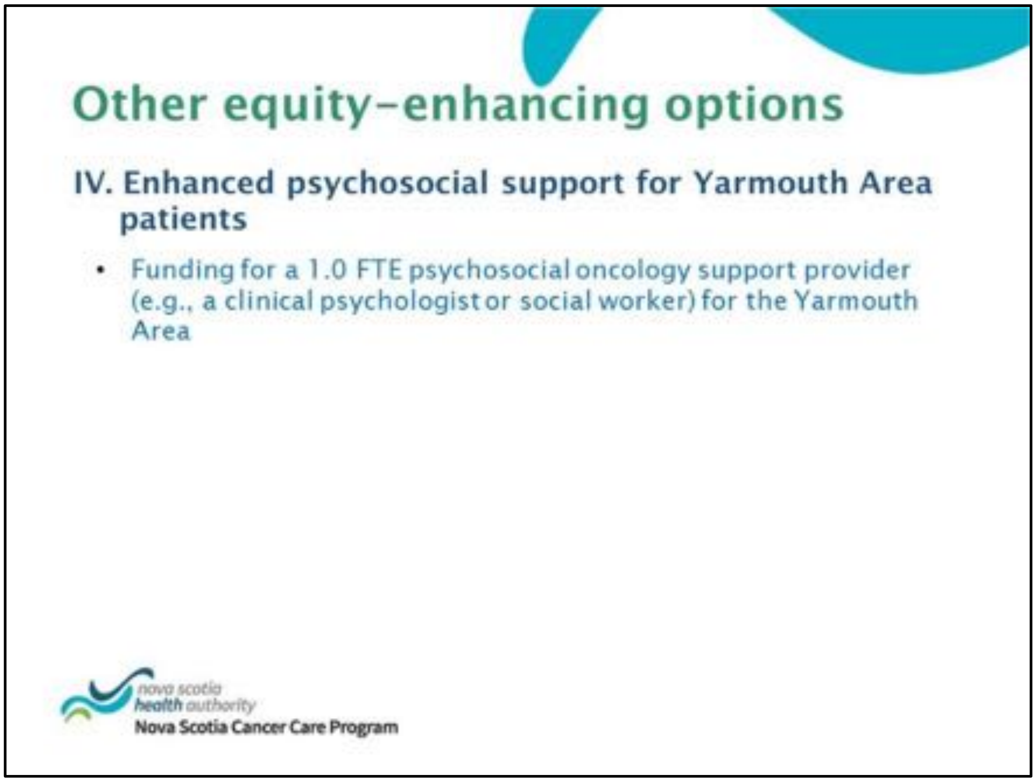

Other equity-enhancing options

IV. Enhanced psychosocial support for Yarmouth Area patients

- Funding for a 1.0 FTE psychosocial oncology support provider (e.g., a clinical psychologist or social worker) for the Yarmouth Area

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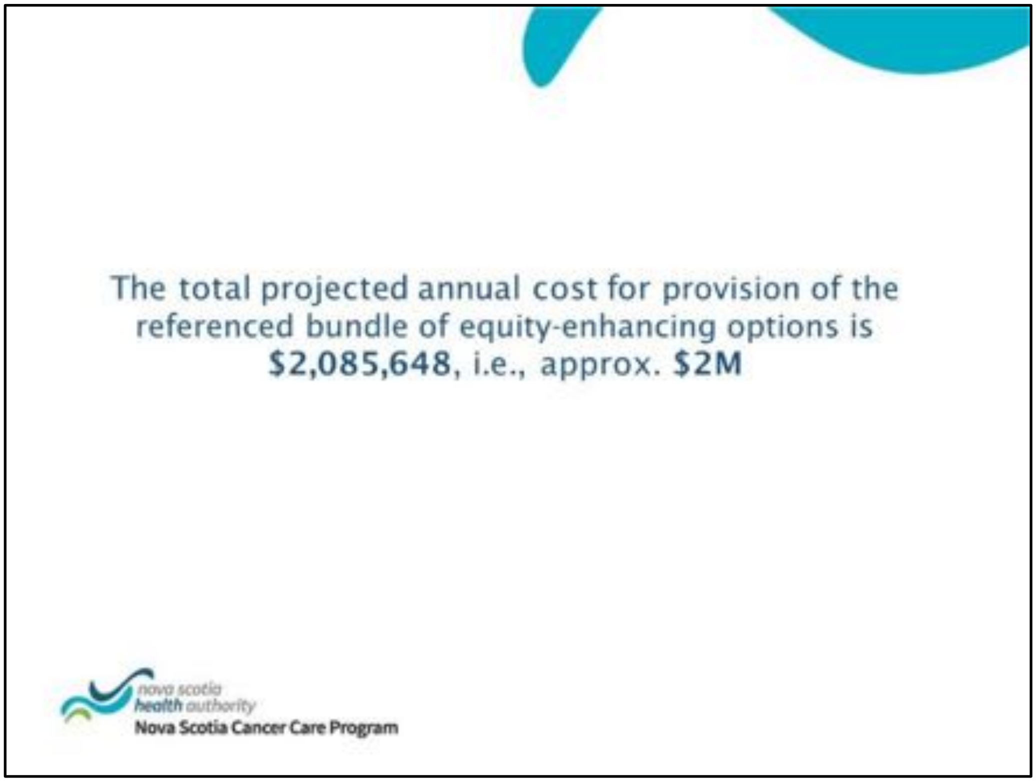

The total projected annual cost for provision of the referenced bundle of equity-enhancing options is **$2,085,648**, i.e., approx. **$2M**

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Appendix C. Guiding/Substantive Principles and Values

(Approved on 27 February 2018)

Equity

The responsibility of health care organizations (e.gs., the Nova Scotia Health Authority and the Nova Scotia Department of Health and Wellness) and health care providers to identify and eliminate or reduce unfair disparities among individuals and sociocultural groups in their opportunities for (good) 'health' and their access to publicly-funded health care and treatment.

- In the cancer care context, this involves the identification and elimination or mitigation of unfair constraints on the access of persons with cancer to publicly-funded cancer care services.

Individual Autonomy

As a key component of *respect for persons*, every individual has the right, and should have the opportunity, to make meaningful decisions about her/his health care and treatment. This principle is operationalized through the practical commitments of health care organizations and providers to person-centered care and informed choice/consent.

- In the cancer care context, this entails respect for, and support of, an individual's decision making about whether, and where, to receive publicly-funded cancer care services.

Patient Welfare Principles

Beneficence and Duty of Care

The obligation of health care providers and organizations to provide compassionate, nonjudgmental, dignity-promoting and culturally-sensitive care to persons who have health care needs.

- In the cancer care context, this includes the responsibility of health care organizations and providers to deliver quality care and therapeutic benefits (through the provision of publicly-funded cancer care services) to persons with cancer.

Nonmaleficence

The obligation of health care organizations and providers to do as little as possible harm to persons with health care needs who are entrusted to their care.

- In the cancer care context, health care organizations and providers are required, as much as possible, to eliminate or reduce health and social burdens that may accrue to individuals through the delivery of publicly-funded cancer services.

Justice

Traditional Distributive Justice

Social benefits including health care and treatment are to be fairly distributed/allocated within a given jurisdiction on a specified basis(es), e.g., in the case of publicly-funded health care delivery, on the bases of health care needs and available health resources.

Formal Justice

Like individuals and sociocultural groups should be treated alike and dissimilar individuals and sociocultural groups should be treated dissimilarly, i.e., like individuals and groups of persons are to be treated alike unless there is a demonstrable, *relevant* difference between/among them that would justify different treatment.

Social Justice

The obligations of decision makers to: 1) pay particular attention in their decision making to the perspectives, interests and needs of members of historically marginalized or otherwise disadvantaged sociocultural groups, 2) engage members of such groups in health care decision making at the meso and macro policy levels, and 3) demonstrate that health policy outcomes have taken the interests of such groups into meaningful account.

Procedural Justice

The fundamental, decision-making obligation to develop and follow fair, due and inclusive processes.

Utility

Following utilitarian theory, the obligation of decision makers to distribute/allocate limited resources within a given jurisdiction so as to produce the greatest good for the greatest number.

Efficiency

The responsibility of health care organizations to accomplish desired health-related goals and activities with an optimally-efficient expenditure of limited resources such as public funds and staff time. Respect for the principle of efficiency in the modern, health care context requires that organizational decision makers, e.g., leaders of the Nova Scotia Cancer Care Program and the Nova Scotia Department of Health and Wellness, pay careful attention to the delivery of health care services in an intentional, strategically-integrated way.

Sustainability

The responsibility of health care organizations and providers to take into meaningful account the sustainability of publicly-funded health systems in their decisions and actions. The paying of such attention to sustainability requires that decision makers make optimally-informed choices about how limited resources are allocated/used today in order to prevent their unnecessary depletion in the future.

Appendix D. Communications Plan

Access to Quality Care – Yarmouth Area (Digby, Yarmouth, Shelburne Counties)

December 15, 2017

Background

Results from the 2014 Provincial Cancer Service Delivery Review, the transitions of care survey and the 2016 Ambulatory Oncology Patient Satisfaction Survey (AOPPS), have indicated that having care closer to home is important to Nova Scotia cancer patients and families. In accordance with patients' wishes, NSHA's Nova Scotia Cancer Care Program is committed to providing as much cancer treatment and care as close to a patient's home as is safely and sustainably possible.

Over the past 15+ years, cancer system leaders and the Department of Health and Wellness have listened to patients and families and worked with health professionals across the province to increase the services available in rural Nova Scotia. This has included an expansion of community cancer clinics where medical oncologists travel to community sites for consultation, using Virtual Health technology so that patients can have appointments with specialists without traveling beyond their local regional hospital, and better coordination of care through Cancer Patient Navigation so that when patients do have to travel for care, tests, investigations and appointments are (as much as possible) coordinated to occur same day/consecutive days.

Currently, radiation therapy is provided for all Nova Scotians, including pediatric patients, at the two adult cancer centres in Sydney and Halifax and patients requiring radiation therapy who live outside these cities must travel to the closest centre for treatment. Since 2005, radiation oncologists have traveled to Yarmouth once or twice a month (or met with patients with the help of video technology) for consultation and follow-up, but patients living in Yarmouth and surrounding area still have to travel three hours to Halifax for radiation therapy.

Access to comprehensive cancer care services by adding radiation treatment services to the existing cancer care services available in Yarmouth has been a longstanding topic of discussion and interest and has been raised on a number of occasions between 2012 and 2017. In summer 2016, the topic emerged again and over the last year local community support has grown.

NSHA's Nova Scotia Cancer Care Program leadership has committed to a full review beginning in fall 2017 with an anticipated timeline of late spring 2018 for completion. This review will draw on the latest evidence and experience from other provinces and most recent patient population statistics for Yarmouth and area (Digby, Yarmouth and Shelburne counties) to determine if changes since the 2014 review would find adding radiation therapy services at Yarmouth Regional Hospital feasible and sustainable for this area and whether this is reasonable within the context of cancer needs across the province. The review team will also be asked to recommend additional ways to ease the burden for Nova Scotians if and when they have to travel for specialty cancer services.

Communication and engagement opportunity

The review of cancer care available in Yarmouth and area, within the context of Western Zone and cancer services in other parts of the province, provides the opportunity to explore if a business case exists to support a radiation therapy service in Yarmouth Regional Hospital. It will also be important to consider issues around potential utilization of such services and access to care as well as ensuring that any additional services are sustainable and integrated as part of the provincial cancer program. The review is also an opportunity to explore recommendations about additional supports for Nova Scotians who have to travel for specialty cancer treatments. However, the extent of monetary and human resource investment to deliver radiation therapy in an additional area of the province, and the trade-offs required in terms of other investment needed in the cancer system, makes this a provincial issue, of interest to all Nova Scotians, government and the media. It should also be noted that a radiation therapy facility in Yarmouth would not be able to provide specialized radiation therapy for patients with certain cancers. These patients would still need to travel for treatment.

Engaging patients and community members from Yarmouth and surrounding area will be an important part of the review. We will continue to engage with those who initiated this latest conversation as well as others in the community to understand current barriers to accessing cancer programs and services and the supports that could help to ease those barriers.

To ensure the review is comprehensive, and transparent, cancer system stakeholders (including patients and their families) in Yarmouth and surrounding area – and all of Western Zone will also need to be kept informed of planned timelines, scope and details of the review as well as have an opportunity to ‘contribute to the discussion.

Goals

- To ensure NSCCP employees who work in Yarmouth and area and all of Western Zone are aware of the plan to conduct a full review of cancer care in Yarmouth and surrounding area.
- To ensure that cancer patients, their families and communities in Yarmouth and surrounding area (and all of WZ) are aware of NSHA’s intent to conduct a full review to determine what is safe, feasible and sustainable in terms of providing more cancer care as close to home as possible.
- To consult and partner with patients and families so we can fully understand their concerns and aspirations and be able to use their feedback to inform recommendations.
- To inform Nova Scotians, particularly those living in southwestern part of the province, of planned review, indicating opportunities for input.
- To share the process for the review, communicating the scope and timeline.
- To provide updates, as appropriate, to cancer system stakeholders.
- To reassure all stakeholders (internal and external) that they will have an opportunity to provide input into the review.
- To commit to a timely response to all questions and concerns regarding the Yarmouth area review.

Objectives

- Establish a project team with local cancer leadership and patient/public representatives.
- Meet with Yarmouth and area cancer program staff, follow up with email communication.
- In person meetings with community leaders: Yarmouth Hospital Foundation board, municipal councilors, Facebook page creator to share review process/listen/answer questions
- Email updates, as appropriate, to all cancer system stakeholders – with a commitment to sharing updates with employees first.
- Engage with cancer program and communication leadership in Western Zone to be the local face of this project.
- Hold focus groups with stakeholders in Yarmouth.
- Promote opportunities for stakeholder input.
- Issue News release – as appropriate

Audiences

Internal

- *NSHA* Board and ELT
- Department of Health and Wellness
- Cancer Program Leaders/staff and zone leadership – Western Zone
- Nova Scotia Cancer Care Program leadership team
- Nova Scotia Cancer Care Program (oncology managers, CPNs, PCN members, cancer specialists)
- Western Zone Cancer Care Program staff
- IWK Health Centre (in terms of pediatric cancer patients from Western Zone)

External

- Cancer Patient Family Network
- Cancer Patient Advisory Council (NSHA, NSCCP)
- Diverse communities (African Nova Scotian, First Nations, Arabic, etc.)
- Yarmouth Hospital Foundation
- Yarmouth municipal officials
- Western Zone cancer patients and families
- Cancer patients and families in other zones
- Nova Scotians
- Media

Key Messages:

- NSHA's Nova Scotia Cancer Care Program is working with cancer leadership, and managers in Western Zone, to conduct a full review of cancer services available in Yarmouth and surrounding communities, exploring additional supports that could ease the burden of travel for specialized cancer treatment when necessary, and determining the feasibility and sustainability of enhancing access to comprehensive cancer services by adding radiation therapy services to existing cancer services in Yarmouth.

- Considering the addition of radiation therapy service in Yarmouth or anywhere is complex. A high quality radiation therapy service requires significant investment, including building and design costs as well as specialized clinical and support staff in addition to ongoing costs. The total costs for such a program also need to be considered with other program priorities and needs across the province. Having a radiation therapy facility in Yarmouth will not eliminate the need for some patients to have to travel to Halifax for specialized treatments.

- The goal of this work is to review cancer services currently provided in Yarmouth and surrounding area, determine the feasibility and sustainability of adding radiation therapy service in Yarmouth, and explore additional supports that could ease the burden when patients have to travel for specialty services.

- A Steering Committee, including cancer health professionals and patient representatives from southwestern Nova Scotia and Nova Scotia Cancer Care Program leaders has been struck to guide the review process. The Steering Committee is responsible for determining the scope of the review and components of work, managing logistics, and helping guide the process to ensure the work progresses smoothly and on schedule.

- Hearing from patients, families, and community members is an important part of the review. Residents of Southwestern Nova Scotia will be invited to share their thoughts through focus groups, email and telephone communication. In addition, there will be a few in person meetings.

- The Steering Committee had its first meeting in mid-October and is in the process of discussing and agreeing on the scope of the project.

- The intent is for the review to be complete by late spring 2018.

- Anyone who has questions or concerns about the review may contact NSHA's Nova Scotia Cancer Care Program toll-free at 1-866-599-2267 or by email at cancercareinfo@nshealth.ca.

Strategy
A number of tactics will be used to engage cancer program employees, system stakeholders, patients, families and public in the review of cancer services available in Yarmouth and surrounding areas and exploration of the feasibility and sustainability of adding radiation therapy service in Yarmouth. These include in-person meetings, focus groups in Yarmouth, and an electronic survey (see engagement plan for details). In addition to reviewing a comprehensive package of background materials, steering committee representatives will meet with key community leaders (Yarmouth Hospital Foundation, Municipalities in SW Nova Scotia and the creator of the Facebook group, which was set up to garner community support for a radiation therapy service in Yarmouth), to share the process for the review and to listen to concerns about improving access to care. The Steering Committee Chair will also invite these community leaders to nominate a representative to participate as a full member of the Steering Committee. Individuals invited to participate in these meetings will be provided with details about the meeting, its intent, and how it will unfold as well as a couple of questions to consider in advance of the meeting. These questions will provide the meeting with structure and will assist in ensuring that the meetings are productive.

Participants will also be invited to email 'further thoughts' to NSCCP, following the meeting. Two focus groups will be held in Yarmouth, but recruitment efforts will extend to the entire Western Zone. These focus groups will be followed by an online survey so that all interested stakeholders will have an opportunity to share their thoughts on the issue. See the engagement plan for details.

Although the focus of the review is cancer services in Yarmouth and surrounding area, the significant cost of considering the addition radiation therapy services in Yarmouth means it needs to be considered within the provincial context.

Updates will be shared, as appropriate, with stakeholders.

Tactic	Audience	Purpose	Outcome	The lead	Timing
Telephone conversations/e-mails / meetings / project charter/ draft strategies for consideration and approval	Paula Bond (ELT and NSHA Board)	To ensure leadership is informed /supports and approves of approach	Support and approval of approach	Drew Bethune	Summer 2017 / ongoing

Meetings / telephone conversations	DHW – MLA – Southwestern NS / Minister of Health and Wellness	To ensure government understands and is supportive of the process	Support / agreement on approach	Drew Bethune	Summer 2017 and ongoing
Meetings	Cancer Care Program leadership	information	Informed leadership team	Drew Bethune / Erika Nicholson	Monthly leadership meetings, August 2017 on
Meetings / email	Steering Committee members (including three public advisors, two from Yarmouth, one from Bridgewater)	Discuss and define scope of project; guide and provide leadership on work to meet objectives	SC has the information needed to provide leadership/guidance	Drew Bethune	Monthly meetings October 2017 on
Meeting	Nova Scotia Cancer Care Program staff – Western Zone	Inform them of the upcoming review and process; respond to questions /concerns	Internal audience most impacted hears information before it is share with external stakeholders	Drew Bethune	January 18, 2018 (before any meetings with external stakeholders and before media release
Email update	NS Cancer Care Program province wide	Inform internal stakeholders before information is shared externally	Internal audience feels valued and informed	Drew Bethune / Erika Nicholson with support from Christine Smith	January 18, 2018 – same day, Just following meeting with Yarmouth and area staff
Media Release	Nova Scotians (will also be shared with staff through Media of the Day)	Nova Scotians are informed of NSCCP's plan to conduct a review and engage with NS on improving access to care in Western Zone	Transparent process	Christine Smith in consultation with Steering Committee, NSHA Media Relations, Cancer Program Leadership and Paula Bond (ELT and Board)	January 18, 2018 – same day as program wide communication
In person meeting	Yarmouth Regional Hospital Foundation	Inform members of process and opportunities for engagement, answer questions, listen to their thoughts about improving access to cancer care in	Foundation members understand the process and feel their concerns are heard. Transparency	Drew Bethune, Jeff Kirby, Ethics Consultant, Christine Smith, Communications Manager	January 18, 2018 (following staff meeting)

		Southwest Nova Scotia			
In person meeting	Town councils (check with Shelly for details)	Inform members of process and opportunities for engagement, answer questions, listen to their thoughts about improving access to cancer care in Southwest Nova Scotia	Town Councils understand the process and feel their concerns are heard. Transparency	Drew Bethune, Jeff Kirby, Ethics Consultant, Christine Smith, Communications Manager	January 18, 2018 (same day or next as Foundation meeting)
In person meeting	Creator of Facebook Page – Derek Lesser	Inform Mr. Lesser of process and opps for engagement; listen to his thoughts; answer questions	Mr. Lesser understand the process and has an opportunity to share his thoughts	Drew Bethune. Jeff Kirby, Christine Smith	January 18, 2018 (following other meetings)
Focus Group recruitment	Cancer patients, families, interested citizens in Western Zone (see Engagement Plan for recruitment details)	To engage those most impacted by the review about the barriers to accessing care and to ask about supports that would make access easier	Cancer patients and families have an opportunity to weigh in on the review and feel heard. Transparency	Leslie Hill with support from other members of the Cancer Care Program Team	Mid January – mid February
Focus Group 1	Cancer patients, families, interested citizens in Yarmouth, surrounding areas including all of WZ (see Engagement Plan for recruitment details)	To engage those most impacted by the review about the barriers to accessing care and to ask about supports that would make access easier	Cancer patients and families have an opportunity to weigh in on the review and feel heard. Transparency	Leslie Hill with support from other members of the Cancer Care Program Team	February 20 2018
Focus group 2	Cancer patients, families, interested citizens in Yarmouth, and surrounding areas including all of WZ (see Engagement Plan for recruitment details)	To engage those most impacted by the review about the barriers to accessing care and to ask about supports that would make access easier	Cancer patients and families have an opportunity to weigh in on the review and feel heard. Transparency	Leslie Hill with support from other members of the Cancer Care Program Team	February 20, 2018
Focus Group Report	Focus group Participants	To summarize stakeholder feedback.	Transparency. FG participants feel heard	Leslie Hill with support from other team members	Late March 2018

Focus Group Report (email)	Steering Committee	To make SC members aware stakeholder feedback	SC members are kept informed of results from stakeholder engagement	Christine Smith – email	Late March 2018
Media release / social media / emails promoting availability of survey	Nova Scotians who are interested in commenting on the Western Zone Review	To provide another opportunity for stakeholder engagement	Transparency Nova Scotians have an opportunity to comment	Christine Smith with support from NSHA Media Relations/Social Media team	March 2018
Survey analysis and summary report	Steering Committee	To ensure SC members have the information they need to advise and guide on unfolding project	To ensure SC members are kept informed of stakeholder engagement results	Christine Smith / Leslie Hill worked with research analyst who had expertise in analysis of qualitative data	May 2018
Formal deliberative engagement session	Invited participants to ensure all perspectives were considered	Consider all evidence and decide on recommendation(s) for inclusion in report to ELT /NSHA Board and government	Transparency Enabling all perspectives to be heard	Jeff Kirby, ethics consultant to facilitate	June 13, 2018
Report and recommendations	Paula Bond (ELT / NSHA Board	To provide NSHA ELT with the review findings including data and summary of engagement activity results leading to the report and recommendations	ELT / NSHA Board have the information are informed	Drew Bethune	July 2018
Report and recommendations	Government (Minister of Health and others)	To provide government with the report and recommendations with the data to support it for consideration	Delivering on the product as promised	Drew Bethune	End of July 2018

Evaluation

- Track incoming phone calls, emails, questions, concerns from cancer system stakeholders, patients and families
- Ask Western Zone to log questions / concerns
- Communication assessment three - six months after the review has occurred to discuss what worked well and how the communication could have been improve

Appendix E. Engagement Plan

Project: Improving Access to Quality Cancer Services – Yarmouth and area

I. Project Background

See Communications Plan

II. Alignment and Rationale

The purpose of this engagement plan is to outline the public participation processes the Nova Scotia Cancer Care Program (NSCCP) will use to engage all stakeholders in this review; mainly those living in Yarmouth and surrounding area (Digby, Yarmouth, Shelburne counties). NSCCP goal is to consider the needs of patients and families using cancer system services and align that with the clinical requirements of providing safe, quality cancer care.

Engagement opportunities to include:

- invite patient/family/public members of Yarmouth and area to be volunteer members of the steering committee,
- hold information meetings with cancer care program leaders and staff from Yarmouth and area,
- hold in-person meetings with community leaders from Yarmouth and area,
- hold focus groups in Yarmouth and area,
- run an electronic survey to offer an opportunity for any persons who are interested in contributing to informing the review process,
- facilitate a deliberative engagement session to determine final recommendations.

This rationale aligns with (1) the strategic vision of NSHA Strategic Priorities of Person Centred, Safe and Sustainable Health and Wellness for Nova Scotians & Engagement with Nova Scotian to Create a Healthier Future, (2) Nova Scotia Cancer Care Program vision of providing world class care for generations, (3) Nova Scotia Health Authorities Act mandate to engage with patients and families and (4) Accreditation Canada standards to work in partnership with and with input from patients and families.

This full engagement approach will help to ensure an open an accountable public participation process.

The feedback received will help to inform the final review and recommendation report to NSHA leadership and Nova Scotia Government. Time line: spring, 2018.

III. Approach: This public participation engagement methodology has been designed with multiple approaches detailed below.

Decision making:

The advice and input provided by cancer care program staff, patients, families and other stakeholders from Yarmouth and area will be carefully reviewed and considered by the Steering

Committee throughout the process and as part of the deliberative engagement process to inform the final report and recommendations presented to NSHA Executive Leadership and Nova Scotia Government.

Participants

This review process is mainly interested in stakeholder feedback of cancer care program staff, patients, families and other stakeholders from Yarmouth and area. Specific targeted participation is detailed in the tables for each engagement approach below.

Recruitment

Recruitment for each engagement approach will be detailed in the tables below.

Goals

To understand all stakeholders views and needs regarding access to cancer services in Yarmouth and area and having cancer care closer to home.

Objectives

1. Meet with NS Cancer Care Program team members in Yarmouth to inform them of the review process.
2. Engage and collaborate with Yarmouth and area patients, families and community members to better understand their perspective with regard to providing care close to home in Nova Scotia.
3. Recruit patient/public advisors to participate on the Review Steering Committee.
4. Consult cancer patients/families and community members via focus groups and a targeted survey.
5. Keep patients and families informed of the review process as appropriate.

Guiding Principles

The International Association of Public Participation (IAP2) Spectrum of Public Participation and the IAP2 Core Values of Public Participation will form the basis of the guiding principles of the Public Engagement approaches for this project. See Appendix A . A robust public participation (P2) plan will support a transparent and patient centred review and help to ensure that the final recommendation(s) understand the values, needs and concerns of patients and families who are travelling for cancer services. Aligning with the IAP2 Spectrum of Public Participation, the project engages patients, families and public across the spectrum from inform, consult, involve and collaborate. (See Table 1)

Table 1. Summary of Public Engagement Methods to inform the Yarmouth and Area Cancer Services Review Process.

IAP2 Spectrum of Public Participation	**Increasing Level of Impact**			
	Inform	**Consult**	**Involve**	**Collaborate**
Date and details	**January 2018** Dr. Drew Bethune, Christine Smith and Jeff Kirby to hold 5 Community Meetings in Yarmouth. • local cancer program staff • Yarmouth Hospital Foundation board members • community champions from a Special Interest Facebook Group • Yarmouth County Vanguard newspaper staff and, • Members of the local municipal government.	**February 2018** Two focus groups in Yarmouth facilitated by Leslie Hill. **April 2018** Survey launch on NSHA's Engage4Health website.	**June 2018** Deliberative engagement session scheduled for June 2018. The outcome will be recommendation(s) for inclusion in a report to be submitted to NSHA Executive and government for review and consideration. Includes patient and public attendees.	**October 2017** Recruit Patient and Family Advisors to be volunteer members of the Steering Review Committee membership.

Approach 1 – Engaging with Cancer Care Program team members: IAP2 Inform

Tactic	Information sharing, visit by NSCCP leaders to Yarmouth, media release, Engage4Health front facing web site launch.
Objectives	1. Firstly, ensure NSCCP staff working in Yarmouth and area are aware of the review and have an opportunity to have questions answered. 2. To ensure remaining NSCCP staff know the review process is occurring. 3. To ensure other stakeholders; including patient/families, community, public know the review process is happening.
Support provided by	Fraser Mooney, Communications and Public Relations Western Zone as one community lead; NSCCP oncology leaders Rob Zwicker and Janet Baker Christine Smith, Manager Communications, NSCCP

	Kelly Thompson, Engagement Advisor, NSHA
Details	Prior to engagement with external groups, a meeting will be held with NSCCP staff in Yarmouth. Following this meeting, media release will announce the review. That same day; in-person meetings will be held with community leaders (Yarmouth Hospital Foundation, Municipalities, creator of Facebook page). Aim: a. Let people know we will extensively review the feasibility of having a radiation therapy service in Yarmouth. b. Want to understand their needs. c. Want to consult them on their concerns d. Share NSCCP requirements around quality, finances, safety to move ahead with any work. e. Commit to seeking their input and answering their questions
Information & support required	Develop media release and Engage4health website
Feedback	Media contact for inquiries will be Christine Smith
Support required	Communications and Public Engagement Team, NSHA C. Smith, F. Mooney, and J. Baker. Rigby (Director, Community and Population Oncology) Admin: K. Kennedy
Timeline	January 2018
Evaluation	N/A

Approach 2 – Steering Committee partnering with patient and families: IAP2 Collaborate

Tactic	Involving Public Advisors as volunteer members of the Steering Committee
Objective	Recruit those who are already engaged in advocating for care closer to home. To invite three Public Advisors to join the steering committee who represent different counties within Western Zone (Yarmouth, Annapolis, Lunenburg areas)
Support provided by	Fraser Mooney, Communications and Public Relations Western Zone; oncology leaders Rob Zwicker and Janet Baker; Targeted recruitment via Cancer Patient Navigators /oncology managers in Western Zone; members of the SWH Facebook page, Yarmouth Foundation. NSHA PFPAC and Engagement team
Details	Recruitment poster to be shared within NSCCP support networks (oncology managers, navigators) to help recruit interested and appropriate volunteers as public advisors to the steering committee. Process for recruitment, screening and onboarding will follow NSHA Guidelines for Effective Engagement.
Information & support required	Develop context/backgrounder document, orientation materials for Public Advisors. (IAP2 Inform).
Feedback	We will keep participants apprised how their feedback is utilized to influence decisions.
Support required	Volunteer Public Advisors will be supported by NSCCP Communications and Engagement staff: Leslie Hill, Coordinator; Engagement Diversity and Vulnerable Populations, NSCCP Christine Smith, Manager Communications, NSCCP

	Admin: K. Kennedy
Timeline for recruitment	October –November 2017 Ideally, recruit three Public Advisors for the first or second steering committee meeting.
Evaluation of public engagement process	At completion of review process- survey Public Advisors, ask for their feedback if the review process met the Core Values of public participation.(TBD)

Approach 3 – Focus groups to consult Yarmouth and area patients/family/public/community-IAP2 Consult

Tactic	Focus Groups to obtain public feedback
Objective	To hold focus groups to seek public input on cancer services and alternatives. To understand barriers to accessing quality cancer services and identify supports to ease the burden of travel when patients have to leave their home community to access specialty services.
Participants	Cancer patients and families /other stakeholders /primarily Yarmouth and area Limit Focus Group registered participants to 12 for each session.
Details	Advertise opportunity through: Cancer Patient Family Network Patient advisors NSCCP Patient Family Advisory Council IWK Youth Council and PFAC Cancer Patient Navigators Yarmouth Hospital Foundation Oncology Managers Cancer Patient Navigators Community Cancer Organizations(including YACC) Media Release FN Health Directors NSHA PFPAC and Public Engagement team Social Media NSCCP leadership
Information & support required	Focus Group Invitations (email, poster, media release). Social support in focus group causes distress. Pre-registration process for participants. Mileage and travel expenses to Focus Group location (TBD-Western Zone). Co Facilitator/volunteer. Evaluation process-TBD Consent to Participate form. Develop questions for focus group (see Appendix B and C)
Feedback	A focus group summary report will be written by L. Hill. To be shared for confirmation of what we hear with focus group participants. Final report to be shared with the Steering Committee, NCSSP leadership and staff, and publicly when appropriate.
Support required	L Hill to facilitate Focus Groups. A volunteer will be required to co-facilitate the session Recorders may be required. As needed support from: Communications and Engagement Working Group: L. Hill, C. Smith, F. Mooney, and J. Baker (Western Zone), K. Rigby (Director, Community and Population Oncology)

Timeline	Recruitment for focus groups will occur in late January, 2018. Focus Groups to be held early to mid-February 2018
Evaluation	Potential questions to ask participants: (TBD) 1. Do they feel heard? 2. Do they feel this was meaningful? 3. Do they feel any questions were not asked?

Approach 4- Electronic Survey on Engage4Health website: IAP2 Consult

Tactic	Electronic Survey
Objective	To follow up on focus group results, and dig deeper/clarify what we heard. Gain additional public input. To provide another forum to engage with communities and understand the implications and advantages of decisions of this review process.
Participants	Anyone will be able to access survey. Target recruitment efforts to Yarmouth and area: patients, family, community members, health professionals.
Details	Survey tool will be developed from information knowledge and gaps of focus group results, and steering committee recommendations. Survey questions may also be informed from priority items in the 2014 Provincial Cancer Services Delivery Review, the 2016 Ambulatory Oncology Patient Satisfaction Survey priority matrix questions and patient comments in the survey. (see Appendix B)
Information & support required for participants	Engage4Health HQ2 platform for survey sharing Development of survey tool March 2018 (see APPENDIX D)
Feedback	Survey results to be shared to, NSCCP leadership.
Support required	Admin: K. Kennedy Engage4Health: K. Thompson
Timeline	Late February to March 2018
Evaluation	N/A

Approach 5- Deliberative Engagement Sessions: IAP2 Collaborate

Tactic	To inform an ethical framework for decision making, NSCCP has involved Jeff Kirby, Ethics Consultant with NSHA and Professor, Department of Bioethics, Faculty of Medicine at Dalhousie University to help plan and facilitate a deliberative engagement session. Deliberative engagement is an approach to decision making that enables participants to consider all relevant information from the project review process (evidence, data, public input etc. to understand the choices that NSCCP must consider in addressing this review.
Objective	To have a fair and supportive decision making process which will inform the review report due in the spring. The deliberative engagement process will take account of all participants' views, be transparent, and provide clear evidence of how the recommendation report was influenced by participants input.
Participants	Steering Committee members (which includes cancer care program staff from southwestern Nova Scotia and Public Advisors), relevant resource people, including Jeff Kirby, and others TBD

Details	With Jeff Kirby, plan a deliberative engagement session once the process of gathering data, evidence, public input is complete. This facilitated session will be an opportunity for the Steering Committee and Public Advisors to review and discuss all relevant information to form draft recommendations with a goal of reaching consensus.
Information & support required	Facilitation Guide to be developed by Jeff Kirby
Feedback	Final report to be shared to NSHA Executive Leadership and Nova Scotia Government.
Support required	Jeff Kirby will facilitate. Other supports TBD.
Timeline	Spring 2018
Evaluation	N/A

IV. Evaluation

Requirements for evaluation are detailed in the tables above for individual engagement approaches.

V. Report Back

Project updates and reports will be shared as per each individual approach above.
For further information, refer to details in the Communication Plan.

VI. Acronyms

a. NSCCP- Nova Scotia Cancer Care Program
b. LINAC- Linear Accelerator
c. NSHA- Nova Scotia Health Authority
d. IAP2- International Association of Public Participation
e. AOPSS-Ambulatory Patient Satisfaction Survey

Appendix F. Media Release/Advisory, January 18, 2018

nova scotia
health authority
Nova Scotia Cancer Care Program

EMBARGOED until 6:30 p.m., January 18, 2018

NSHA to review Yarmouth and area cancer services

FOR IMMEDIATE RELEASE
Jan. 18, 2018

YARMOUTH, N.S. – Nova Scotia Health Authority's (NSHA) Nova Scotia Cancer Care Program is conducting a review of cancer services in Yarmouth, Digby and Shelburne counties, to determine the feasibility and sustainability of adding radiation therapy services at Yarmouth Regional Hospital.

"Being diagnosed with cancer is stressful and patients and families in southwestern Nova Scotia have told us that traveling to Halifax for radiation therapy is an added strain," said Dr. Drew Bethune, Medical Director, Nova Scotia Cancer Care Program.

"They have asked us to take another look at the possibility of having these services at the Yarmouth Regional Hospital and that's what we are doing. We are also considering other supports to help improve access to care for patients when they need to travel for specialty cancer services."

A steering committee of cancer health professionals, patient and public representatives from southwestern Nova Scotia and Cancer Care Program leaders are guiding the process.

"Having cancer program staff, patients and community stakeholder representatives from Yarmouth and surrounding area as members on the steering committee is key to ensuring an informed and transparent process," said Erika Nicholson, Senior Director, Nova Scotia Cancer Care Program. "Patients, families and others who are interested in sharing their thoughts will be invited to participate in a focus group, or complete an electronic survey."

Dr. Helmut Hollenhorst, a radiation oncologist from Halifax and a steering committee member, traveled to Yarmouth regularly between 2005 and 2015, providing patients with consultation and follow-up so they didn't have to travel for these services. Today, these consults occur through Telehealth video technology. He said radiation therapy is a highly specialized cancer treatment and a decision to add a service in Yarmouth or elsewhere is complex and must consider the patient perspective, the initial and ongoing costs, as well as other factors.

“Having to travel for treatment is a challenge, especially when you’re not feeling well,” he said. “As part of the review, we must ask for input and listen very carefully to patients and families. We also need to consider the significant investment of building and design, equipment purchase and maintenance, as well as our ability to successfully recruit a specialized clinical team and support staff and cover ongoing operational costs. Even with a facility in Yarmouth, patients who need complex radiation therapy would still have to travel to Halifax.”

As part of the review, work is already underway to:

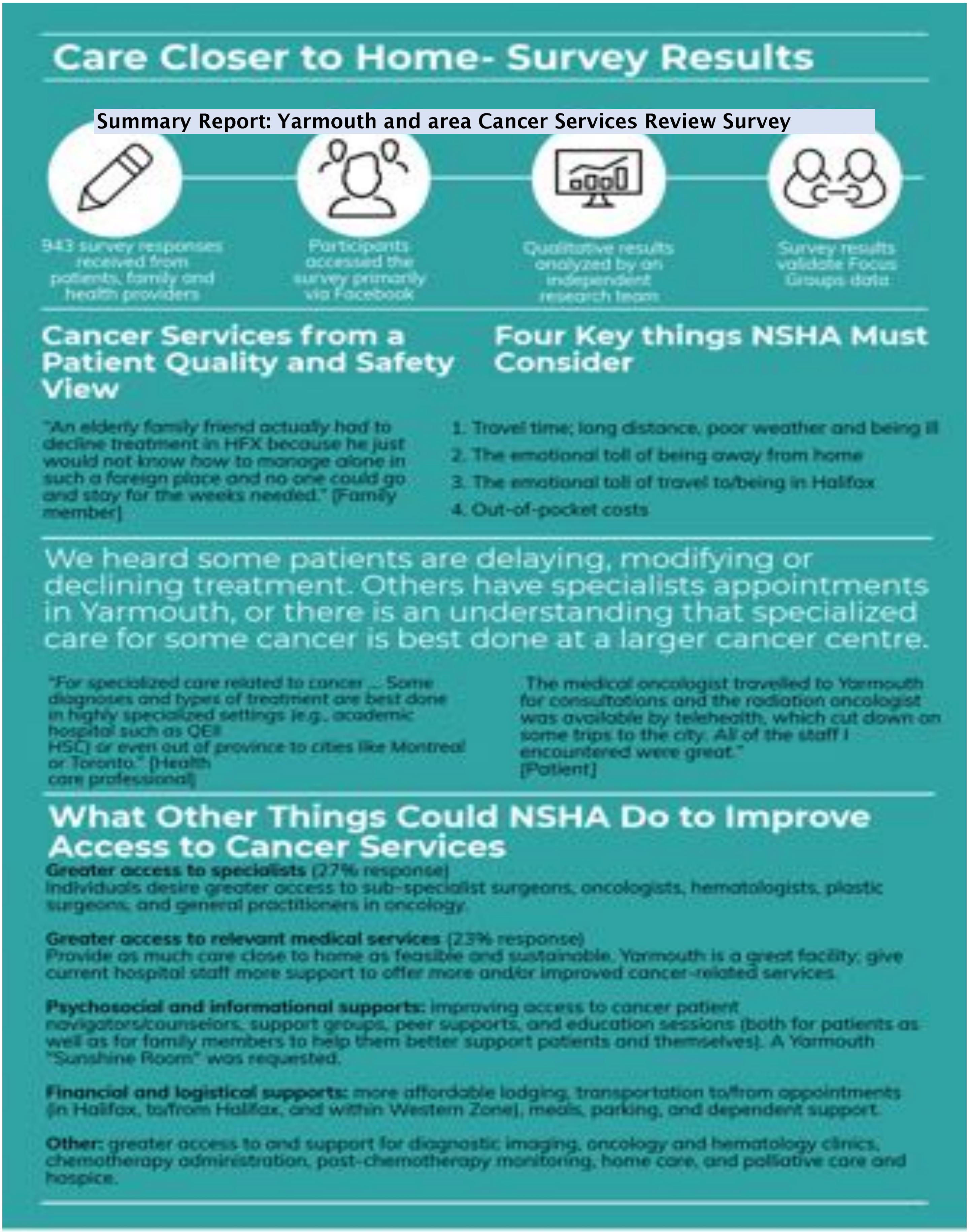
- Study recent cancer statistics to determine the potential number of patients in southwestern Nova Scotia who would benefit
- Reach out to other provinces for information and expertise
- Research cost estimates to design and build physical space (bunker), purchase and maintain equipment, should a decision be made to do so
- determine the size, makeup and budget for a clinical team needed to operate a radiation therapy service; and
- Consider other cancer priorities and needs across the province and the trade-offs that would be necessary to add radiation therapy services in Yarmouth.

The goal is to have the review complete by late spring 2018.

-30-

Media contact: Christine Smith
Nova Scotia Health Authority
902-222-9739
christine.smith@nshealth.ca

Appendix G. Survey Response Report - Care Close to Home – Survey Results



Care Closer to Home- Survey Results

Summary Report: Yarmouth and area Cancer Services Review Survey

943 survey responses received from patients, family and health providers

Participants accessed the survey primarily via Facebook

Qualitative results analyzed by an independent research team

Survey results validate Focus Groups data

Cancer Services from a Patient Quality and Safety View

"An elderly family friend actually had to decline treatment in HFX because he just would not know *how* to manage alone in such a foreign place and no one could go and stay for the weeks needed." [Family member]

Four Key things NSHA Must Consider

1. Travel time; long distance, poor weather and being ill
2. The emotional toll of being away from home
3. The emotional toll of travel to/being in Halifax
4. Out-of-pocket costs

We heard some patients are delaying, modifying or declining treatment. Others have specialists appointments in Yarmouth, or there is an understanding that specialized care for some cancer is best done at a larger cancer centre.

"For specialized care related to cancer ... Some diagnoses and types of treatment are best done in highly specialized settings (e.g., academic hospital such as QEII HSC) or even out of province to cities like Montreal or Toronto." [Health care professional]

"The medical oncologist travelled to Yarmouth for consultations and the radiation oncologist was available by telehealth, which cut down on some trips to the city. All of the staff I encountered were great." [Patient]

What Other Things Could NSHA Do to Improve Access to Cancer Services

Greater access to specialists (27% response)
Individuals desire greater access to sub-specialist surgeons, oncologists, hematologists, plastic surgeons, and general practitioners in oncology.

Greater access to relevant medical services (23% response)
Provide as much care close to home as feasible and sustainable. Yarmouth is a great facility; give current hospital staff more support to offer more and/or improved cancer-related services.

Psychosocial and informational supports: improving access to cancer patient navigators/counselors, support groups, peer supports, and education sessions (both for patients as well as for family members to help them better support patients and themselves). A Yarmouth "Sunshine Room" was requested.

Financial and logistical supports: more affordable lodging, transportation to/from appointments (in Halifax, to/from Halifax, and within Western Zone), meals, parking, and dependent support.

Other: greater access to and support for diagnostic imaging, oncology and hematology clinics, chemotherapy administration, post-chemotherapy monitoring, home care, and palliative care and hospice.

Background and Introduction

Nova Scotia Cancer Care Program (NSCCP), a program of NSHA, is committed to providing as much cancer treatment and care as close to a patient's home as is safely and sustainably possible. Nova Scotia cancer patients and families have indicated that having care closer to where they live is important. In Yarmouth and area, the possibility of having access to Radiation Therapy treatment at Yarmouth Regional Hospital has been a longstanding topic of discussion. Increasing interest re-emerged in 2016 /2017. In Fall 2017, NSHA's NSCCP agreed to review access to cancer services available in Yarmouth and area. The purpose of the review is two-fold: to determine the feasibility and sustainability of adding radiation therapy services at Yarmouth Regional Hospital and, to determine what supports would help to improve access to quality cancer treatment and services in the province. In addition to analyzing cancer statistics, projection data, associated financial and human resource needs, the review engaged with patients, their families and local community. NSCCP recognized the needs and interests of all stakeholders, including that of patient and families, to promote sustainable decision making.

Survey Methodology

Hearing patient, public and community member perspective regarding cancer services was important to ensure the public concerns and aspirations were heard and understood. (See Engagement Plan for additional information)

The survey included twelve questions, three open-ended questions, and nine choice-based questions with text boxes for comments. (See Appendix for Final Survey Questions)

Survey questions were developed by considering (i) the 2014 Provincial Review of Cancer Services, (ii) input from the steering committee members and (iii) from summary results of the focus groups and community meetings.

The survey opportunity was promoted and shared through a media release, NSHA news and NSHA Media of the Day. It was also sent to Focus Group participants, oncology managers, Cancer Patient Navigators in Western Zone, First Nations Health Directors, and to the community Facebook Group in Yarmouth. A paper version of the survey was available in a number of areas in Yarmouth and surrounding area.

The electronic survey was available on NSHA Engage4Health website. This web-based engagement tool was able to house background information about the project, list links to news media and a project timeline.

The survey was open from March 20 to April 6, 2018. All paper surveys received were included in the analysis.

Three details overlooked in the survey development which may have enhanced the survey and data analyses were:

1. Assume that a significant number of respondents may answer the survey. Due to past community advocacy on this issue, the Facebook group engagement, and media interest in the story.
2. Set up the survey with tags or codes in the text responses to allow for easier qualitative data analysis. This was the first time using the Engage4Health survey platform, and learning occurred during the project.
3. Activation of Google Analytics™ with Engage4Health survey platform. This would have enabled the analytics tracker in the program to stratify traffic sources with individual responses. If there was any doubt that a large response rate from one source (the Facebook advocacy group) was skewing the results, we would be able to understand that without question. (see Appendix for additional information and link to Google Analytics)

Due to the large response rate, a, Dalhousie University researcher and research assistant, were hired to analyze the qualitative data. The detailed report from this team and methodology utilized to analyze the qualitative data and the codes can be found in the appendixes.

Results

A total of nine hundred and forty three participants responded to the survey. The average respondent to the survey was a patient/survivor or family member of a cancer patient between 51and 65 years old. Almost all respondents found the travel to Halifax for treatment difficult, with a large percentage having to take time off work or school to accommodate travel. Approximately half of respondents had to delay or cancel appointments in Halifax for cancer treatment, usually due to weather.

Respondents indicated that NSHA should equally consider the issues around travel, quality of care and cost as a recommendation on cancer services in Yarmouth is deliberated. We asked respondents to reflect if they would ever consider NOT having radiation treatment if they had to travel and 52.9% would consider the possibility. The majority of respondents felt it was not reasonable to ask patients to travel to other parts of the province for cancer care, unless for very specialized services. Respondents wanted greater access to additional services and to specialists closer to their home.

Summaries of individual question within the survey are below.

Individual Question Response Summaries

(Green highlight indicates the highest response to the quantitative questions)

Q1. Please choose a category that best describes you:

Patient	68 (7.2%)	208 (22%) patient experience
Cancer Survivor/former patient	140 (14.8%)	

Family Member	535 (56.7%)	535 (56.7%)
Health Professional	91 (9.7%)	91 (9.7%)
Other category not listed	109 (11.6%)	109 (11.6%)

Q2. If you chose other, please explain.

The most common response was ‘community member’.

Other respondents to this question provided personal details not relevant to the analysis.

Q3. Please choose the age range that best describes you

Under 35	88 (9.3%)
35-50	238 (25.2%)
51-65	400 (42.4%)
Over 65	217 (23%)

Q4. Have you, or has someone close to you, had to travel to Halifax for cancer services?

Yes	871 (92.4%)
No	72 (7.6%)

Q5. Were there things that made going to Halifax for cancer treatment difficult?

n=871 (the 72 respondents from Q4, who did not have to travel for treatment were excluded from participating in this question)

Yes	842 (96.7%)
No	29 (3.3%)

Q6. Please explain your response to question 5.

772 (83%) individuals responded to this question. Of these, 489 (63%) people indicated that **out-of-pocket costs** related to traveling for care are challenging. Costs mentioned included transportation, lodging (including for driver/support person), food, and parking. Many noted the added difficulties of low-income patients and families, who struggle to cover these costs while dealing with the stress of a cancer diagnosis and its treatment.

> *“With no income coming in due to illness and significant travel expenditures to travel to Halifax, my mother-in-law nearly filed for bankruptcy. She will live in poverty until she, herself, passes.”* -Family member

The second and third most frequently mentioned challenges associated with traveling for care were **travel time** (48%) and the **emotional toll of being away**

from home (33%), respectively. Individuals noted the discomfort and inconvenience of traveling a long distance, and several indicated that they or a loved one refused treatment because they could not handle the travel distance. Many also noted the complexity of travelling such long distances with someone who is ill (e.g., in pain or experiencing nausea) or very old. Many participants provided stories of their experiences of travelling with someone while very ill:

> *"My mom had throat cancer and the cancer was on the outside and would bleed. Many times on our way to Halifax, it would start to bleed and it was hard to stop it …"* -Family member
>
> *"My husband was suffering extreme pain from compression factures in his spine due to Multiple Myeloma. Travelling for 3+ hours in a car was excruciating."* -Family member

Individuals noted the emotional burden they experience being away from home for extended periods of time to have radiation therapy. They mentioned the difficulty of being away from family/friend supports, being alone and feeling isolated, and of being away from family during a stressful and scary time. They also highlighted the stress and burden experienced by family members who are unable to travel to Halifax and have to remain at home. One individual highlighted the impact of this burden by stating:

> *"… feeling extremely miserable from the effect of chemo and radiation, family wasn't able to make the trip, alone, depression set in, increased anxiety, wanting to give up."* -Family member

Q7. Did anyone have to take time off work or school to drive you or someone close to you to Halifax for treatment?

866 responded, 77 skipped the question

Yes	748 (86.4%)
No	118 (13.6%)

Q8 What issues do you think NSHA needs to consider in making a decision about the possibility of opening a radiation treatment centre in Yarmouth? (Choose all that apply.)

Travel	891 (37.8%)
Quality of Care	648 (27.5%)
Cost	650 (27.6%)
Other category not listed	168 (7.1%)

Q9 What other things do we need to consider, please explain.

152 (16%) individuals responded to this question. From these individuals, by far, the two most prevalent issues across all respondents were the **emotional toll of**

being away from home (51%) and the **emotional toll of travel to/being in Halifax** (26%). These two issues are clearly related, yet subtly different in terms of how individuals described them. The emotional toll of being away from home (described in Q4 above) largely reflects a lack of family/friend support and feelings of loneliness and isolation.

Individuals remarked the emotional toll of travel to/being in Halifax was characterized by the added stress of travelling to Halifax (e.g., long drives are exhausting; there is additional stress created by the financial burden of travel), living out of a suitcase, being in unfamiliar surroundings while ill, and the discomfort with driving in Halifax.

> *"My mom would work herself sick worrying about the upcoming drive. It was a sin to see how nervous this made her prior to the day of the drive."*
> -Family member

Though less frequently discussed, family members also emphasized the necessity to consider **travel time** (19%), **out-of-pocket costs** (12%), and **missed work** (7%) when making a decision about radiation therapy services in Yarmouth. Missed work refers to such things as absence from work and subsequent loss of productivity and income, having to hire others to manage own business while away, for both the patient and his/her caregiver/driver.

Q10 Please let us know about the costs that concern you.

474 (72.9%) of respondents who cited costs as a concern provided additional detail.

They were concerned with the financial burden of travel to Halifax for both the patient and family/caregivers, including: gas, mileage, wear and tear on vehicles *("I had to buy a new car that could handle travelling so much"),* car rentals, the cost of hiring a driver, food, parking, long distance phone calls, lodging for the patient and his/her support person/driver. There were comments about the difficulties of finding affordable accommodations and accommodations specifically for the support person/driver because some subsidized accommodations available to cancer patients do not cover the cost of accommodation for a support person/drivers. Other comments included additional burden for low income patients and families who struggle financially and may not have income because the patient is too sick to work. Respondents noted instances where patients chose not to get radiation treatment because they could not afford the out-of-pocket costs. Many also noted that it is reasonable to travel for treatment in situations where the person can afford it or financial support is made available to cover the expense of travel, accommodations, and meals.

Q11 Did you or someone close to you ever have to delay or cancel a cancer treatment related appointment in Halifax for any reason?

Yes	481 (51%)
No	462 (49%)

Q12 Please explain why? (For the yes respondents of question 11)

427 (46%) individuals responded to this question. Two-thirds (68%) stated delays or cancellations due to **weather and driving conditions.** Many described cancelling their trip because of acute weather events, but others discussed rescheduling treatment regimens in anticipation of poor weather and driving conditions during the winter months. The latter was noted by one participant:

> *"Appointment scheduled during winter [was] rescheduled to spring to avoid possible need for unexpected short notice cancellation due to inclement weather making long distance travel not possible."* -Family member

The next most common reasons for delays or cancellations (cited by 15-18% of individuals responding) was **needing help with transportation** (e.g., difficulty finding a driver, no access to vehicle/reliable vehicle), **travel time** (most notably inability to travel when ill), and **out-of-pocket costs.**

Q13 Would you think about not having radiation therapy for cancer treatment if you had to travel?

Yes	499 (52.9%)
No	444 (47.1%)

Q14 Why? (for respondents who answered yes in question 13)

- Cost 428(86%)
- Nowhere to stay 275(55%)
- Work 217(43%)
- No way to get there 209(42%)
- Childcare 121(24%)
- Farm/animal care 110(22%)
- Other reason not listed 130(26%) (detailed in responses to question 15)

Q15 If you chose other, please explain.

130 (26%) individuals responded to this question. The three most common reasons for considering not to have radiation treatment, even if indicated, were: **travel time** (30% -most notably travelling when ill), the **emotional toll of being away from home (35%)**, and the **emotional toll of travelling to/being in Halifax (22%).** The emotional toll is reflected in the following comments:

> *"My supports would not be able to stay with me during treatment or visit outside of their work schedule. Facing possible death away from home*

> *and loved ones is for soldiers, not everyday people."* -Other/Community member
>
> *"I know of several people who have chosen to have their breasts removed rather than go through the emotional trauma of travelling to the city for treatments. This is unacceptable!"* -Family member

Q16 When is it reasonable for patients to travel to another area of the province for cancer treatment? Please explain.

697 (75%) individuals responded to this question. Of these, 203 (29%) responded that it was **never** reasonable to travel to another area of the province for cancer treatment. 171 (25%) responded that it is reasonable to travel to **access specialized expertise and services**, or for rare cancers that require certain expertise. For example, they considered travel to other areas of the province reasonable for exceptional or very specialized treatments (including subspecialist surgeons), for second or third line therapies, in circumstances when the patient is in need of additional medical attention, or to participate in clinical trials. One respondent highlighted several of these concepts, saying

> *"For specialized care related to cancer … Some diagnoses and types of treatment are best done in highly specialized settings (e.g., academic hospital such as QEII HSC) or even out of province to cities like Montreal or Toronto.*" -Health care professional

In response to this question, individuals also relayed and reiterated their concerns related to travel to other areas of the province for cancer treatment. The most common concerns mirror those discussed in previous questions and related to: the **emotional toll of being away from home**, **out-of-pocket costs**, the **emotional toll of travelling to/being in Halifax**, and **travel time** (most notably travelling when ill).

Q17 Besides radiation therapy, what other things could we do to improve access to cancer services in your area?

526 (57%) individuals responded to this question. Of these, the two most common responses were **greater access to specialists** (27%) and **greater access to relevant medical services** (23%). Individuals desire greater access to sub-specialist surgeons, oncologists, hematologists, plastic surgeons, and general practitioners in oncology (GPOs). They believe that greater access to these specialists locally will reduce travel to Halifax and also lead to quicker diagnoses and shorter wait times.

Individuals desire greater access to and support for diagnostic imaging, oncology and hematology clinics, chemotherapy administration, post-chemotherapy monitoring, home care, and palliative care and hospice. They realize this means more human resources (e.g., nurses) and infrastructure (e.g., equipment, beds) to support and deliver such services. The desire for better chemotherapy-related services was highlighted by one respondent who said:

> *"Upgrade the cancer support staff in Yarmouth so post chemo patients could be monitored closer to home [versus] sit in Halifax for weeks for a 1 hour appointment daily."* -Patient/survivor

Individuals also felt that improvements could be made in **financial, logistical psychosocial and informational supports.** Financial and logistical supports would enable more affordable lodging, transportation to/from appointments (in Halifax, to/from Halifax, and within Western Zone), meals, parking, and support for dependents who remain at home while the patient is away.

> *"Investment in transportation for communities who have to travel for specialist treatment, this would benefit other patients, not just cancer e.g. cardiac, neuro and support accommodation for patient and caregiver."*- Health care professional

Psychosocial and informational supports are about improving access to cancer patient navigators/counselors, support groups, peer supports, and education sessions (both for patients as well as for family members to help them better support patients and themselves). Individuals referenced resources and supports elsewhere they would like available in Yarmouth, such as the Sunshine Room at the QEII Health Sciences Centre in Halifax and the Macmillan Cancer Supports in the UK.

> *"Counselors [sic] at the centre who could talk with patients, advise them, explain things and … be THERE for patients…a shoulder to cry on!"* - Family member

Individuals also cited improved access to medications (especially oral therapies), recruitment and retention of primary care providers, and greater use of telehealth/ Internet for appointments as things that would improve cancer services/care in the Yarmouth area.

Q18 Is there anything else you would like to tell us about cancer treatment and services in your area?

391 (42%) individuals responded to this question. Most reiterated prior comments, describing concerns around the **emotional toll of travelling to/being in Halifax**, the **emotional toll of being away from home**, **out-of-pocket costs**, and **travel time.** Of these, 55 (14%) individuals provided positive remarks around the quality of their cancer care in Yarmouth, including being grateful for chemotherapy services/satellite clinics and the helpfulness and compassion of staff. The following quotations highlight these perceptions:

> *"The services I received in Yarmouth were excellent- drug teaching, pharmacy consult, Pt. navigator was top notch (my best "go to" resource to help with everything) Lab work was easy, and results provided by oncology nurse, even though my chemo was in Hfx."* -Patient/survivor

> *“We have a good oncology unit with very good nurses. They are there for you when you have questions. If they don’t know the answer they will find it. Also the pharmacy/pharmacist are super knowledgeable about what drugs you are taking. Can’t say enough about that unit.”* -Patient/survivor

33 (8%) individuals remarked on **equity and fairness** as it relates to the delivery of cancer services in Yarmouth, and the disparities created by virtue of their geography, and resulting feelings of marginalization.

Discussion

There had been some concern if the large number of responses which came from traffic through Facebook might skew the results. There is a Facebook user group from the Yarmouth area, whose members are advocating for cancer services for south western Nova Scotia. Approximately 78% of respondents found the survey through Facebook, as detailed by the Traffic Sources Report in the Appendix.

Unfortunately, it was not possible to stratify the results based on traffic source. A Google Analytics application had to be activated in the survey tool prior to survey launch in order see this data set in the survey results. After careful consideration, the researchers concluded that due to the long history of interest and advocacy in this region anyway, the traffic source data would not be a concern in data analysis.

As the earlier focus group results clearly indicated; the support of family and friends is needed by patients who travel for cancer services. The issues and concerns regarding cost, travel and emotional toll are not unique to just the patients, but also impacts their families and support network. Therefore, results for patients/survivors responses versus the family caregivers were not stratified in the survey summary.

Considering the qualitative and qualitative data together, four issues came to the forefront:

- Travel time, particularly issues with travelling long distances in poor weather and when someone is ill due to their cancer or its treatment
- Emotional toll of being away from home
- Emotional toll of travel to/being in Halifax
- Out-of-pocket costs

Individuals consistently noted these four issues as especially burdensome given most people are living with considerable anxiety and fear because of their (or their loved one’s) diagnosis. Many described the emotional toll that comes with being in unfamiliar surroundings, far from family, friends and support networks, while undergoing treatments that are often exhausting and fraught with side effects (e.g., nausea, pain). These situations were portrayed as overwhelming and demoralizing. Many patients also discussed the added burden of worrying about loved ones and work/other responsibilities at home while trying to focus on their own treatments and care in Halifax. As noted from Question 6, the two most prevalent issues that individuals felt ***NSHA must consider*** when making a decision about providing radiation therapy services in Yarmouth were the emotional toll of being away from home and the emotional toll of travel to/being in Halifax.

> *"An elderly family friend actually had to decline treatment in HFX because he just would not know how to manage alone in such a foreign place and no one could go and stay for the weeks needed."* -Family member
>
> *"The loneliness of being away from family and friends at a time when you need them the most, fear of spending your limited time left ALONE and Scared."* -Family member

Individuals commonly described challenges related to finding ways to travel to Halifax for their appointments and treatments. The inability to find transportation sometimes resulted in cancelled appointments. Issues such as not having access to a reliable vehicle or not being able to find an available driver were frequently mentioned. Individuals noted the need for a driver to help a patient travel to Halifax often exacerbates out-of-pocket costs with regard to food and lodging.

Several additional findings related to the qualitative data are notable. One is that issues related to coordination of care (e.g., challenges coordinating care and appointments between hospital sites) and equity/fairness (e.g., equal access for equal need) were mentioned but not prevalent across the dataset. Although such issues may be pertinent to the issue of travelling for cancer treatment, they were not mentioned often. This may reflect phrasing of the survey questions themselves or simply that the most pressing concerns relate to the four issues identified above.

Some individuals spoke positively about their experiences during the cancer journey and about cancer services in Yarmouth. One patient said:

> *"I was so impressed with the care I received … The medical oncologist travelled to Yarmouth for consultations and the radiation oncologist was available by telehealth, which cut down on some trips to the city. All of the staff I encountered were great."* -Patient/survivor

However, these positive remarks sometimes came with the caveat that hospital staff need more support to offer more and/or improved cancer-related services. Several individuals noted the hospital in Yarmouth is a great facility that could handle additional services and potentially attract skilled expertise.

Conclusion

The large number of survey responses confirms that having additional cancer services, particularly radiation services, is an important issue for patients and families in Yarmouth and area. The survey results indicate there are four central issues of importance to patients and families who have to travel to Halifax for specialty cancer services:

- Travel time, particularly issues with travelling long distances in poor weather and when someone is ill due to their cancer or its treatment
- Emotional toll of being away from home
- Emotional toll of travel to/being in Halifax
- Out-of-pocket costs

Aside from having a radiation therapy available at the Yarmouth Regional Hospital, respondents were very thoughtful about other supports for cancer patients:

- **Greater access to specialists** (27% response)
  Individuals desire greater access to sub-specialist surgeons, oncologists, hematologists, plastic surgeons, and general practitioners in oncology.
- **Greater access to relevant medical services** (23% response)
  Provide as much care close to home as feasible and sustainable. Yarmouth is a great facility; give current hospital staff more support to offer more and/or improved cancer-related services.
- **Psychosocial and informational supports:** improving access to cancer patient navigators/counselors, support groups, peer supports, and education sessions (both for patients as well as for family members to help them better support patients and themselves). A Yarmouth "Sunshine Room" was requested.
- **Financial and logistical supports:** more affordable lodging, transportation to/from appointments (in Halifax, to/from Halifax, and within Western Zone), meals, parking, and dependent support.
- **Other supports:** greater access to and support for diagnostic imaging, oncology and hematology clinics, chemotherapy administration, post-chemotherapy monitoring, home care, and palliative care and hospice.

Having a radiation therapy facility and/or additional cancer services in Yarmouth to serve area residents is important to the community. Some respondents shared experiences of patients delaying and modifying cancer therapy choices or choosing not to have certain treatments due to the financial and emotional costs. From a quality and safety perspective, it must be deliberated how to serve patients who feel they need delay, decline or modify recommended treatment plans due to issues around travelling for cancer services.

Appendices

Survey Tool

Survey: Yarmouth Area Cancer Services Review

Nova Scotia cancer patients and families have told us that having health care closer to where they live is important. Nova Scotia Health Authority (NSHA) wishes to provide as much cancer treatment and care as close to a patient's home as possible. Ensuring that the treatments patients receive are provided safely by health professionals who have the right training is also very important.

In Yarmouth and surrounding area, there has been a lot of interest in having radiation treatment services offered at Yarmouth Regional Hospital.

In fall 2017, the provincial government asked NSHA to do a review of cancer services for this area. The purpose of the review is to:

- See if adding radiation treatment at Yarmouth Regional Hospital is affordable, safe and possible
- Look at ways to make it easier for patients to get quality cancer treatment and services
- Hear from patients, their families and community members about changes that would make getting cancer treatment and services easier

The review includes gathering and studying data and asking patients and families what they think. We have four patient/ public advisors as members on the Steering Review Committee. We have talked to community leaders in Yarmouth. We have heard from 24 patients and family members during recent focus groups held in Yarmouth.

Now, we want to hear from you! You may complete this printed survey or do it online. The survey deadline is April 6, 2018.

Survey Questions:

1. **Please choose the category that best describes you.**
   - ○ Patient
   - ○ Cancer survivor/former patient
   - ○ Family member
   - ○ Community member
   - ○ Health professional

○ Other (please explain):

2. **Please choose the age range that best describes you.**
   - ○ Under 35
   - ○ 35 – 50
   - ○ 51 – 65
   - ○ Over 65

3. **Have you or has someone close to you had to travel to Halifax for cancer services? If your answer to this question is no, please go to question 6.**
   - ○ Yes
   - ○ No

4. **If you answered yes to question 3, were there things that made going to Halifax for cancer treatment hard?**
   - ○ Yes
   - ○ No

     If yes, please explain:

5. **Did anyone have to take time off work or school to drive you or someone close to you to Halifax for treatment?**
   - ○ Yes
   - ○ No
   - ○ Comment:

6. **What issues do you think the NSHA needs to think about in making a decision about whether it is possible to have radiation treatment in Yarmouth? (choose all that apply)**
   - ○ Travel Distance
   - ○ Quality of Care
   - ○ Cost
   - ○ Other (please explain):

7. **Did you or someone close to you ever have to delay or cancel an appointment in Halifax for any reason?**
   - ○ Yes
   - ○ No

If yes, please explain why?

8. **Would you think about not having radiation treatment if you had to travel?**
   - ○ Yes
   - ○ No (go to question 10)

   Comment:

9. **If yes, why? (Check all that apply)**
   - ○ Work
   - ○ Child Care
   - ○ Elder Care
   - ○ No Way to Get There
   - ○ No Where to Stay
   - ○ Cost
   - ○ Farm/ Animal Care
   - ○ Other reasons (please explain)
   - ○ N/A

10. **When is it reasonable for patients to travel to another area of the province for cancer treatment? Please explain.**

11. **Besides radiation therapy, what other things could we do to improve cancer services in your area?**

12. **Is there anything else you would like to tell us about cancer treatment and services in your area?**

Thank you for taking the time to do this survey. If you have questions or concerns about the survey please contact Leslie Hill, toll-free at 1-866-599-2267 or email her at leslie.hill@nshealth.ca

Traffic Sources: Care Close to Home Survey

REFERRER URL	Visits
m.facebook.com	737
www.thevanguard.ca	243
www.facebook.com	238
cjls.com	72
www.nshealth.ca	62
android-app	15
lm.facebook.com	13
www.cjls.com	13
www.thecoastguard.ca	9
www.annapoliscountyspectator.ca	6
www.google.ca	6
l.facebook.com	5
www.digbycourier.ca	5
outlook.live.com	4
t.co	3

Google Analytics vs. EHQ Engage4Health Reporting

For interest only, this link explains how activating Google Analytics™ with the Engage4Health survey platform would have provided additional data when looking at traffic sources data.

http://helpdesk.bangthetable.com/report-on-your-consultation/google-analytics-vs-ehq-reporting

Qualitative Data Analysis Report

This information is incorporated into the full summary report.

One Page Summary

Two researchers from the Department of Surgery, Dalhousie University, analyzed the data from the qualitative (textbox) components of the Care Closer to Home survey. An adapted Framework Method was used to analyze the data. This work was completed between April 30, 2018 and May 25, 2018.

Nine hundred and forty three individuals responded to the survey, but the number responding to the individual textbox questions varied from 14-73%. There were no notable differences in responses emerging between those who identified as patients/survivors, family members, health care professionals, or other/community members.

While there were differences in findings across the survey questions, four key challenges emerged:

- Travel time, particularly issues with travelling long distances in poor weather and when someone is ill due to their cancer or its treatment
- Emotional toll of being away from home
- Emotional toll of travel to/being in Halifax
- Out-of-pocket costs

The two most prevalent issues that individuals felt *NSHA must consider when making a decision about providing radiation therapy services in Yarmouth* were:

- Emotional toll of being away from home
- Emotional toll of travel to/being in Halifax

Additional findings include:

- 291 individuals stated they (or a person close to them) had to delay or cancel an appointment in Halifax due to poor weather
- 203 individuals indicated it is never reasonable to travel to another area of the province for cancer treatment
- 171 individuals responded that it is reasonable to travel to access specialized expertise and services (e.g., subspecialist surgeons), or for rare cancers that require certain expertise
- Issues related to coordination of care and equity/fairness were not prevalent across the dataset, despite their potential relevance to the issue of travelling for cancer treatment

Methodological approach

Analysis of the qualitative data were performed by Dr. Robin Urquhart (Assistant Professor and Ramia Scientist, Department of Surgery, Dalhousie University) and her Research Associate, Laura Lee Madden (LM). Dr. Urquhart's research focuses on cancer health services research, including issues related to access to care, quality of care, coordination of care, and patient outcomes. She has expertise in qualitative methods.

An adapted Framework Method was used to analyze the raw text data from survey questions 4, 6, 7, 8/9, 10, 11, and 12. This approach sits within the collection of analysis methods often termed thematic analysis. One of the defining features of the Framework Method is the matrix output, which is essentially a table or spreadsheet that organizes and summarizes the data according to individuals and codes (descriptive or conceptual labels applied to excerpts of raw data). This matrix provides a structure by which researchers can organize and reduce the data, and analyze it by individual and code, allowing the research team to readily compare and contrast data across and within individuals. This analysis method aligns well with research that involves pre-defined issues and occurs in a limited timeframe. Dr. Urquhart has experience with this method.

Guided by this approach, the two researchers developed a set of codes to guide the coding and categorization of data. All codes were inductive – meaning they were not set *a priori*, but came directly from the data. Due to similarity of responses, the same set of codes was used for questions 4, 6, 7, and 8/9. Specifically, this set of codes was:

- Travel time
- Travelling while sick/old
- Needing help with transportation
- Weather and driving conditions
- Emotional toll of travel to/being in Halifax
- Emotional toll of being away from home
- Physical/practical difficulties of being away from home
- Missed work
- Out-of-pocket costs
- Coordination of care
- Responsibilities at home
- Expertise
- Saving money
- Waiting
- Equity and fairness

This set of codes was expanded for questions 10, 11, and 12. For the purposes of reporting, the codes travel time and travelling while sick/old were grouped together under simply travel time. Descriptions for all codes can be found in an appendix. Since the codes were all inductive, the different codes demonstrate the breadth of responses in the dataset.

LM coded all of the textual data and placed it in matrixes, examining the data by patient/survivor, family member, health care professional, and other/community member. Textual responses that included more than one concept (e.g., an individual discussed both weather challenges and the emotional toll of being away from home) would have been coded multiple times. The data were organized according to respondent type: patient/survivor, family member, health care professional, and other/community member. The two researchers met regularly to review and discuss coding as it progressed. RU wrote the summary report.

Findings by Question

Note: Descriptions of categories (e.g., out-of-pocket costs, travel time) are provided only the first time they are mentioned. In subsequent descriptions of findings, the reader will have to refer back to the description provided in an early question.

Q4. If you answered yes to question 3, were there things that made going to Halifax for cancer treatment hard? If yes, please explain.

772 (83%) individuals responded to this question. For all types of respondents, **out-of-pocket costs** was the most frequent issue that made going to Halifax for cancer treatment hard. In fact, 489 (63%) of the individuals who responded to this survey question found out-of-pocket costs challenging. Statements related to out-of-pocket costs included references to costs related to transportation, lodging (including for driver/support person), food, and parking. Many noted the difficulties faced by low-income patients and families, who struggle to cover these costs amidst the stress of a cancer diagnosis and its treatment.

> *"With no income coming in due to illness and significant travel expenditures to travel to Halifax, my mother in law nearly filed for bankruptcy. She will live in poverty until she, herself, passes."* [Family member]

The second and third most frequent issues that made going to Halifax for cancer treatment hard were **travel time** (48%) and the **emotional toll of being away from home** (33%), respectively. There were no differences amongst types of respondents. Referring to travel time, individuals noted the discomfort and inconvenience with the long distance. Several individuals pointed out that they or someone they loved refused treatment because they could not handle the travel distance. Many also noted the complexity of travelling such long distances with someone who is ill (e.g., in pain or experiencing nausea) or very old. Many participants provided stories of their experiences of travelling with someone while very ill:

> *"My mom had throat cancer and the cancer was on the outside and would bleed. Many times on our way to Halifax, it would start to bleed and it was hard to stop it …"* [Family member]

> *"My husband was suffering extreme pain from compression factures in his spine due to Multiple Myeloma. Travelling for 3+ hours in a car was excruciating."* [Family member]

Individuals noted the emotional burden they experience being away from home for extended periods of time to undergo radiation therapy. Individuals remarked on the difficulty of being away from family/friend supports, being alone and feeling isolated, and of separating families during such a stressful and scary time. They also highlighted the stress and burden experienced by family members who are unable to travel to Halifax and have to remain at home. One individual highlighted the impact of this burden when stating:

> *"… feeling extremely miserable from the effect of chemo and radiation, family wasn't able to make the trip, alone, depression set in, increased anxiety, wanting to give up."* [Family member]

Q6. What issues do you think the NSHA needs to think about in making a decision about whether it is possible to have radiation treatment in Yarmouth? Other (please explain).

152 (16%) individuals responded to this question. From these individuals, by far, the two most prevalent issues across all types of respondents were the **emotional toll of being away from home** (51%) and the **emotional toll of travel to/being in Halifax** (26%). These two issues are clearly related, yet subtly different in terms of how individuals described them. The emotional toll of being away from home (described in Q4 above) largely reflects a lack of family/friend support and feelings of loneliness and isolation.

Individuals remarked the emotional toll of travel to/being in Halifax was characterized by the added stress of travelling to Halifax (e.g., long drives are exhausting, there is additional stress created by the financial burden of travel), living out of a suitcase, being in unfamiliar surroundings while ill, and the discomfort with driving in Halifax.

> *"My mom would work herself sick worrying about the upcoming drive. It was a sin to see how nervous this made her prior to the day of the drive."* [Family member]

Though less frequently discussed, family members also emphasized the necessity to consider **travel time** (19%), **out-of-pocket costs** (12%), and **missed work** (7%) when making a decision about radiation therapy services in Yarmouth. Missed work refers to work absence and subsequent loss of productivity, inability to miss work, having to hire others to manage own business while away, and so on, for both the patient and his/her caregiver/driver.

Q7. Did you or someone close to you ever have to delay or cancel an appointment in Halifax for any reason? If yes, please explain.

427 (46%) individuals responded to this question. Two-thirds (68%) stated delays or cancellations due to **weather and driving conditions.** Many described cancelling their trip because of acute weather events, but others discussed rescheduling treatment regimens in anticipation of poor weather and driving conditions during the winter months. The latter was noted by one participant, who remarked:

> *"Appointment scheduled during winter [was] rescheduled to spring to avoid possible need for unexpected short notice cancellation due to inclement weather making long distance travel not possible."* [Family member]

The next most common reasons for delays or cancellations (cited by 15-18% of individuals responding) was **needing help with transportation** (e.g., difficulty finding a driver, no access to vehicle/reliable vehicle), **travel time** (most notably inability to travel when ill), and **out-of-pocket costs**.

Q8. Would you think about not having radiation treatment if you had to travel? Q9: If yes, why? Other reasons (please explain).

130 (14%) individuals responded to this question. The three most common reasons for considering not having radiation treatment, even if indicated, were: **travel time** (most notably travelling when ill), the **emotional toll of being away from home**, and the **emotional toll of travelling to/being in Halifax.** 30%, 35%, and 22% of individuals who responded to this question noted these reasons, respectively. The emotional toll is reflected in the following comments:

> *"My supports would not be able to stay with me during treatment or visit outside of their work schedule. Facing possible death away from home and loved ones is for soldiers, not everyday people."* [Other/Community member]

> *"I know of several people who have chosen to have their breasts removed rather than go through the emotional trauma of travelling to the city for treatments. This is unacceptable!"* [Family member]

Q10. When is it reasonable for patients to travel to another area of the province for cancer treatment? Please explain.

697 (75%) individuals responded to this question with an explanation (or textual response). 203 (29%) of these individuals qualitatively responded that it was **never** reasonable to travel to another area of the province for cancer treatment. 171 (25%) responded that it is reasonable to travel to **access specialized expertise and services**, or for rare cancers that require certain expertise. For example, they considered travel to other areas of the province reasonable for exceptional or very specialized treatments (including subspecialist surgeons), for second or third line therapies, in circumstances when the patient is in need of additional medical attention, or to participate in clinical trials. One participant highlighted several of these concepts when stating:

> *"For specialized care related to cancer … Some diagnoses and types of treatment are best done in highly specialized settings (e.g., academic hospital such as QEII HSC) or even out of province to cities like Montreal or Toronto."* [Health care professional]

In response to this question, individuals also relayed and reiterated their concerns related to travel to other areas of the province for cancer treatment. The most common concerns mirror those discussed in previous questions and related to: the **emotional**

toll of being away from home, **out-of-pocket costs**, the **emotional toll of travelling to/being in Halifax**, and **travel time** (most notably travelling when ill).

Q11. Besides radiation therapy, what other things could we do to improve access to cancer services in your area?

526 (57%) individuals responded to this question. From those individuals, the two most commonly noted things that could be improved to benefit cancer patients and their families in the Yarmouth area were **greater access to specialists** (27%) and **greater access to relevant medical services** (23%). Individuals desire greater access to sub-specialist surgeons, oncologists, hematologists, plastic surgeons, and general practitioners in oncology (GPOs). They believe that greater access to these specialists locally will reduce travel to Halifax but also lead to quicker diagnoses and shorter wait times.

With respect to medical services, individuals desire greater access to and support for diagnostic imaging, oncology and hematology clinics, chemotherapy administration, post-chemotherapy monitoring, home care, and palliative care and hospice. They recognized more human resources (e.g., nurses) and infrastructure (e.g., equipment, beds) are required to support such services. The desire for better chemotherapy-related services was highlighted by one participant who said:

> *“Upgrade the cancer support staff in Yarmouth so post chemo patients could be monitored closer to home [versus] sit in Halifax for weeks for a 1 hour appointment daily.”* [Patient/survivor]

The next two commonly noted things that individuals felt could be improved locally were **financial and logistical supports** and **psychosocial and informational supports.** Financial and logistical supports referred to supports that would enable more affordable lodging, transportation to/from appointments (in Halifax, to/from Halifax, and within Western Zone), meals, parking, and dependent support.

> *“Investment in transportation for communities who have to travel for specialist treatment, this would benefit other patients, not just cancer e.g. cardiac, neuro and support accommodation for patient and caregiver.”* [Health care professional]

Psychosocial and informational supports referred to improving access to cancer patient navigators/counselors, support groups, peer supports, and education sessions (both for patients as well as for family members to help them better support patients and themselves). Individuals referenced resources and supports elsewhere they would like to see available in Yarmouth, such as the Sunshine Room at the QEII Health Sciences Centre in Halifax and the Macmillan Cancer Supports in the UK.

> *"Councillors [sic] at the centre who could talk with patients, advise them, explain things and all an all be THERE for patients…a shoulder to cry on!"* [Family member]

Individuals also cited improved access to medications (especially oral therapies), recruitment and retention of primary care providers, and greater use of telehealth/ Internet for appointments as things that would improve cancer services/care in the Yarmouth area.

Q12. Is there anything else you would like to tell us about cancer treatment and services in your area?

391 (42%) individuals responded to this question. Most reiterated their prior comments, describing concerns around the **emotional toll of travelling to/being in Halifax**, the **emotional toll of being away from home**, **out-of-pocket costs**, and **travel time**. 55 (14%) individuals who responded to this question provided positive remarks around the quality of their cancer care in Yarmouth, including being grateful for chemotherapy services/satellite clinics and the helpfulness and compassion of staff. The following quotations highlight these perceptions:

> *"The services I received in Yarmouth were excellent- drug teaching, pharmacy consult, Pt. navigator was top notch (my best "go to" resource to help with everything) Lab work was easy, and results provided by oncology nurse, even though my chemo was in Hfx."* [Patient/survivor]

> *"We have a good oncology unit with very good nurses. They are there for you when you have questions. If they don't know the answer they will find it. Also the pharmacy/pharmacist are super knowledgeable about what drugs you are taking. Can't say enough about that unit."* [Patient/survivor]

33 (8%) individuals remarked on **equity and fairness** as it relates to the delivery of cancer services in Yarmouth, the disparities created by virtue of their geography, and feelings of marginalization as a result of these disparities.

Overarching Synthesis

When considering the data as a whole, four issues came to the forefront as being particular challenges for patients:

- Travel time, particularly issues with travelling long distances in poor weather and when someone is ill due to their cancer or its treatment
- Emotional toll of being away from home
- Emotional toll of travel to/being in Halifax
- Out-of-pocket costs

Individuals continually noted these issues as especially burdensome given most people are living with considerable anxiety and fear because of their (or their loved one's) diagnosis. Many described the emotional toll that comes with being in unfamiliar surroundings (i.e., Halifax), far from family, friends, and support networks, while undergoing treatments that are often exhausting and fraught with side effects (e.g., nausea, pain). These situations were portrayed as overwhelming and demoralizing. Many patients also discussed the added burden of worrying about loved ones and work/other responsibilities at home while trying to focus on maintaining function (and healing) in Halifax. As noted in Question 6 above, the two most prevalent issues that individuals felt ***NSHA must consider*** when making a decision about providing radiation therapy services in Yarmouth were the emotional toll of being away from home and the emotional toll of travel to/being in Halifax.

> *"An elderly family friend actually had to decline treatment in HFX because he just would not know how to manage alone in such a foreign place and no one could go and stay for the weeks needed."* [Family member]
>
> *"The loneliness of being away from family and friends at a time when you need them the most, fear of spending your limited time left ALONE and Scared."* [Family member]

Individuals commonly described challenges related to finding ways to travel to Halifax for their appointments and treatments. The inability to find transportation sometimes resulted in cancelled appointments. Issues such as not having access to a reliable vehicle or not being able to find an available driver were frequently mentioned. Individuals noted the need for a driver to help a patient travel to Halifax often exacerbates out-of-pocket costs with regard to food and lodging.

Several additional findings related to the qualitative data are notable. One is that issues related to coordination of care (e.g., challenges coordinating care and appointments between hospital sites) and equity/fairness (e.g., equal access for equal need) were mentioned but not prevalent across the dataset. Although such issues may be pertinent to the issue of travelling for cancer treatment, they were stated infrequently. This may reflect phrasing of the survey questions themselves or simply that individuals' most pressing concerns relate to the four issues identified above.

Another finding is that, for questions 10, 11, and 12, some individuals spoke positively about their experiences during the cancer journey and about cancer services in Yarmouth. This was described by one patient who stated:

> *"I was so impressed with the care I received … The medical oncologist travelled to Yarmouth for consultations and the radiation oncologist was available by telehealth, which cut down on some trips to the city. All of the staff I encountered were great."* [Patient/survivor]

However, these positive remarks sometimes came with the caveat that hospital staff need more support to offer more and/or improved cancer-related services. Several individuals noted the hospital in Yarmouth is a great facility that could handle additional services and potentially attract skilled expertise.

Codes for Questions 4, 6, 7, 8/9

Travel time: Travel time includes references by individuals that the length of time and distance of travel to Halifax is too long, difficult, uncomfortable, challenging, unreasonable, or unacceptable for both patients and their caregivers/drivers. This code also includes references to patients refusing to undergo treatment because of the need to travel long distances.

Travelling while sick/old[1]: Travelling while sick/old includes references to the difficulties of travelling with or as someone who is sick from cancer, sick from cancer treatments, or very old. This includes issues around the patient (or sometimes driver) not being strong enough to make the trip, needing to stop often, driving under the influence of chemo/radiation drugs, and being too sick, tired, nauseous, or in pain. This code also includes references to patients refusing treatment because of the discomfort of travelling while so sick or old.

Needing help with transportation: This code refers to the challenges around finding transportation to get to Halifax for cancer treatment. Often patients are too ill to drive

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[1] For the purposes of the report, travel time and travelling while sick/old were grouped together under simply travel time.

themselves. This code includes references to the challenges of finding a driver who is healthy, has time, and has access to a reliable vehicle. This code also includes references to being unable to find a driver and therefore driving alone while sick or not going at all. Also included are references to taking a bus, shuttle or ferry, or the lack of availability of these options.

Weather and driving conditions: This code refers to the poor weather and road conditions that make the drive to Halifax difficult, dangerous, and stressful. It includes references to snowstorms, hurricanes, icy or snowy roads, postponed or missed appointments due to weather, having to plan trips around weather conditions, and car accidents for patients while travelling to/from appointments in Halifax.

Emotional toll of travel to/being in Halifax: This code refers to the emotional toll of travelling to Halifax on patients, as well as the patients' caregivers, drivers, and family members who wish to visit the patient in Halifax. This includes the physical and mental exhaustion, anxiety, and stress of a long drive and the prospect of an upcoming long drive, the stress of the additional travel costs, the discomfort and stress of driving in an unfamiliar city with traffic and difficult parking, and patients' worrying about being a burden on the family and friends who drive them. The distress caused by long drives and city driving may prevent family and friends from visiting patients. This code also refers to the stress and discomfort of finding accommodation in Halifax, living out of a suitcase, and staying in an unfamiliar place. This code also includes references to the stress caused by the disruption of people lives and the fact that stress caused by travelling to and staying in Halifax is harmful to healing.

Emotional toll of being away from home: This code refers to the emotional toll of being far from family, friends, community, and the associated supports. This includes references to the need for family and friends to provide support and improve a patient's mental outlook, the challenges for friends and family to visit when they don't have time or money to travel so far or to stay in Halifax, the discomfort and anxiety of being sick, alone, and socially isolated, the emotional toll of separating a family (including the toll on the family and friends left behind), and the need for someone to travel with the patient for support and friendship. This code also refers to the emotional toll of being away from the comfort and familiarity of one's own home. This includes references to homesickness, being away from home during a stressful and scary time, the negative effects of missing work and worrying about home while away, missing pets, and not being in one's own space and able to sleep in one's own bed. This codes also includes references to how being close to family support and the comfort of home can improve a patients mental and emotional wellbeing and help with healing.

Physical/practical difficulties of being away from home: This code refers to situations where patients need someone to accompany them to Halifax to help them with physical and practical difficulties such as driving between accommodations and the cancer centre, walking between the car and cancer centre, speaking or translating for the patient, driving in the city, and navigating the health care system. This also includes references to mobility issues and the need for someone to take care of the patient when staying overnight or for long periods of time because the patient is too sick or elderly. This code also refers to the challenges of being far from the support of family and friends to share the burden of caregiving, given that it is usually just one main caregiver who accompanies the patient to Halifax.

Missed work: Missed work refers to either the patient or his/her family member, support person, or driver being required to take time off work to go to Halifax (for treatment or to accompany the patient). Included in this code is the resulting lost productivity, financial hardship, difficulties surrounding taking off work, or inability of individuals to take off work because of the risk of losing their employment or EI benefits. Instances included patients having to drive self to Halifax or hire a driver or take a shuttle because no family member/support person could afford to miss work to drive them.

Out-of pocket costs: Out-of-pocket costs refers to the financial burden of travel to Halifax on both the patient and family/caregivers. These costs include: gas, mileage, wear and tear on vehicles, car rentals, the cost of hiring a driver, food, parking, and long distance phone calls. These costs also include lodging for the patient and his/her support person/driver. References were made to the difficulties of finding accommodations, affordable accommodations, and accommodations specifically for the support person/driver because accommodations available to cancer patients do not allow support person/drivers. References were also made to patients and families being low income, not having enough money, and not having income because the patient was too sick to work. Participants noted instances where patients chose not to get radiation treatment because they could not afford the out-of-pocket costs. Participants noted in response to question #10 that it is reasonable to travel for treatment in situations where the person can afford it or financial support is made available to cover the expense of travel, accommodations, and meals.

Coordination of care: Coordination of care includes references to mixed up appointment times, the slow movement of test results across settings, and overall poor communication that sometimes results in: patients and caregivers/drivers travelling long distances unnecessarily; last minute appointment cancellations when the patient and caregiver/driver have already been driving for several hours or waiting in the waiting room for several hours; the added stress of worrying about cancelled appointments; and early morning or late afternoon appointments that require patients and caregivers/drivers to spend the night before or after the appointment in Halifax. This code also includes the frustration of being offered a last minute appointment that patients cannot take advantage of because they would not be able to make it to the hospital in time for the appointment due to the long drive. Also includes references to the frustration and added stress of long travel times for very short appointments, the challenges of daily radiation treatment for multiple weeks that require patients to live in Halifax for the duration, delayed treatments, lack of referrals by physicians to existing patient supports, and poor/slow communication with patient regarding questions and test results.

Responsibilities at home: Responsibilities at home refers to challenges around leaving loved ones and dependents at home. This includes children, family (including those ill or with a disability), aging parents or partners, pets, and the household in general.

The challenges associated with leaving responsibilities at home include finding child care, the cost of paying someone to care for dependents, the stress on children to not have their parent(s) with them, worrying about dependents while away for treatment, not being able to support one's partner, and not being able to find someone to care for dependents.

Expertise: This code refers to the concerns expressed by participants around the need for appropriate expertise in Yarmouth if radiation therapy is brought in. This code includes references to needing properly trained staff to use and fix the machines.

Saving money: This code includes references to how the government could save money by bringing radiation treatment to Yarmouth. Participants referred to no longer having to grant tax claims for people's trips back and forth to Halifax, no longer having to provide patients with housing in Halifax, and faster recovery time of patients costing less to the health system. This also includes references to how patients would be able to maintain their employment during treatment if they did not have to travel for treatment.

Waiting: This code refers to concerns about wait times and waiting. This includes references to the long wait times for services such as radiation therapy, cancer care services in general, and outpatient care. It also includes comments about how bringing radiation treatment to Yarmouth would decrease wait times, references to waiting long periods of time before an appointment, and the long wait time between diagnosis and a patient's first treatment.

Equity and fairness: This code includes references to the unequal treatment between people in the Southwest part of Nova Scotia as compared to people in Halifax and/or Cape Breton, as well as references to the idea that everyone pays the same taxes, has the same vote, and therefore deserves the same access to services. It also includes references to inequities, disparities, the unfairness of having to travel so far, and the idea that everyone should have equal access to services, regardless of geographic location or urban versus rural lifestyles. This codes also includes references to how other provinces provide better access to services than Nova Scotia.

Additional codes for Question 10

Never: This code refers to participants' responses to question #10 that state that it is never reasonable for patients to travel to another area of the province for cancer treatment. It includes statements such as: there isn't, not sure there is, I wish you never had to travel, it is not reasonable, shouldn't have to, it should be available closer, and no one should have to.

Always: This code includes participants' responses to question #10 that state that it is always reasonable for patients to travel to another area of the province for cancer treatment. This code includes comments stating the distance that patients need to travel are small in comparison to other provinces, that it is not realistic to build a radiation treatment centre in Yarmouth, that money should be put elsewhere in health care, and that travelling for treatment is a tradeoff between quality of life and access to service.

Within a reasonable distance: This code includes responses to question #10 that it is reasonable for patients to travel to another area of the province for cancer treatment if the distance needed to travel is reasonable. A reasonable distance was considered to be within 50 to 100 kilometers, within half an hour drive, within an hour drive, and within a two-hour radius. This code also included statements such as it is reasonable as long as there is no financial burden and/or it doesn't cause undue stress, and the service should be close enough where a day trip can get you there, treated and home in a reasonable amount of time.

For limited amounts of appointments: This code includes responses to question #10 that it is reasonable for patients to travel to another area of the province for cancer treatment if it is for a limited amount of appointments. This includes references that it would be acceptable if it were less than 4 times per year, from time to time, a one-time thing, a few times a year, one to two days, or for just one week.

To access specialized expertise and services: This code includes responses to question #10 that it is reasonable for patients to travel to another area of the province for cancer treatment if the patient is seeking access to specialized expertise or services. This includes rare types of treatments, specialized and/or very expensive treatments, experimental treatments, emergency situations, subspecialist surgery, seeking a second opinion, treatments requiring new technology, and cancer care for children.

When there is no other option: This code includes responses to question #10 that it is reasonable for patients to travel to another area of the province for cancer treatment when there is no other option, treatments or qualified professionals are not available in the patient's area, or the care cannot be provided safely close to home.

Isolated and rural locations: This code includes responses to question #10 that it is reasonable for patients to travel to another area of the province for cancer treatment when the patient lives in an isolated and rural location, there isn't a hospital nearby, or there aren't enough people with cancer in the area to justify having the treatment available there. In general, this was assumed to not be describing Yarmouth.

For better quality of care: This code includes responses to question #10 that it is reasonable for patients to travel to another area of the province for cancer treatment when they can receive better quality care in another area.

To avoid wait times and overcrowding: This code includes responses to question #10 that it is reasonable for patients to travel to another area of the province for cancer treatment in order to avoid long wait times and overcrowding.

Additional codes for Question 11

Greater access to specialists: This code refers to participants' statements that greater access to specialists would improve access to cancer services in their areas. Participants referred to the need for oncologists, cancer specialists, specialized surgeons, hematologists, plastic surgeons, and GPOs. Participants suggested hiring specialists, attracting more specialists to the area, decreasing the wait time to see specialists, increasing support for oncology clinics, having specialists travel to the area regularly, and introducing travelling clinics. This code also includes references to increased access to diagnostics and decreased wait times for diagnosis, surgery, and post-diagnosis consult appointments.

Greater access to relevant medical services: This code refers to participants' statements that greater access to (and shorter wait times for) relevant medical services would improve access to cancer services in their areas. Relevant medical services included chemotherapy treatments (all types), more nurses and qualified personnel, more hospital beds and equipment, more space in the oncology unit, stem cell therapy, immunotherapy, testing, MRIs, CT scans, PET tests, dialysis, post-chemo monitoring, cancer treatments, services for children with cancer, diagnostic testing, biopsies, hematology clinics, palliative care and hospice, and home care. This code also includes references to there not being enough staff or support for staff at hospitals in the area, staff being stretched beyond their capacity, the need to open Digby hospital, and the lack of services in the area.

Greater access to doctors (unspecified): This code refers to participants' statements that greater access to doctors would improve access to cancer services in their areas but did not specify what kind of doctors.

Greater access to primary care: This code refers to participants' statements that greater access to primary care would improve access to cancer services in their areas. This includes references to the lack of primary care providers (PCPs) available in the area, the need to attract PCPs to the area, the fact that many people in the area do not have a PCP, and that people are reliant on emergency departments for their primary care. This code also includes references to the low quality of care received from some PCPs, the idea that cancer patients should be prioritized in terms of getting a PCP sooner than others, and the suggestion that PCPs should be more involved in their patients' cancer care and educated so that they are able to do so. In addition, this code includes statements about the need for better, earlier, and more frequent cancer screening/testing as well as the need to educate people on the importance of cancer screening/testing, the importance of a healthy active lifestyle, and disease prevention.

Greater access to psychosocial and informational supports: This code refers to participants' statements that greater access to psychosocial and informational supports would improve access to cancer services in their areas. Psychosocial and informational supports include navigators, advisors, counsellors, social workers, support groups, education sessions, outreach programs, education/information for patients, families, and caregivers (regarding for example: what to expect going forward with cancer treatments, coping mechanisms, medication guidelines), Cancer Chat Canada chapter in east coast, mental health supports, the provision of a sunshine room or serenity room (similar to the ones in Halifax and Truro), a buddy check in program, family knowledge centre, prevention awareness programs, help with housecleaning and getting groceries, and places to find appropriate clothing, prosthetics, wigs, etc.

Greater access to alternative health options: This code refers to participants' statements that greater access to alternative health options would improve access to cancer services in their areas. Participants referred to alternative health options in general, as well as options such as homeopathic doctors, overall wellness approaches, yoga, meditation, acupuncture, nutrition therapy, foot massage therapy, reiki, massage therapy, reflexology, music therapy and healing touch.

Greater access to radiation treatment locally: This code refers to participants' reiteration of the importance of having radiation treatment locally.

Greater access to follow-up/survivorship care: This code refers to participants' statements that greater access to follow-up/survivorship care would improve cancer services in their areas. This includes references to insufficient follow-up care in the area and the need for follow-up exams and visits, a wellness centre for cancer survivors, and counselling following treatment.

Medications: This code refers to participants' concerns regarding cancer care medications. This includes concerns around the cost of cancer drugs, the idea that all cancer medication (e.g. oral chemo) should be provided free of charge or covered by insurance, and the provision and coverage of medical cannabis.

Financial and logistical supports: This code refers to participants' statements that financial and logistical supports would improve access to cancer services in their areas. These supports include financial support (for transportation, accommodation, meals, and child care), the provision of free or affordable lodging in Halifax and Yarmouth for patients and patients' families, and the provision of free or affordable shuttles or rides (both locally and to Halifax).

Use telehealth/internet for appointments: This code refers to participants' statements that the use of telehealth, the internet, skype, facetime, video conferencing, and/or email in place of driving many hours for short in-person appointments would improve access to cancer services in their areas.

Cancer centre: This code refers to participants' statements that a cancer centre in Yarmouth would improve access to cancer services in their areas.

Codes to capture references to topics not specific to the survey questions

Lots of people with cancer in the area: This code includes participants' references to the perceived high rates of cancer in the tri-county/Yarmouth area as well as in Nova Scotia more generally. These statements were used to justify that Yarmouth should be provided with radiation treatment/cancer services. This code also includes references to how a radiation treatment facility in Yarmouth would serve not only Yarmouth, but the surrounding area and the tri-county area.

Already have a great hospital in Yarmouth: This code includes references to how Yarmouth already has a great hospital with great staff that is capable of incorporating radiation treatment into its offered services.

Positive Comments: This code refers to positive comments made by participants about their experiences or the experiences of others with regard to cancer treatment and care in Nova Scotia.

Positive comments about Halifax hospitals and staff: This code refers to positive comments made by participants about their experiences or the experiences of others with regard to cancer treatment and care, specifically in Halifax.

Positive comments about local hospital and staff: This code refers to positive comments made by participants about their experiences or the experiences of others with regard to cancer treatment and care, specifically in Yarmouth or in other local hospitals.

There is no treatment or limited treatment in the area: This code includes responses to question #12 noting the lack of cancer services or treatments in their areas.

Concerns about bringing radiation therapy to Yarmouth: This code includes comments made by participants about their concerns that bringing radiation therapy to Yarmouth is not a good idea. Concerns include statements that it would not be sustainable due to lack of expertise and specialty doctors, that it would be an unfair financial boost to the area that would benefit relatively few patients, and that the money would be put to better use elsewhere in the health care system.

The health care system should be managed better: This code refers to statements by participants that the health care system in general should be managed better. This includes comments about how the formulation of the NSHA was a mistake resulting in a lack of local accountability, how the government should fix the health care system, how the health care system is not well run or broken, and how the government should better support patients and use resources more effectively.

Report submitted by Leslie Hill, Coordinator; Engagement, Diversity and Vulnerable Populations, NSCCP

June 10, 2018 (edits July 6, 2018)

Appendix H. Public Service Announcement, March 16, 2018

nova scotia
health authority
Nova Scotia Cancer Care Program

NSHA asks Yarmouth area patients, families and community members for their feedback on cancer treatments and services

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Yarmouth, NS--Hearing from patients, their families and community members is an important part of the Yarmouth Area Cancer Services Review.

Nova Scotians who want to share their thoughts about cancer treatments and services available in Yarmouth and the surrounding area are invited to complete a survey. The survey is available both online and on paper. The link to the online version is (need to add in direct link).
Paper copies are available at:

- Yarmouth Regional Hospital (Cancer Patient Navigator's office)
- Yarmouth Hospital Foundation office (main floor, Yarmouth Regional Hospital)
- Yarmouth Town Hall
- Municipality of Yarmouth
- Roseway Hospital (reception desk)
- Digby General Hospital (reception desk)
- Collaborative Care Clinic – Digby
- Primary Care / Collaborative Care Clinic - Meteghan
- First Nations Health Centres (Leslie to specify)

The deadline for completing the survey is April 6, 2018. Anyone who has questions can call 1-866-599-2267.

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About Nova Scotia Health Authority:

Nova Scotia Health Authority (NSHA) provides health services to Nova Scotians and a wide array of specialized services to Maritimers and Atlantic Canadians. NSHA operates hospitals, health centres, and community-based programs across the province. Our team of health professionals includes: employees, doctors, researchers, learners and volunteers. We work in partnership with community groups, schools, governments, foundations, and auxiliaries and community health boards. Visit www.nshealth.ca for more information.

Appendix I. Focus Group Report

Summary Report: Focus Group Consultations

Project: Improving access to quality cancer services- Yarmouth and area

Background

Nova Scotia Cancer Care Program (NSCCP), a program of NSHA, is committed to providing as much cancer treatment and care as close to a patient's home as is safely and sustainably possible. Nova Scotia cancer patients and families have indicated that having care closer to where they live is important. In Yarmouth and area, the possibility of having access to Radiation Therapy treatment at Yarmouth Regional Hospital has been a longstanding topic of discussion. Increasing interest re-emerged in 2016 /2017. In Fall 2017, NSHA's NSCCP agreed to review access to cancer services available in Yarmouth and area. The purpose of the review is two-fold: to determine the feasibility and sustainability of adding radiation therapy services at Yarmouth Regional Hospital and, to determine what supports would help to improve access to quality cancer treatment and services in the province. In addition to analyzing cancer statistics and projection data, associated financial and human resource needs, the review engaged with patients, their families and local community. NSCCP recognized the needs and interests of all stakeholders, including those of patients and families, to promote sustainable decision making.

Summary

Tuesday, February 20, 2018, NSCCP staff held two focus groups to engage with patients and families from Yarmouth and area. Public Advisors on the Steering Review Committee attended as community support for the meetings, but we not involved as participants. The objective was to understand their experience travelling for cancer services and to ask what supports would improve access to these services.

All participants had an opportunity to share their personal experiences as a patient or as a support person to someone who had to travel for cancer services. Twelve participants attended a session from 3:30pm-5:00pm and eleven participants attended a second session from 6:30- 8:00pm. One registered participant had to cancel but feedback via a phone call.

> "Cancer patients should be well taken care of, we are sick, we should be able to have treatments locally"
>
> -Focus Group Participant

During the session, participants agreed that patients who receive treatment at the cancer clinic in Yarmouth and have the support of the Cancer Patient Navigator have excellent local care. *"Darolyn is better than the best"* As not all services, clinics or oncology appointments are available in Yarmouth, patients need to go to Halifax for radiation as well as other cancer-related appointments. Due to the complexity of cancer care, patients understand that some appointments, surgeries, and treatments in Halifax are unavoidable. Even so, participants discussed the importance of **having as many cancer services as possible** in Yarmouth as well as providing better supports when people do have to travel to Halifax for cancer services.

Participants explained that the **burden of traveling for cancer services is more than the long drive and winter weather, but also how travelling increases pressures on finances, family, children, work, lifestyle, health, and emotional wellbeing**. This is worsened when travel involves having to stay in Halifax for long periods of time.

> "If you live in Halifax, you can have your radiation, and maybe go back to work that day…or home to your own bed. We don't have the ability to make those choices."

Participants discussed that NSHA needs to shift its approach to ensure services are equitable for rural patients, not just equal. Patients and families recognized the cost and the challenges of recruiting and retaining staff to offer radiation therapy in Yarmouth, but they feel it is time to seriously consider this service for patients of the Western Zone. *"Don't look to balance the books on the back of patients."* There was agreement that patients in areas surrounding Yarmouth want radiation services within the Yarmouth Regional Hospital to improve the experience of cancer care. Participants understood the need for appropriate staffing and equipment to make radiation treatments safe but they also said that **safety needs to be patient centred**, too*. "I postponed radiation for three months so I wouldn't have to travel in the winter months"—"How many people decide not to have radiation because of the driving?"*

Participants were asked to consider, hypothesizing that radiation services were approved for Yarmouth, if it would be stressful to wait for treatment if there were a delay due to staffing or equipment issues? There was agreement that at least they could easily go home, or know they could sleep in their own bed that night.

Patient rationale for adding radiation services to Yarmouth Regional Hospital:

Four main themes were addressed by participants in both Focus Groups.

1. Health providers assume there is family support and that is not always the case for rural patients.
    - Support persons or family members have to take time off work to help support patients to get to Halifax.
    - There is the added stress on family members to be available to help.
    - **Sometimes patients have no family support** and must try and drive by themselves or make arrangements by shuttle or with a sympathetic friend, or not take the treatment suggested.
2. It is **a long and sometimes dangerous drive** (winter) when a patient is sick.
    - Some patients need to drive themselves to Halifax even when they felt too sick to do so.
3. **The additional financial stress** on family, friends and patients.

   - Even if you have the ability to take time away from work (short term disability), the financial costs of meals, accommodation, gas and parking can be significant.
      - one participant shared these financial details for travel to Halifax for a month of radiation and 6 rounds of chemo: “Fuel 1389.57, Parking 93.35, Food 1509.24, Lodging 2989.45 (patient free, but support person charged), KM of travel 9390 (I will add that due to the many trips to Halifax (15) we had to upgrade our vehicle)”
   - The patient and the support person needs time off work, which can increase financial pressures depending on the employer, benefits etc.
   - There are some local funds to access, but additional access to funds are needed to help with travel expenses.

4. The **coordination of care and appointments for rural patients** should be improved when they travel to Halifax.

   “Driving 6 hours for a three minute appointment is unacceptable”

   - Patients are supportive of using e-mail, phone appointments, and tele-oncology when appropriate.
   - Patients need more notice of appointments and what is coming up in the treatment plan. Some patients had only 2-3 days’ notice when they had to be in Halifax for markings, consults, etc.

     Patients need to advance plan baby sitters, time off work, finding a drive to the city, care for pets and home.
   - There was agreement, that once you are having radiation, the clinic does try to book appointments with geography and patients’ needs in mind. There needs to be more flexibility in the booking system when patients and families need to drive greater distances and may be away overnight.

People understood that even if a radiation unit were approved as part of the full review recommendation; building a radiation unit would take time and they need to be better supported now. Focus group participants reflected on possible changes which could be accomplished in the cancer system now to reduce the pressures on patients and families in the short term. One patient did comment, *“If improved services (radiation) were here already we wouldn’t have to make all these other improvements”*

> I have to say that my comments are not intended to take away from the excellent services that are being provided but only to point out the shortfalls and hardships that are being encountered by rural patients.
>
> -Focus Group Participant

Enhancing Cancer Services Now

Eight main suggestions from participants with regard to enhancing services were provided through the focus group discussions:

1. Improve **access and availability of**

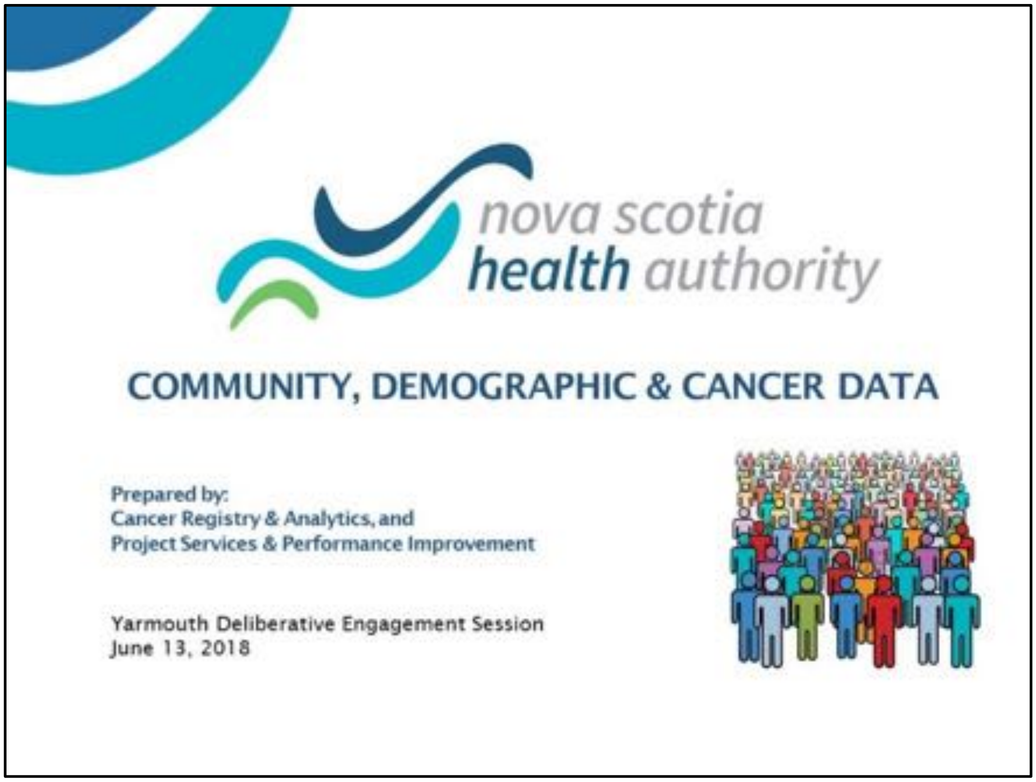
accommodations in Halifax for cancer patients that is more patient centred and affordable.
  - The Lodge cannot support some of the sensitive dietary needs of all cancer patients (head and neck cancers, oesophageal cancer, and food allergies).
  - Allow a support person to stay with the patient for free if wanted. The cost to a support person can be prohibitive. Having a support person is very important to patients. If the patient cannot care for their personal needs on their own there needs to be a support person or a nurse to help. *"These facilities, i.e. The Lodge and Point Pleasant, you have to be self-supporting and we saw many that struggled with personal care while on their own away from their home support givers."*
  - Have some accommodations which are supportive of family first policies, children, pet visits –a family friendly accommodation.
  - Sharing a room with someone who you don't know when you are sick can be stressful, some people meet lifelong friends, but others would prefer to be alone.
  - Though Point Pleasant Lodge is open on the weekends, there was overall agreement that this is not an ideal facility (expensive food, no free parking) and not cancer patient centred.
  - On weekends, if patients stay in Halifax (weather related, health related) accommodations in Halifax are expensive. Some participants shared information about alternative places to stay which others had never heard of previously.
  - Possible Solution: Perhaps NSHA can collaborate with Private and NGO organizations in order to help improve services for cancer patients.
- Improvements **to bus/shuttle services between Yarmouth and Halifax** Cancer Centre
  - Limit the stops to small towns to pick people up (the current private shuttle takes over 5 hours).
  - Access to washroom facilities (patients can be ill and need to stop).
  - Perhaps a shuttle just for cancer patients so they do not feel self-conscious if they need to stop, feel ill.
- Improved **access to the cancer centre from the Sobeys Cancer Support Centre Lodge**. Though the buildings are physically close, the walk from the Lodge to the Cancer Centre is not ideal and poses an accessibility issue.
  - Some patients have to take a taxi from the Lodge to the Halifax Cancer Centre as they cannot get up the hill (due to their health, or the poor conditions between the buildings).
  - Possible solution: a free shuttle running from the Lodge to the Cancer Centre.
- Improve **access to information of available services specific for rural patients** needing to travel to Halifax for care. Not everyone goes to the Yarmouth Cancer Clinic, or is referred to the patient navigator to receive important information to

help support their cancer care.
    - Patients need to be able to read and easily access the most relevant information for their situation. It is overwhelming to read all of the information which is given to them.
- Improved **access to psychosocial supports** is important to rural patients.
    - Cancer on its own is stressful and when patients add the personal, financial, and transportation difficulties associated with travel to Halifax, this increases anxiety for patients and family greatly.
    - There was a suggestion that a non-clinical cancer clinic should be added to the services in Yarmouth for patients and families.
- Improve **coordination of appointments**.
    - With the aim to reduce trips to Halifax. This could be achieved by increasing use of technology for appointments as appropriate i.e. e-mail, phone, and telehealth.
- Improve use of **language services technology** so treatment plans are given in the patients' desired language. This improves understanding of treatment plans and decreases risk of misunderstanding directions.
    - Increase use of translation services.
- Improve **access and availability in Yarmouth to other cancer supports** such as
    - Lymphedema clinic
    - Wellness clinic.

Report respectfully submitted by: Leslie Hill, March 8, 2018 (edit July 6, 2018)
Reviewed by and edits provided by participants of both Focus Group sessions. We gratefully acknowledge their time to attend the session and provide first person voice to this review process.

> "If you have never had to do it, you don't know the half of it. At a time when you need your family and friends most, you are all alone."
> -Focus Group Participant

Appendix J. DES Presentation - Community, Demographics and Cancer Data



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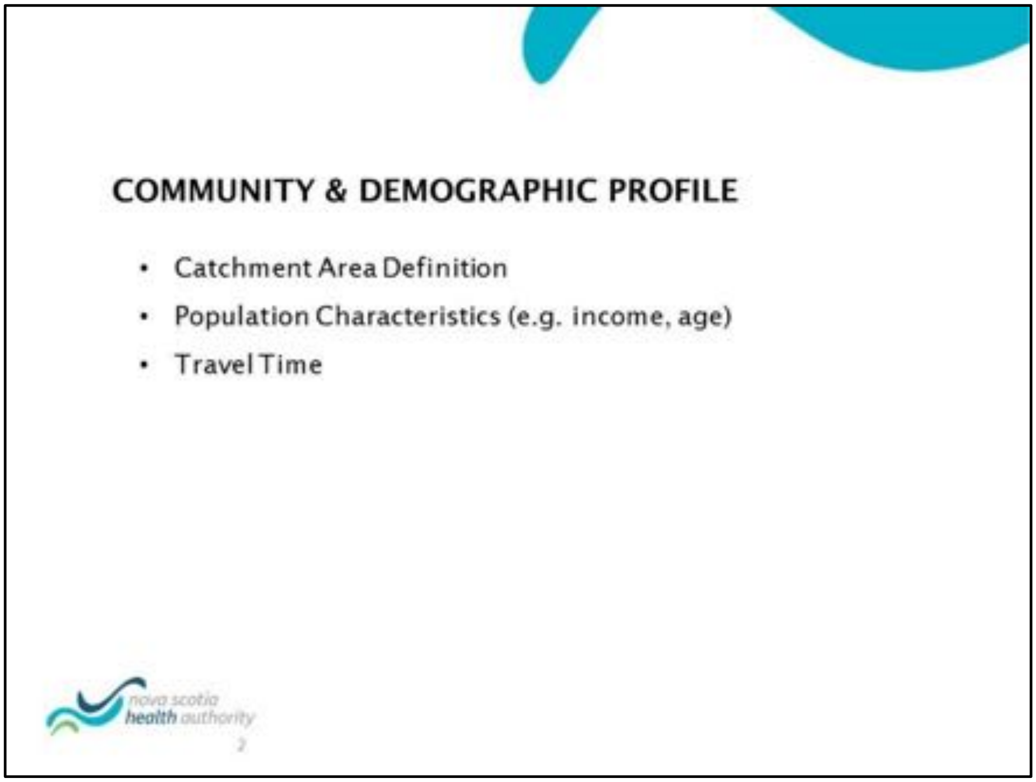
COMMUNITY, DEMOGRAPHIC & CANCER DATA

Prepared by:
Cancer Registry & Analytics, and
Project Services & Performance Improvement

Yarmouth Deliberative Engagement Session
June 13, 2018



COMMUNITY & DEMOGRAPHIC PROFILE

- Catchment Area Definition
- Population Characteristics (e.g. income, age)
- Travel Time

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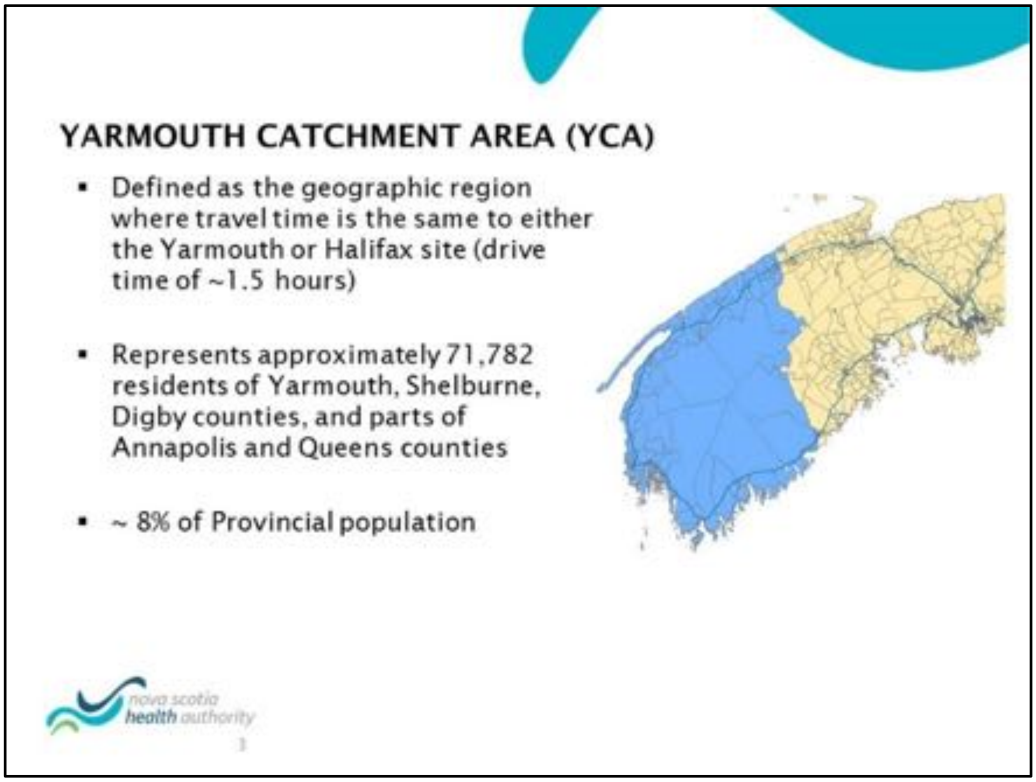
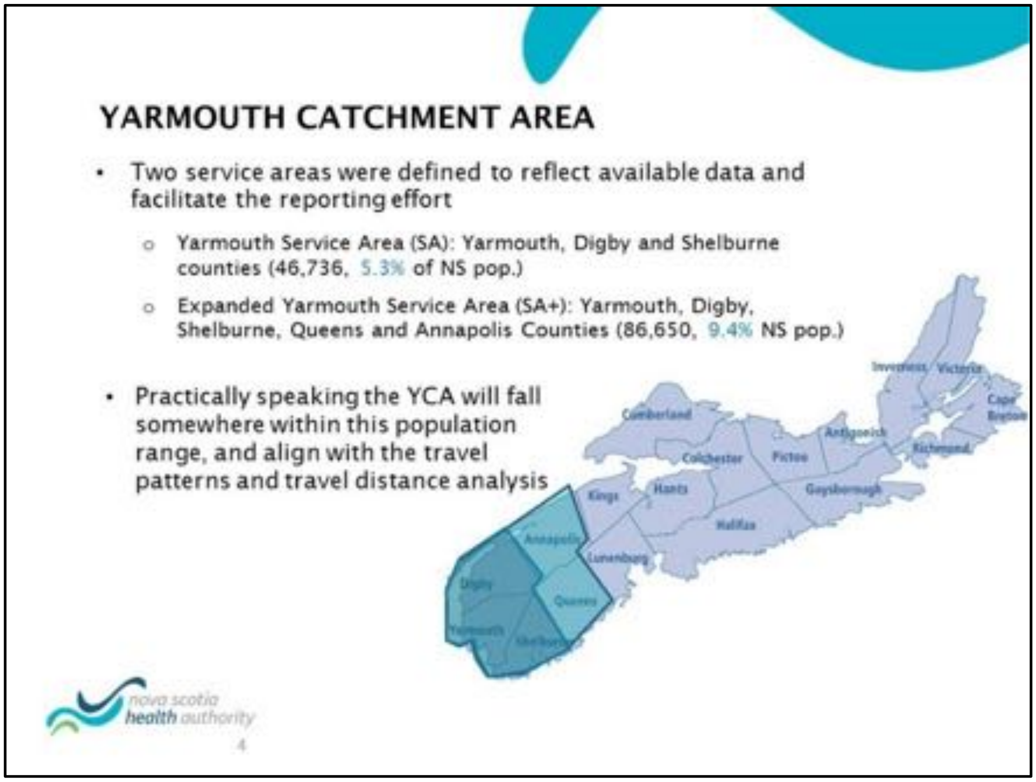


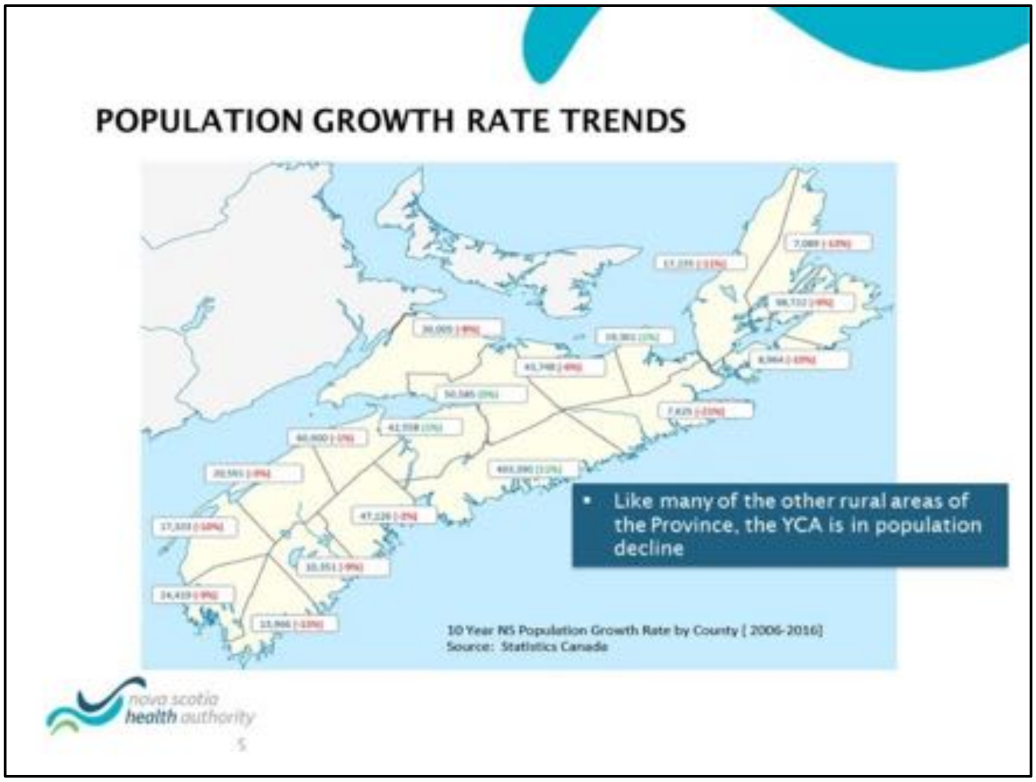
YARMOUTH CATCHMENT AREA (YCA)

- Defined as the geographic region where travel time is the same to either the Yarmouth or Halifax site (drive time of ~1.5 hours)
- Represents approximately 71,782 residents of Yarmouth, Shelburne, Digby counties, and parts of Annapolis and Queens counties
- ~ 8% of Provincial population



YARMOUTH CATCHMENT AREA

- Two service areas were defined to reflect available data and facilitate the reporting effort
  - Yarmouth Service Area (SA): Yarmouth, Digby and Shelburne counties (46,736, 5.3% of NS pop.)
  - Expanded Yarmouth Service Area (SA+): Yarmouth, Digby, Shelburne, Queens and Annapolis Counties (86,650, 9.4% NS pop.)
- Practically speaking the YCA will fall somewhere within this population range, and align with the travel patterns and travel distance analysis



POPULATION GROWTH RATE TRENDS

- Like many of the other rural areas of the Province, the YCA is in population decline

10 Year NS Population Growth Rate by County [2006-2016]
Source: Statistics Canada

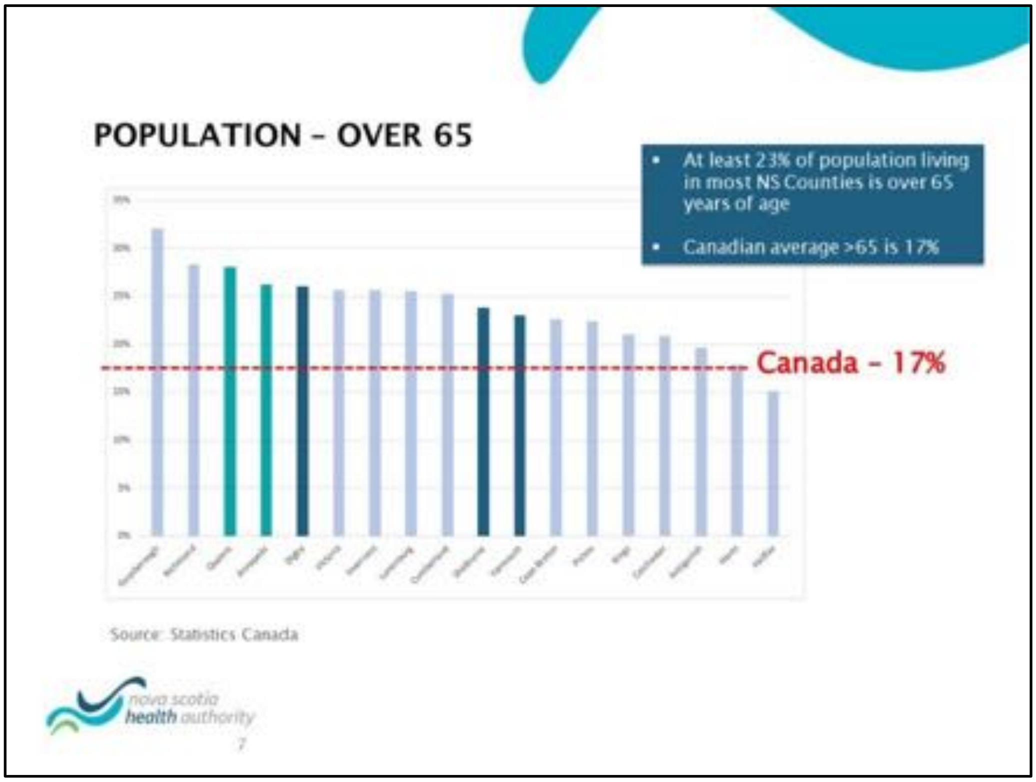
POPULATION GROWTH TREND 2006–2016

Nova Scotia Population Trends

County	5 year trend	10 year trend
Guysborough	-11%	-21%
Shelburne	-7%	-13%
Victoria	-7%	-13%
Inverness	-6%	-11%
Digby	-5%	-10%
Richmond	-5%	-10%
Cape Breton	-5%	-9%
Yarmouth	-5%	-9%
Queens	-5%	-8%
Cumberland	-5%	-8%
Pictou	-4%	-6%
Annapolis	0%	-3%
Lunenburg	-2%	-2%
Kings	-2%	-1%
Colchester	-2%	0%
Antigonish	-3%	1%
Hants	-1%	1%
Halifax	6%	11%
Nova Scotia	0.5%	1.2%

Source: Statistics Canada

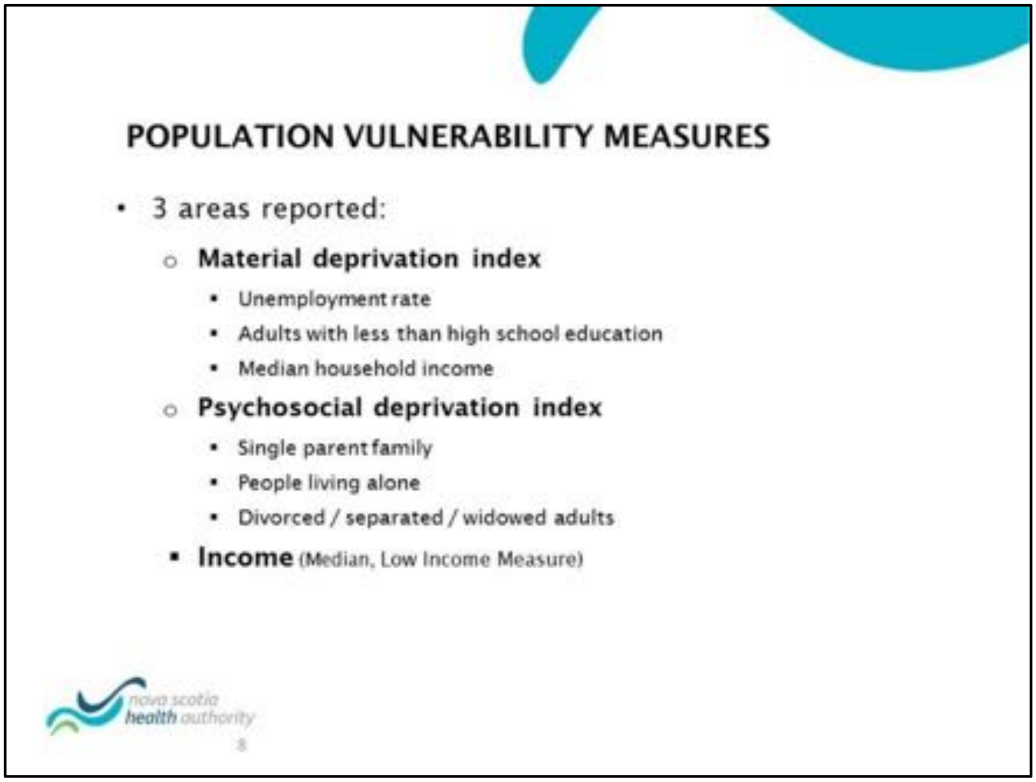
- Shelburne, Digby, Yarmouth and Queens counties are showing a greater decline than the Annapolis area



POPULATION – OVER 65

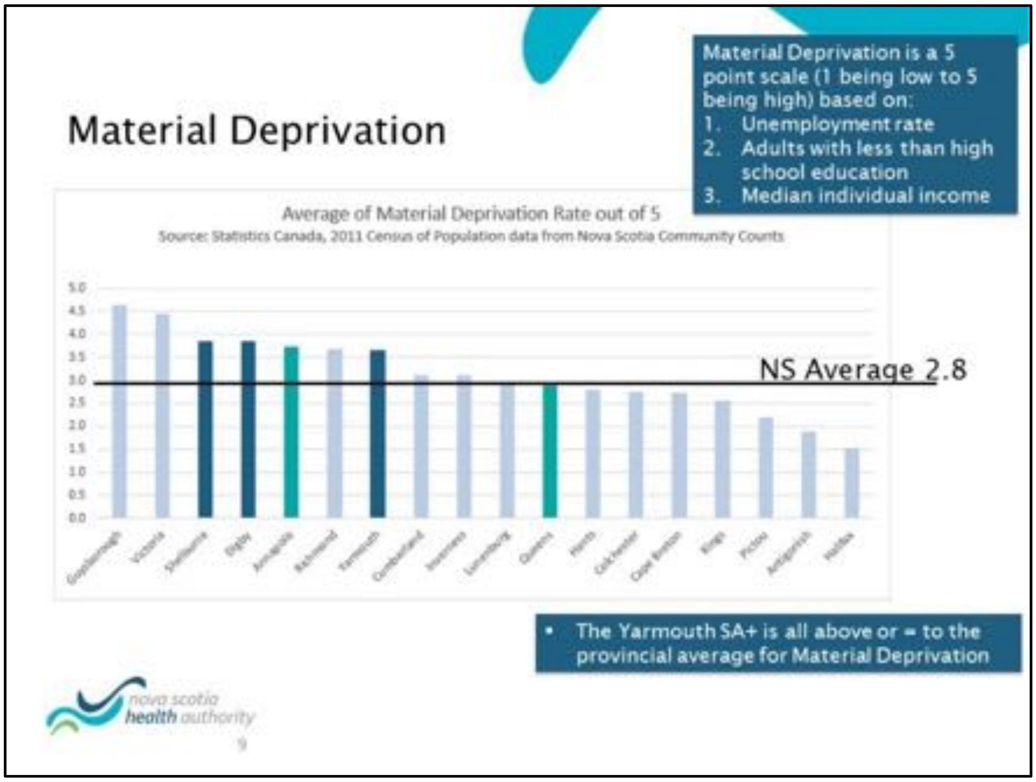
- At least 23% of population living in most NS Counties is over 65 years of age
- Canadian average >65 is 17%

Source: Statistics Canada



POPULATION VULNERABILITY MEASURES

- 3 areas reported:
  - **Material deprivation index**
    - Unemployment rate
    - Adults with less than high school education
    - Median household income
  - **Psychosocial deprivation index**
    - Single parent family
    - People living alone
    - Divorced / separated / widowed adults
  - **Income** (Median, Low Income Measure)



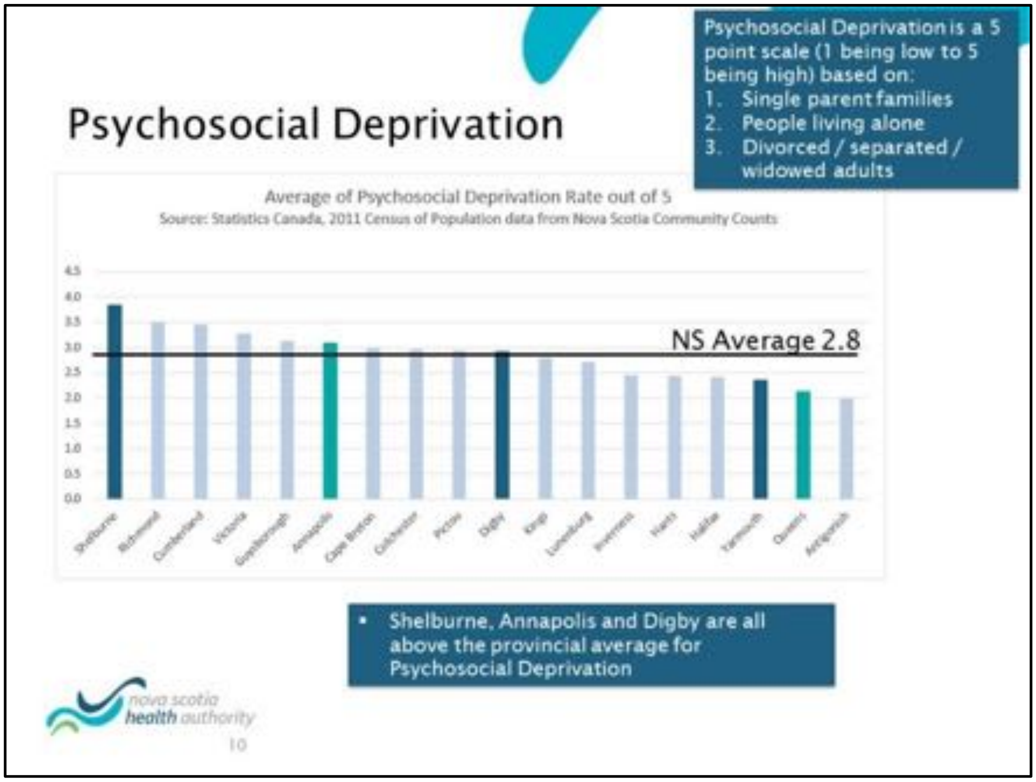
Material Deprivation

Material Deprivation is a 5 point scale (1 being low to 5 being high) based on:
1. Unemployment rate
2. Adults with less than high school education
3. Median individual income

Average of Material Deprivation Rate out of 5

Source: Statistics Canada, 2011 Census of Population data from Nova Scotia Community Counts

- The Yarmouth SA+ is all above or = to the provincial average for Material Deprivation



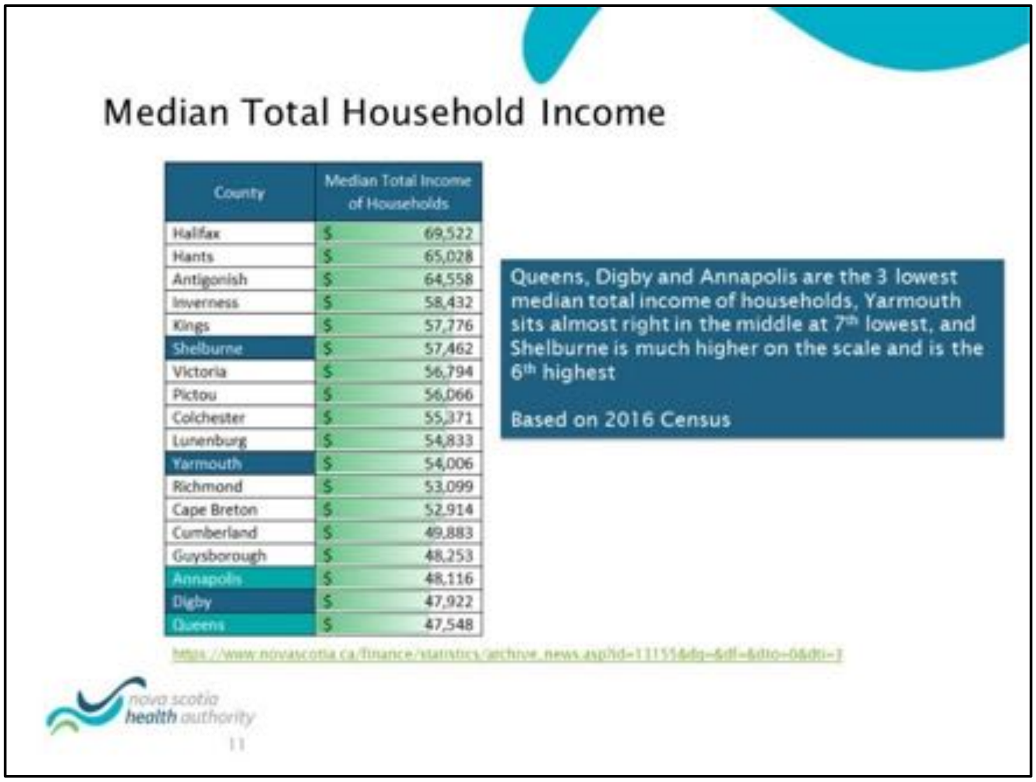
Psychosocial Deprivation

Psychosocial Deprivation is a 5 point scale (1 being low to 5 being high) based on:
1. Single parent families
2. People living alone
3. Divorced / separated / widowed adults

Average of Psychosocial Deprivation Rate out of 5

Source: Statistics Canada, 2011 Census of Population data from Nova Scotia Community Counts

- Shelburne, Annapolis and Digby are all above the provincial average for Psychosocial Deprivation



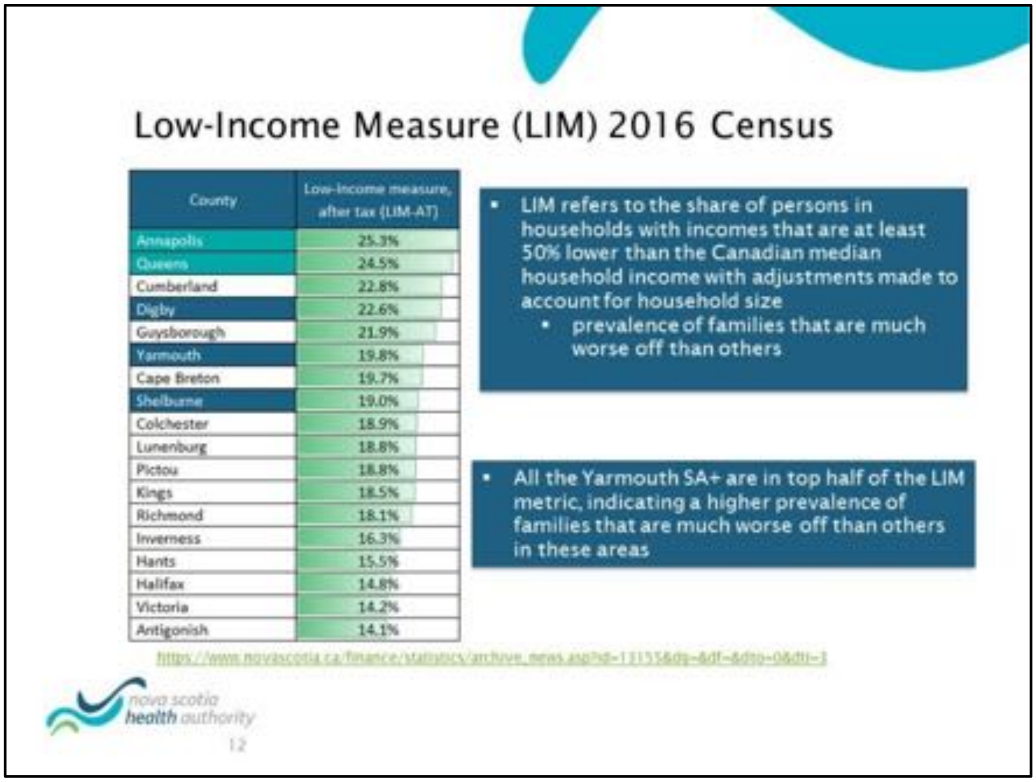
Median Total Household Income

County	Median Total Income of Households
Halifax	$ 69,522
Hants	$ 65,028
Antigonish	$ 64,558
Inverness	$ 58,432
Kings	$ 57,776
Shelburne	$ 57,462
Victoria	$ 56,794
Pictou	$ 56,066
Colchester	$ 55,371
Lunenburg	$ 54,833
Yarmouth	$ 54,006
Richmond	$ 53,099
Cape Breton	$ 52,914
Cumberland	$ 49,883
Guysborough	$ 48,253
Annapolis	$ 48,116
Digby	$ 47,922
Queens	$ 47,548

Queens, Digby and Annapolis are the 3 lowest median total income of households, Yarmouth sits almost right in the middle at 7th lowest, and Shelburne is much higher on the scale and is the 6th highest

Based on 2016 Census

https://www.novascotia.ca/finance/statistics/archive_news.asp?id=13155&dg=&df=&dto=0&dti=3



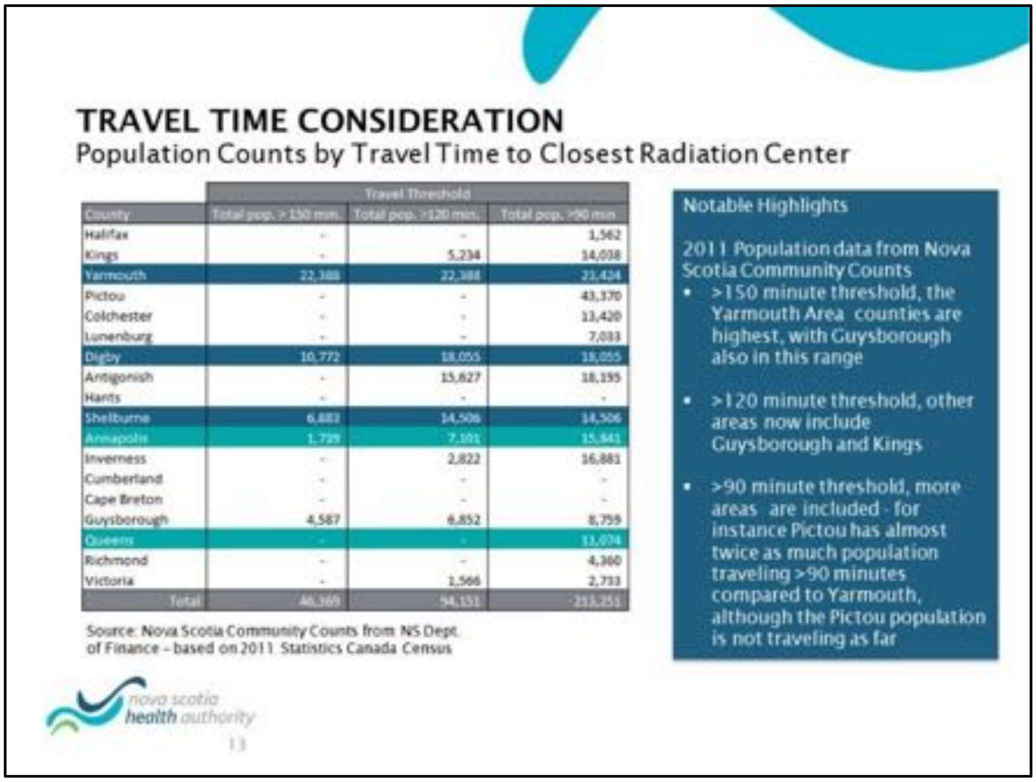
Low-Income Measure (LIM) 2016 Census

County	Low-income measure, after tax (LIM-AT)
Annapolis	25.3%
Queens	24.5%
Cumberland	22.8%
Digby	22.6%
Guysborough	21.9%
Yarmouth	19.8%
Cape Breton	19.7%
Shelburne	19.0%
Colchester	18.9%
Lunenburg	18.8%
Pictou	18.8%
Kings	18.5%
Richmond	18.1%
Inverness	16.3%
Hants	15.5%
Halifax	14.8%
Victoria	14.2%
Antigonish	14.1%

- LIM refers to the share of persons in households with incomes that are at least 50% lower than the Canadian median household income with adjustments made to account for household size
    - prevalence of families that are much worse off than others

- All the Yarmouth SA+ are in top half of the LIM metric, indicating a higher prevalence of families that are much worse off than others in these areas

https://www.novascotia.ca/finance/statistics/archive_news.asp?id=13155&dg=&df=&dto=0&dti=3



TRAVEL TIME CONSIDERATION

Population Counts by Travel Time to Closest Radiation Center

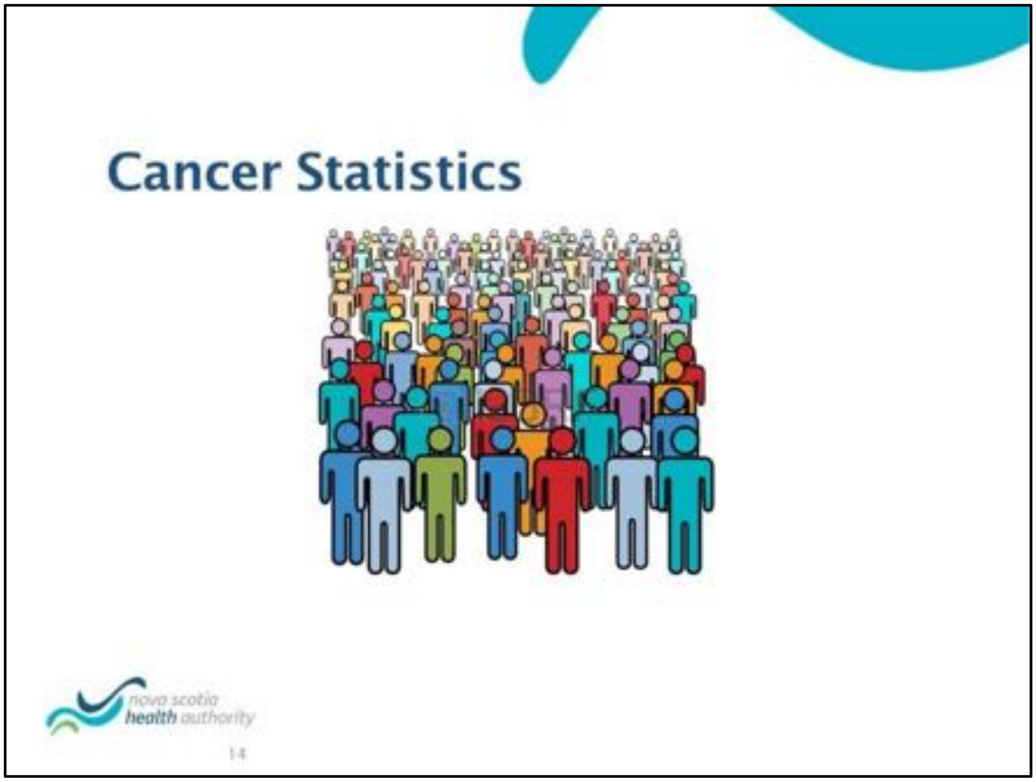
	Travel Threshold		
County	Total pop. > 150 min.	Total pop. >120 min.	Total pop. >90 min
Halifax	-	-	1,562
Kings	-	5,234	14,038
Yarmouth	22,388	22,388	21,424
Pictou	-	-	43,370
Colchester	-	-	13,420
Lunenburg	-	-	7,033
Digby	10,772	18,055	18,055
Antigonish	-	15,627	18,195
Hants	-	-	-
Shelburne	6,883	14,506	14,506
Annapolis	1,739	7,101	15,841
Inverness	-	2,822	16,881
Cumberland	-	-	-
Cape Breton	-	-	-
Guysborough	4,587	6,852	8,759
Queens	-	-	11,074
Richmond	-	-	4,360
Victoria	-	1,566	2,733
Total	46,369	94,151	213,251

Source: Nova Scotia Community Counts from NS Dept. of Finance – based on 2011 Statistics Canada Census

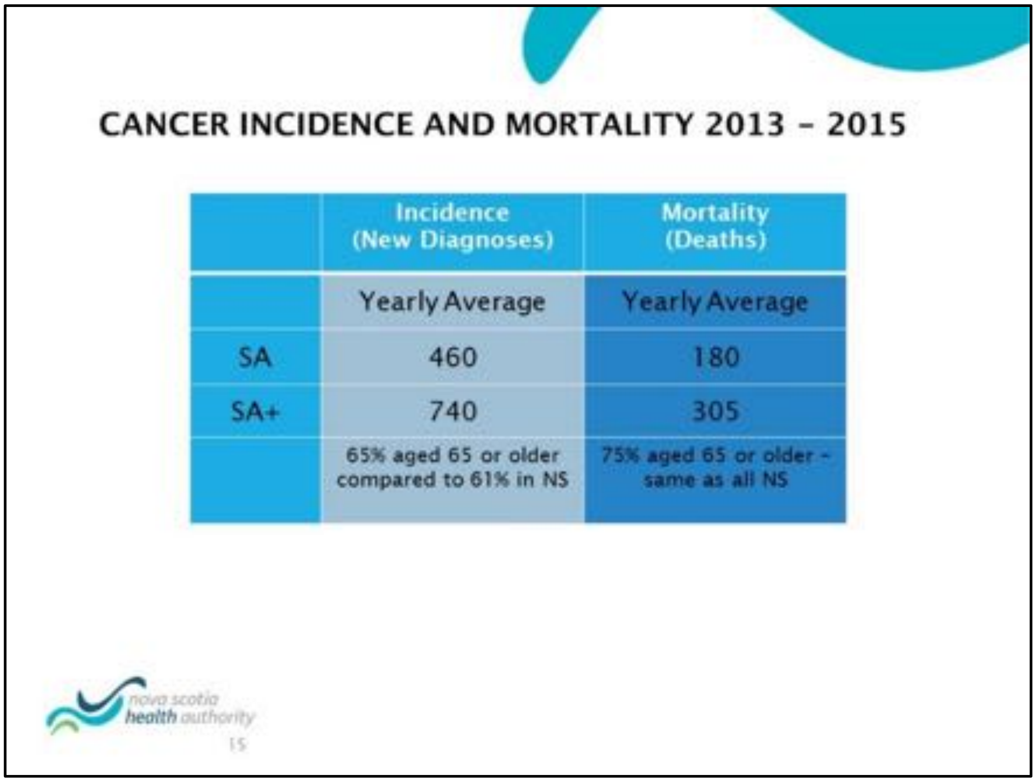
Notable Highlights

2011 Population data from Nova Scotia Community Counts

- >150 minute threshold, the Yarmouth Area counties are highest, with Guysborough also in this range
- >120 minute threshold, other areas now include Guysborough and Kings
- >90 minute threshold, more areas are included - for instance Pictou has almost twice as much population traveling >90 minutes compared to Yarmouth, although the Pictou population is not traveling as far

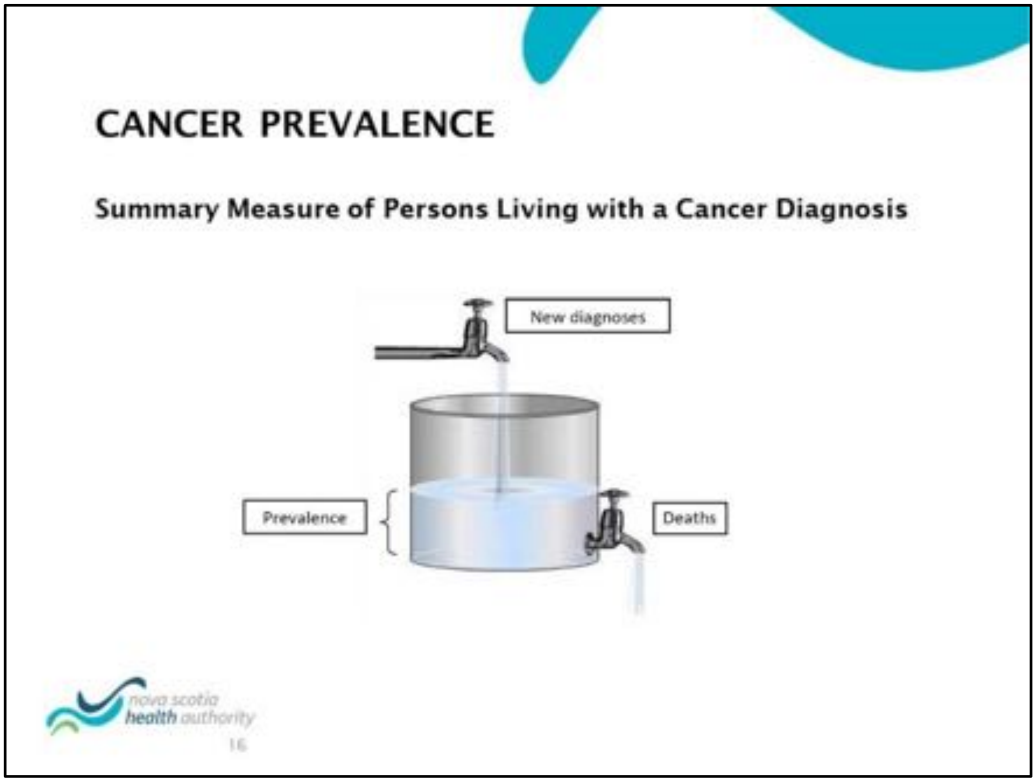


Cancer Statistics



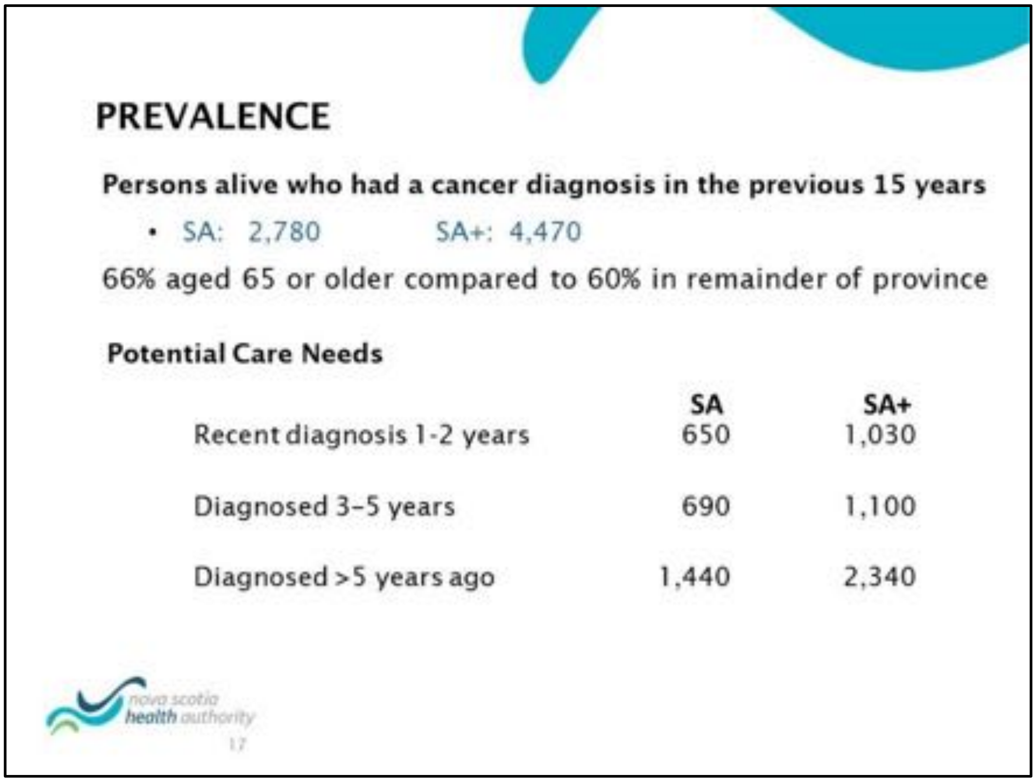
CANCER INCIDENCE AND MORTALITY 2013 – 2015

	Incidence (New Diagnoses)	Mortality (Deaths)
	Yearly Average	Yearly Average
SA	460	180
SA+	740	305
	65% aged 65 or older compared to 61% in NS	75% aged 65 or older – same as all NS



CANCER PREVALENCE

Summary Measure of Persons Living with a Cancer Diagnosis



PREVALENCE

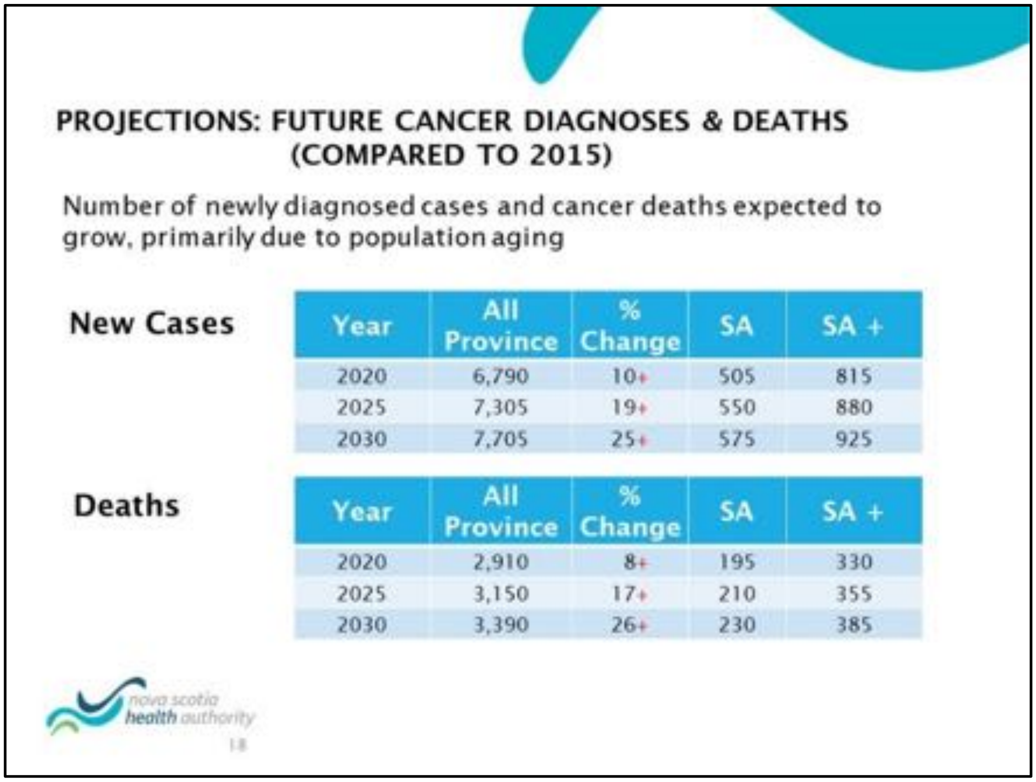
Persons alive who had a cancer diagnosis in the previous 15 years

- SA: 2,780 SA+: 4,470

66% aged 65 or older compared to 60% in remainder of province

Potential Care Needs

	SA	SA+
Recent diagnosis 1-2 years	650	1,030
Diagnosed 3-5 years	690	1,100
Diagnosed >5 years ago	1,440	2,340



PROJECTIONS: FUTURE CANCER DIAGNOSES & DEATHS (COMPARED TO 2015)

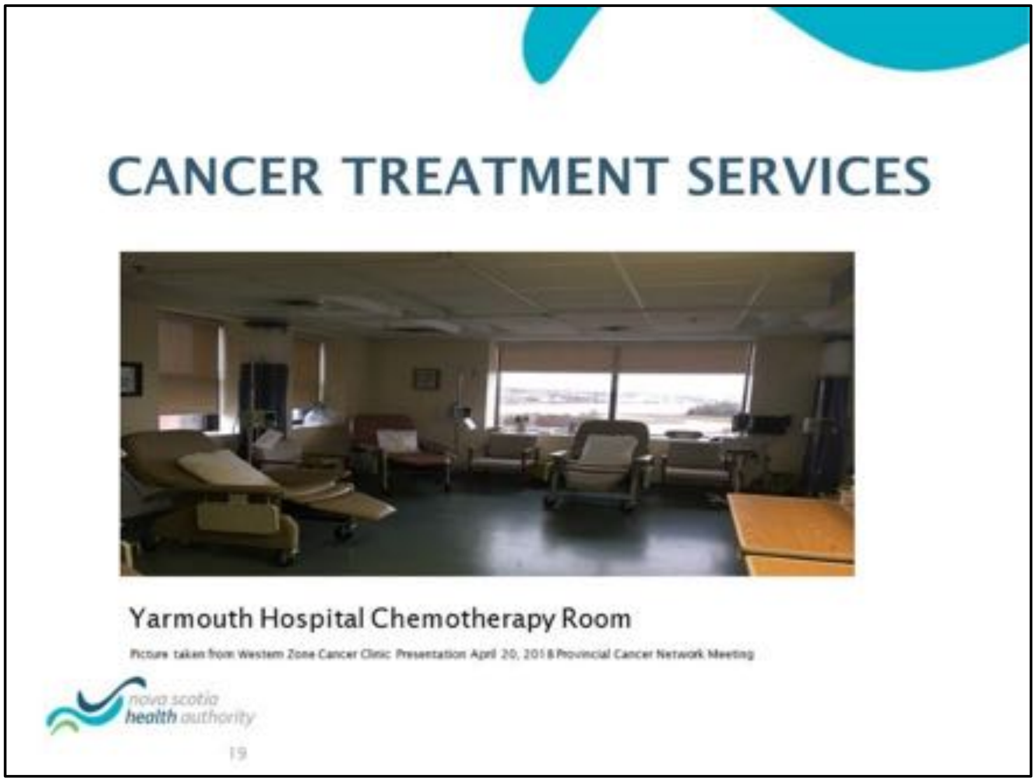
Number of newly diagnosed cases and cancer deaths expected to grow, primarily due to population aging

New Cases

Year	All Province	% Change	SA	SA +
2020	6,790	10+	505	815
2025	7,305	19+	550	880
2030	7,705	25+	575	925

Deaths

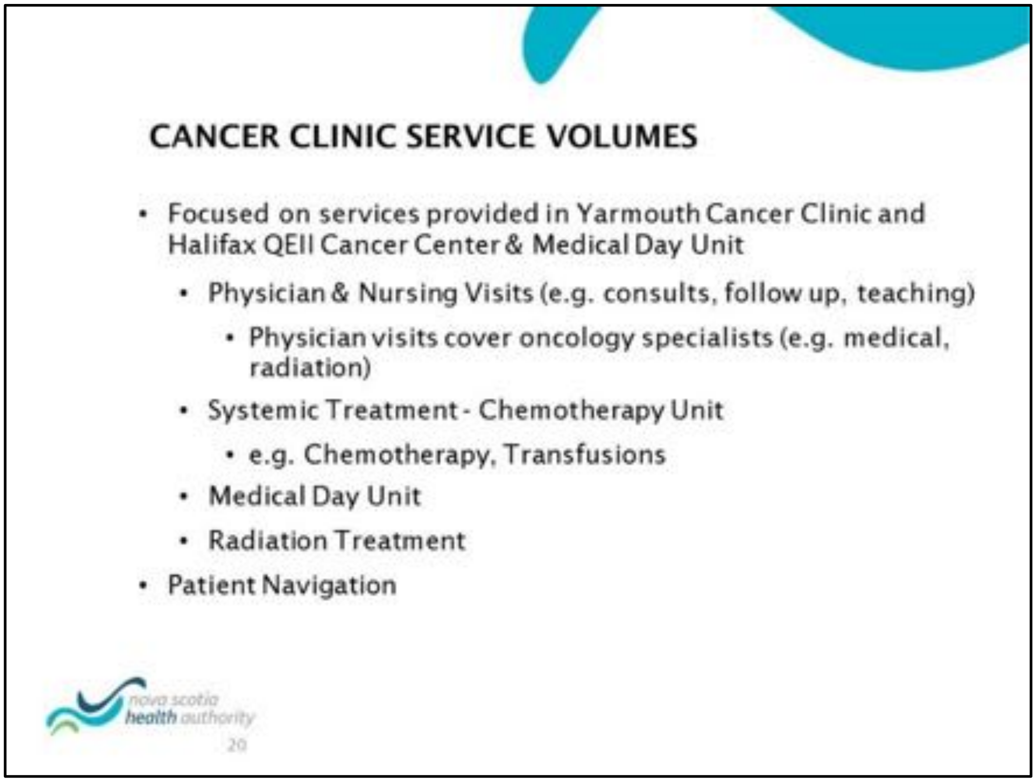
Year	All Province	% Change	SA	SA +
2020	2,910	8+	195	330
2025	3,150	17+	210	355
2030	3,390	26+	230	385



CANCER TREATMENT SERVICES

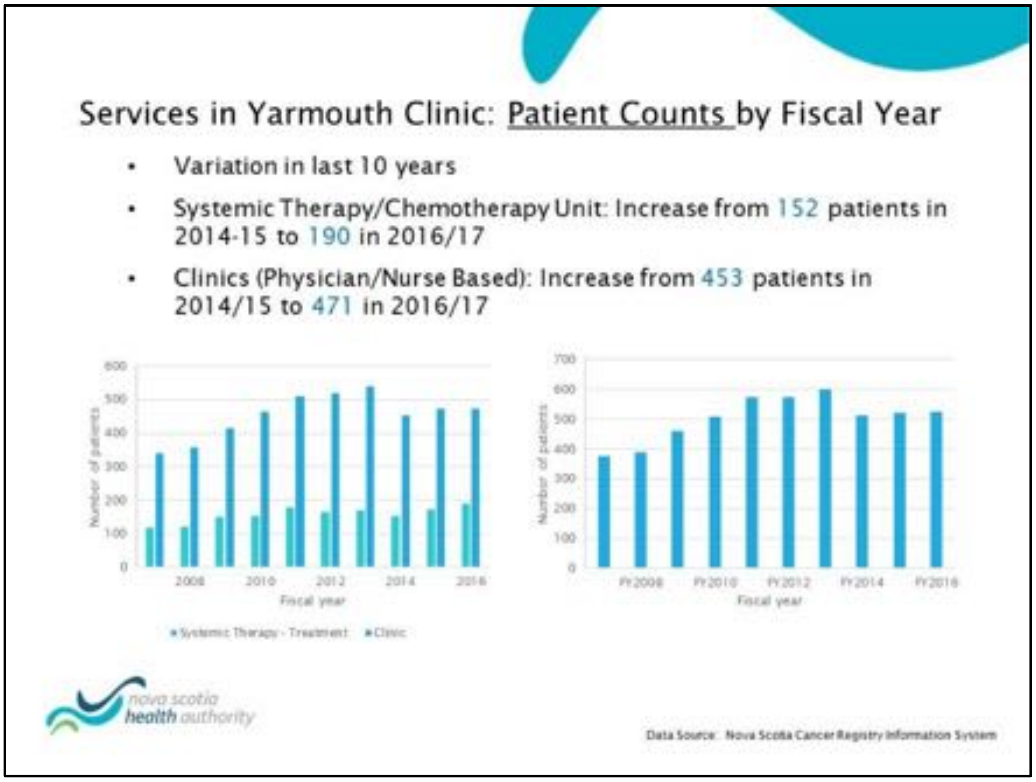
Yarmouth Hospital Chemotherapy Room

Picture taken from Western Zone Cancer Clinic Presentation April 20, 2018 Provincial Cancer Network Meeting



CANCER CLINIC SERVICE VOLUMES

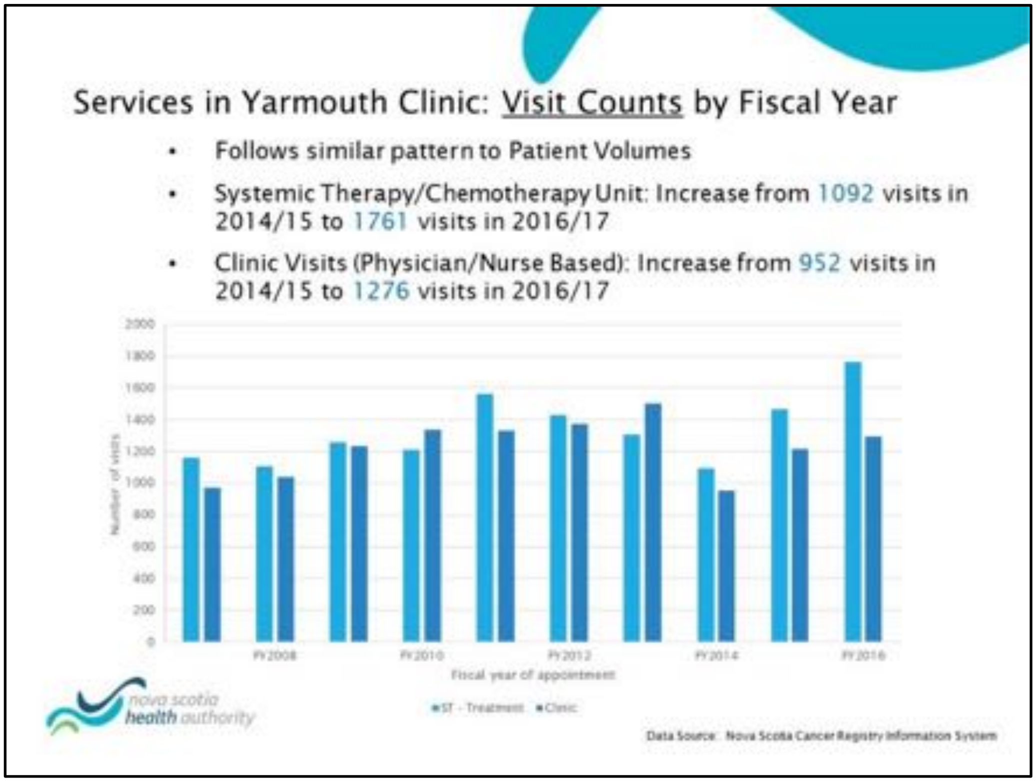
- Focused on services provided in Yarmouth Cancer Clinic and Halifax QEII Cancer Center & Medical Day Unit
  - Physician & Nursing Visits (e.g. consults, follow up, teaching)
    - Physician visits cover oncology specialists (e.g. medical, radiation)
  - Systemic Treatment - Chemotherapy Unit
    - e.g. Chemotherapy, Transfusions
  - Medical Day Unit
  - Radiation Treatment
- Patient Navigation



Services in Yarmouth Clinic: Patient Counts by Fiscal Year

- Variation in last 10 years
- Systemic Therapy/Chemotherapy Unit: Increase from 152 patients in 2014-15 to 190 in 2016/17
- Clinics (Physician/Nurse Based): Increase from 453 patients in 2014/15 to 471 in 2016/17

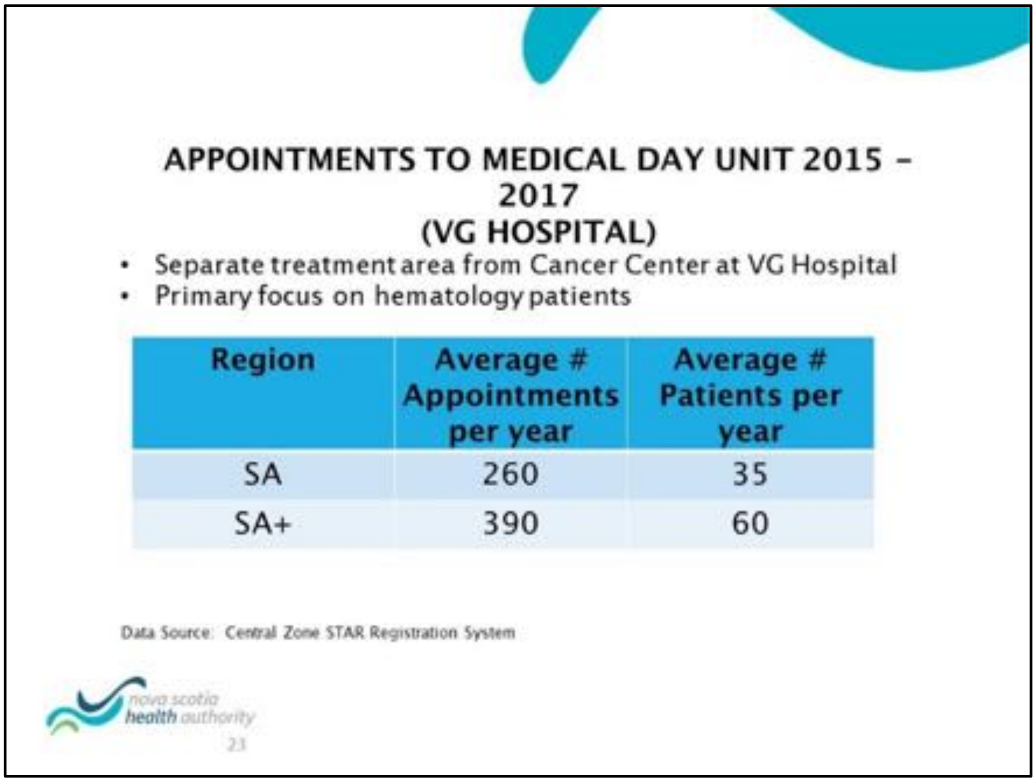
Data Source: Nova Scotia Cancer Registry Information System



Services in Yarmouth Clinic: Visit Counts by Fiscal Year

- Follows similar pattern to Patient Volumes
- Systemic Therapy/Chemotherapy Unit: Increase from 1092 visits in 2014/15 to 1761 visits in 2016/17
- Clinic Visits (Physician/Nurse Based): Increase from 952 visits in 2014/15 to 1276 visits in 2016/17

Data Source: Nova Scotia Cancer Registry Information System

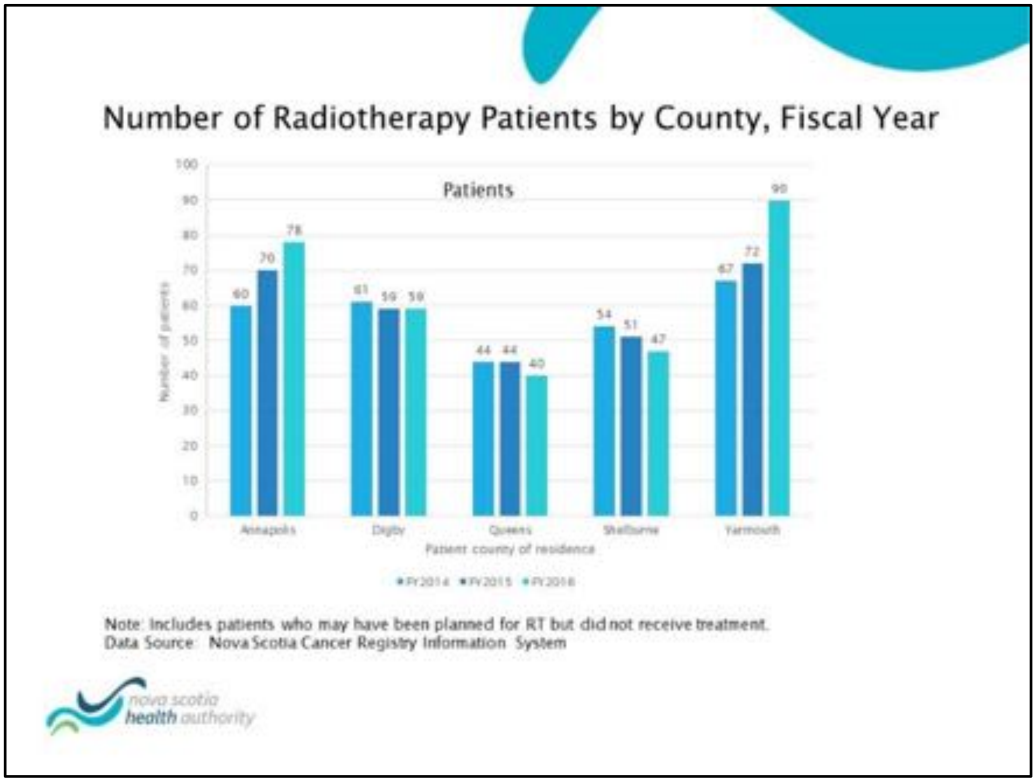


APPOINTMENTS TO MEDICAL DAY UNIT 2015 – 2017 (VG HOSPITAL)

- Separate treatment area from Cancer Center at VG Hospital
- Primary focus on hematology patients

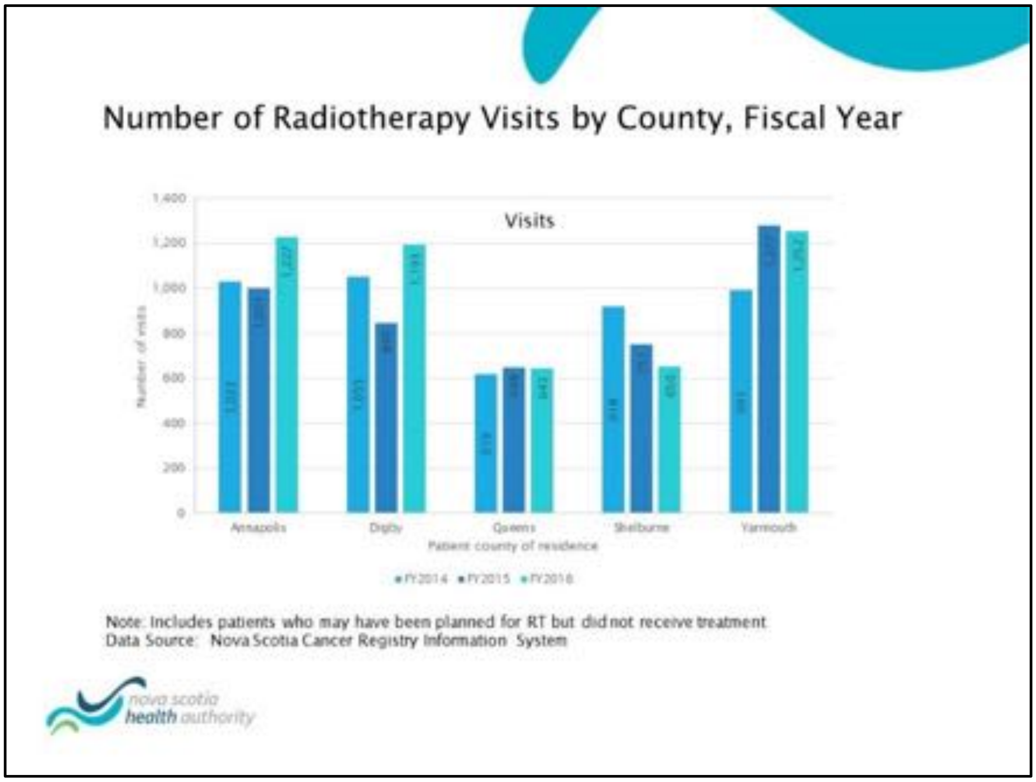
Region	Average # Appointments per year	Average # Patients per year
SA	260	35
SA+	390	60

Data Source: Central Zone STAR Registration System



Number of Radiotherapy Patients by County, Fiscal Year

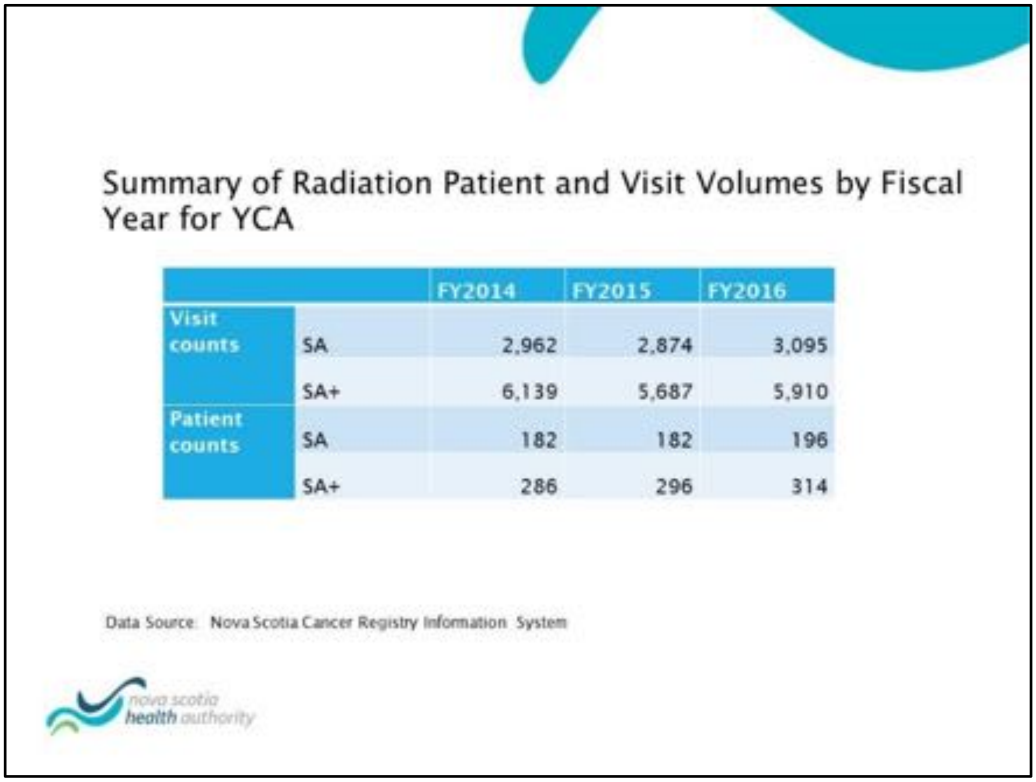
Note: Includes patients who may have been planned for RT but did not receive treatment.
Data Source: Nova Scotia Cancer Registry Information System



Number of Radiotherapy Visits by County, Fiscal Year

Note: Includes patients who may have been planned for RT but did not receive treatment

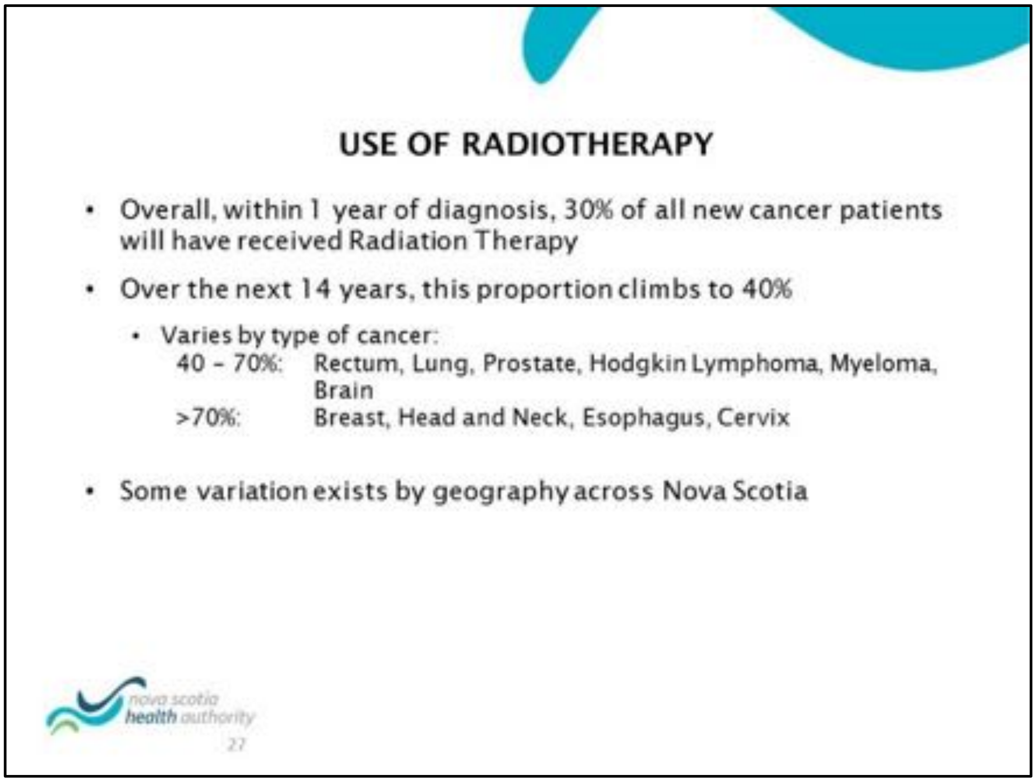
Data Source: Nova Scotia Cancer Registry Information System



Summary of Radiation Patient and Visit Volumes by Fiscal Year for YCA

		FY2014	FY2015	FY2016
Visit counts	SA	2,962	2,874	3,095
	SA+	6,139	5,687	5,910
Patient counts	SA	182	182	196
	SA+	286	296	314

Data Source: Nova Scotia Cancer Registry Information System



USE OF RADIOTHERAPY

- Overall, within 1 year of diagnosis, 30% of all new cancer patients will have received Radiation Therapy
- Over the next 14 years, this proportion climbs to 40%
    - Varies by type of cancer:

40 – 70%:	Rectum, Lung, Prostate, Hodgkin Lymphoma, Myeloma, Brain
>70%:	Breast, Head and Neck, Esophagus, Cervix

- Some variation exists by geography across Nova Scotia

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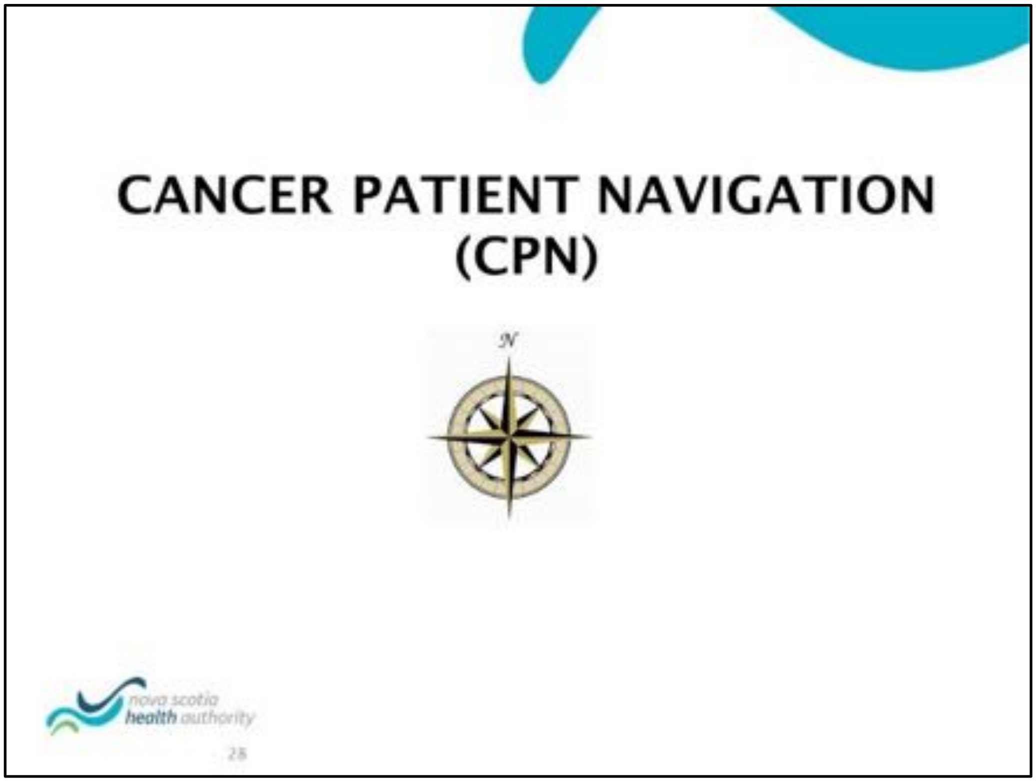

CANCER PATIENT NAVIGATION (CPN)

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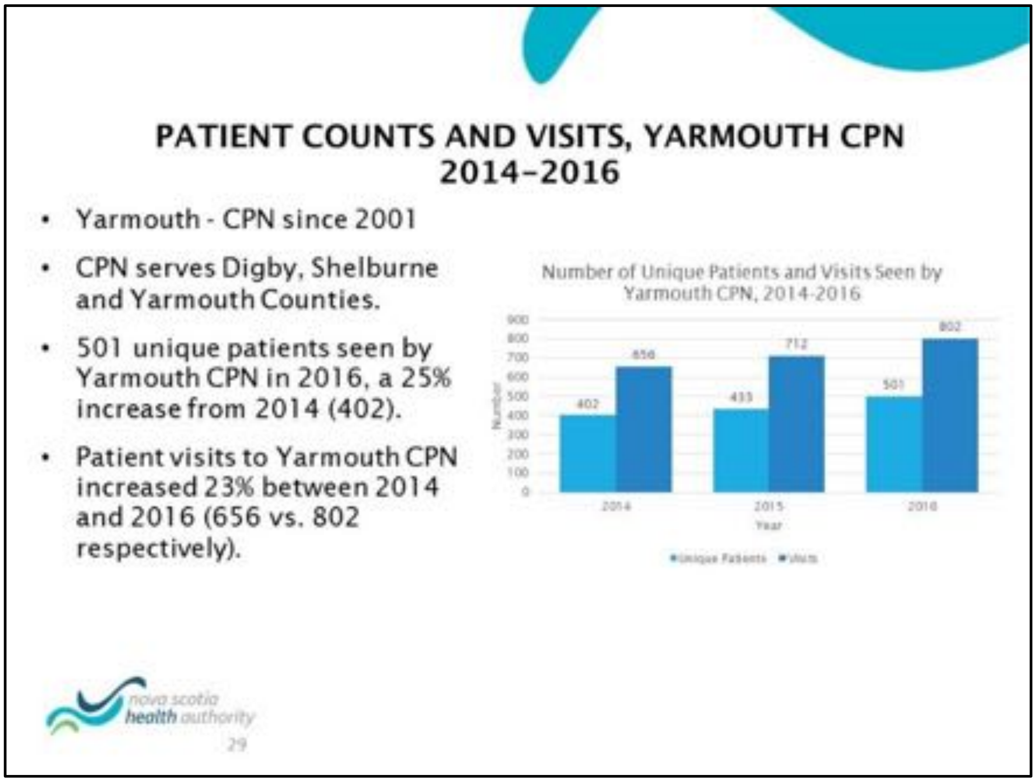
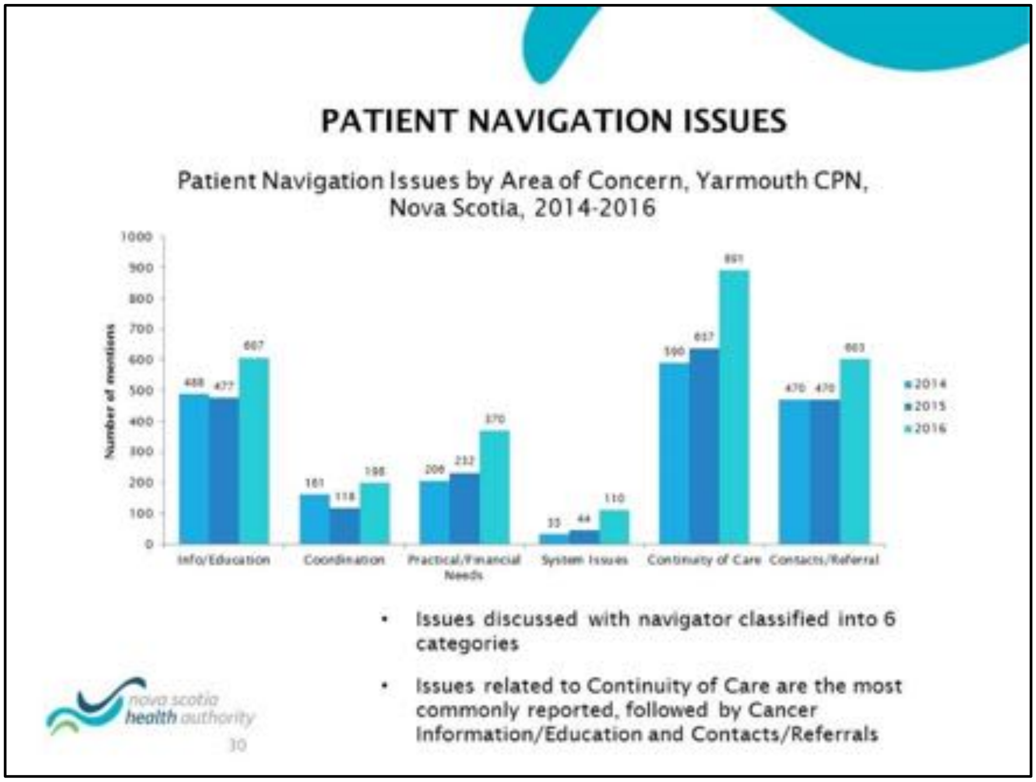


PATIENT COUNTS AND VISITS, YARMOUTH CPN 2014-2016

- Yarmouth - CPN since 2001
- CPN serves Digby, Shelburne and Yarmouth Counties.
- 501 unique patients seen by Yarmouth CPN in 2016, a 25% increase from 2014 (402).
- Patient visits to Yarmouth CPN increased 23% between 2014 and 2016 (656 vs. 802 respectively).

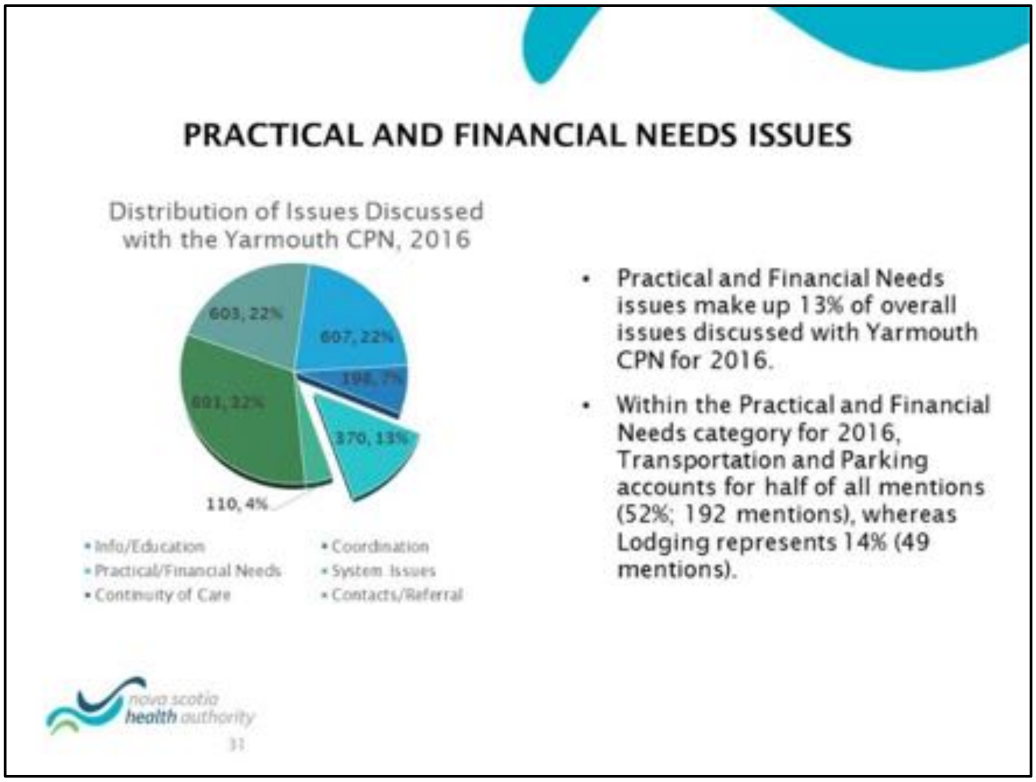
Number of Unique Patients and Visits Seen by Yarmouth CPN, 2014-2016



PATIENT NAVIGATION ISSUES

Patient Navigation Issues by Area of Concern, Yarmouth CPN, Nova Scotia, 2014-2016

- Issues discussed with navigator classified into 6 categories
- Issues related to Continuity of Care are the most commonly reported, followed by Cancer Information/Education and Contacts/Referrals



PRACTICAL AND FINANCIAL NEEDS ISSUES

- Practical and Financial Needs issues make up 13% of overall issues discussed with Yarmouth CPN for 2016.
- Within the Practical and Financial Needs category for 2016, Transportation and Parking accounts for half of all mentions (52%; 192 mentions), whereas Lodging represents 14% (49 mentions).

Appendix K. DES Presentation Radiation Cost Suite Estimate

Yarmouth and Area Cancer Care Review

Radiation Suite and Operations
Cost Estimate Summary

13 June 2018

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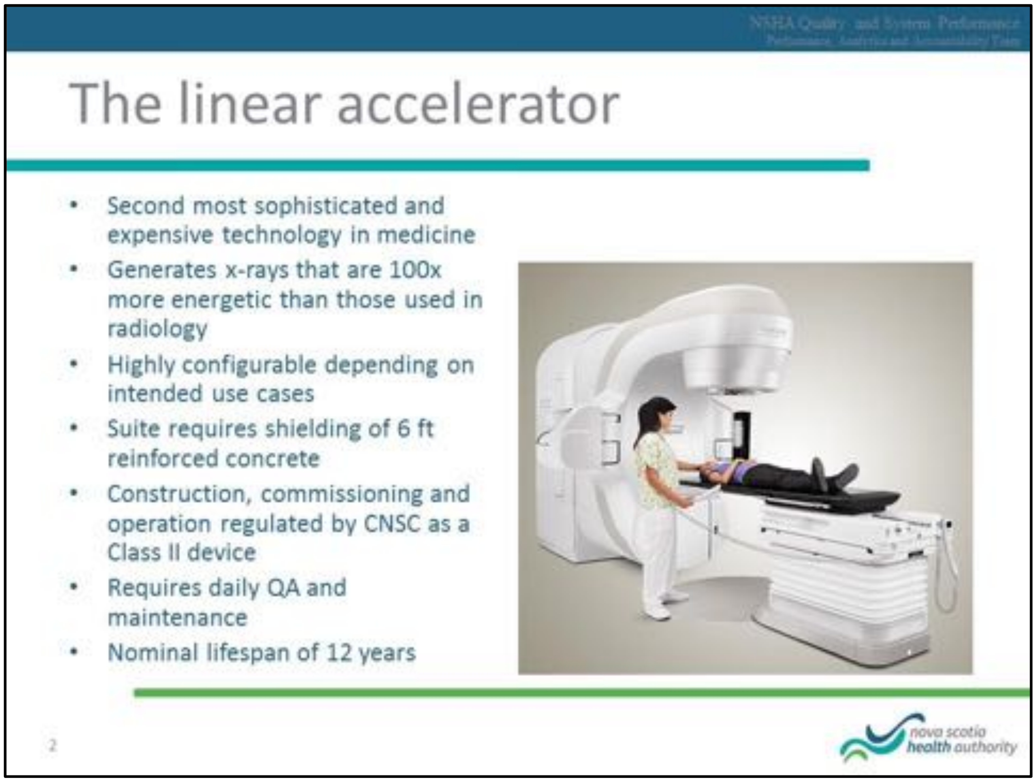

NSHA Quality and System Performance
Performance, Analytics and Accountability Team

The linear accelerator

- Second most sophisticated and expensive technology in medicine
- Generates x-rays that are 100x more energetic than those used in radiology
- Highly configurable depending on intended use cases
- Suite requires shielding of 6 ft reinforced concrete
- Construction, commissioning and operation regulated by CNSC as a Class II device
- Requires daily QA and maintenance
- Nominal lifespan of 12 years

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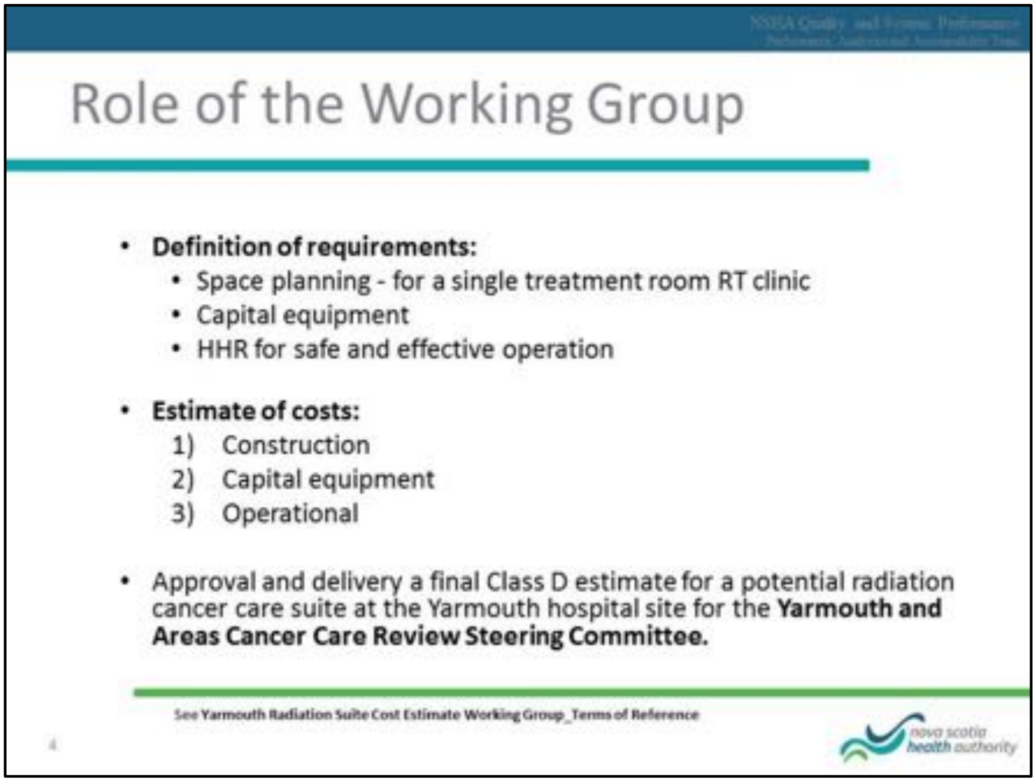
Overview

- Working Group
- Methodology
- Cost Estimate Details
  - Construction costs
  - Equipment costs
  - Health Human Resources costs
  - Operational costs
- Cost Estimate Summary
- Assumptions and Limitations



Role of the Working Group

- **Definition of requirements:**
  - Space planning - for a single treatment room RT clinic
  - Capital equipment
  - HHR for safe and effective operation

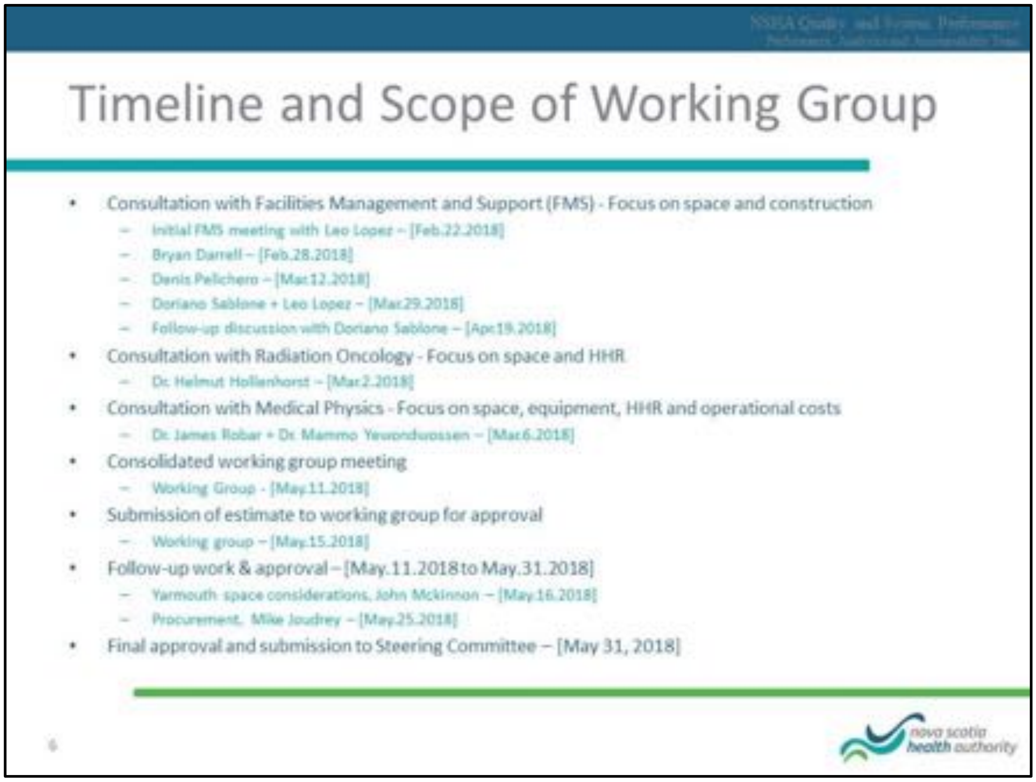
- **Estimate of costs:**
  1) Construction
  2) Capital equipment
  3) Operational

- Approval and delivery a final Class D estimate for a potential radiation cancer care suite at the Yarmouth hospital site for the **Yarmouth and Areas Cancer Care Review Steering Committee.**

See **Yarmouth Radiation Suite Cost Estimate Working Group_Terms of Reference**

Working Group

Name	Role/Representative
Liam Shannon	WG Lead
Terry Boudreau	System Performance
Dr. Helmut Hollenhorst	Radiation Oncology
Dr. James Robar	Medical Physics
Leo Lopez	Facilities Management and Support (FMS)
Doriano Sablone	Facilities Management and Support (FMS)
Peggy Green	Yarmouth/WZ Management/Operations Lead
John McKinnon	Space Planning WZ
Bryan Darrell	Infrastructure Management NS Government
Denis Pellichero	Department of Transportation and Infrastructure Renewal Building Services
Michael Joudrey	WZ Procurement Manager
Debbie Wentzell	Yarmouth/WZ Management/Operations Lead
James Bain	IM/IT



Timeline and Scope of Working Group

- Consultation with Facilities Management and Support (FMS) - Focus on space and construction
  - Initial FMS meeting with Leo Lopez – [Feb.22.2018]
  - Bryan Darrell – [Feb.28.2018]
  - Denis Pelichero – [Mar.12.2018]
  - Doriano Sablone + Leo Lopez – [Mar.29.2018]
  - Follow-up discussion with Doriano Sablone – [Apr.19.2018]
- Consultation with Radiation Oncology - Focus on space and HHR
  - Dr. Helmut Hollenhorst – [Mar.2.2018]
- Consultation with Medical Physics - Focus on space, equipment, HHR and operational costs
  - Dr. James Robar + Dr. Mammo Yewondwossen – [Mar.6.2018]
- Consolidated working group meeting
  - Working Group - [May.11.2018]
- Submission of estimate to working group for approval
  - Working group – [May.15.2018]
- Follow-up work & approval – [May.11.2018 to May.31.2018]
  - Yarmouth space considerations, John Mckinnon – [May.16.2018]
  - Procurement, Mike Joudrey – [May.25.2018]
- Final approval and submission to Steering Committee – [May 31, 2018]

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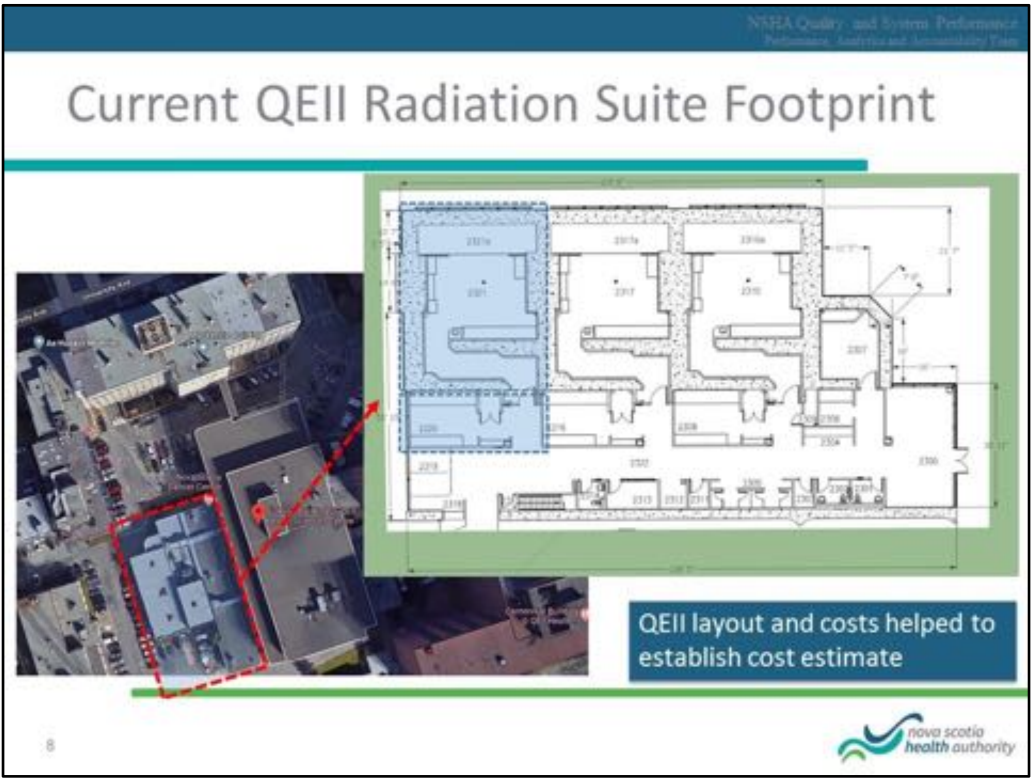
Possible Site Planning of New Build

- Possible construction site of Radiation Suite
- New build attached to existing facility footprint



NSHA Quality and System Performance
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Current QEII Radiation Suite Footprint

QEII layout and costs helped to establish cost estimate

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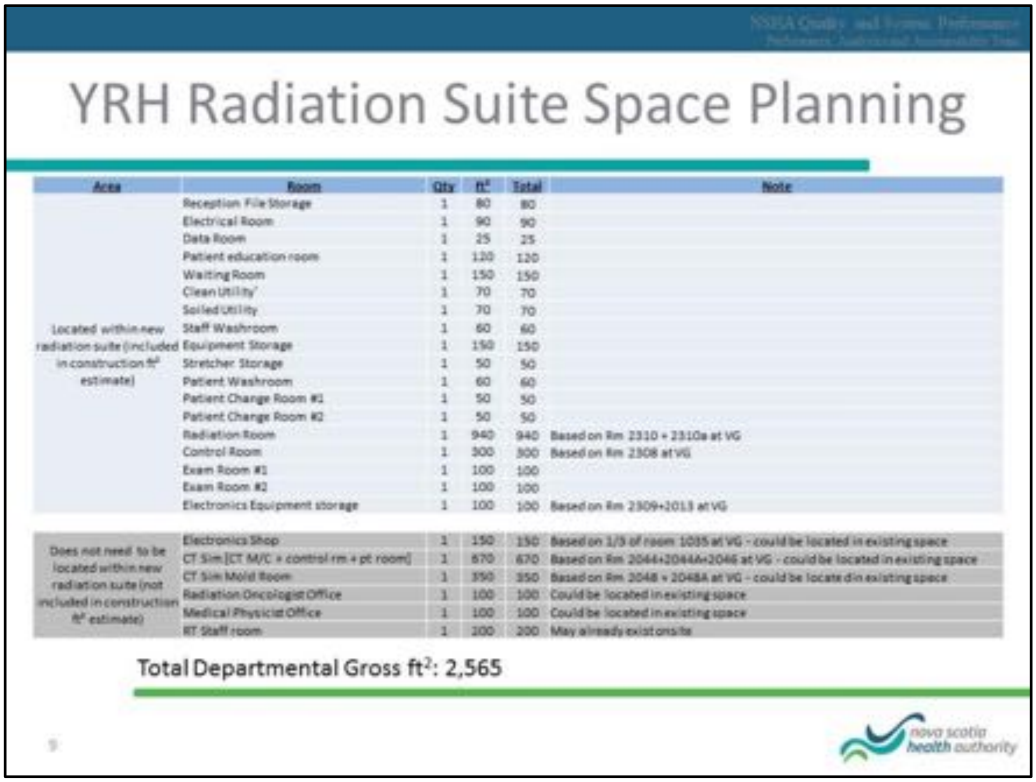
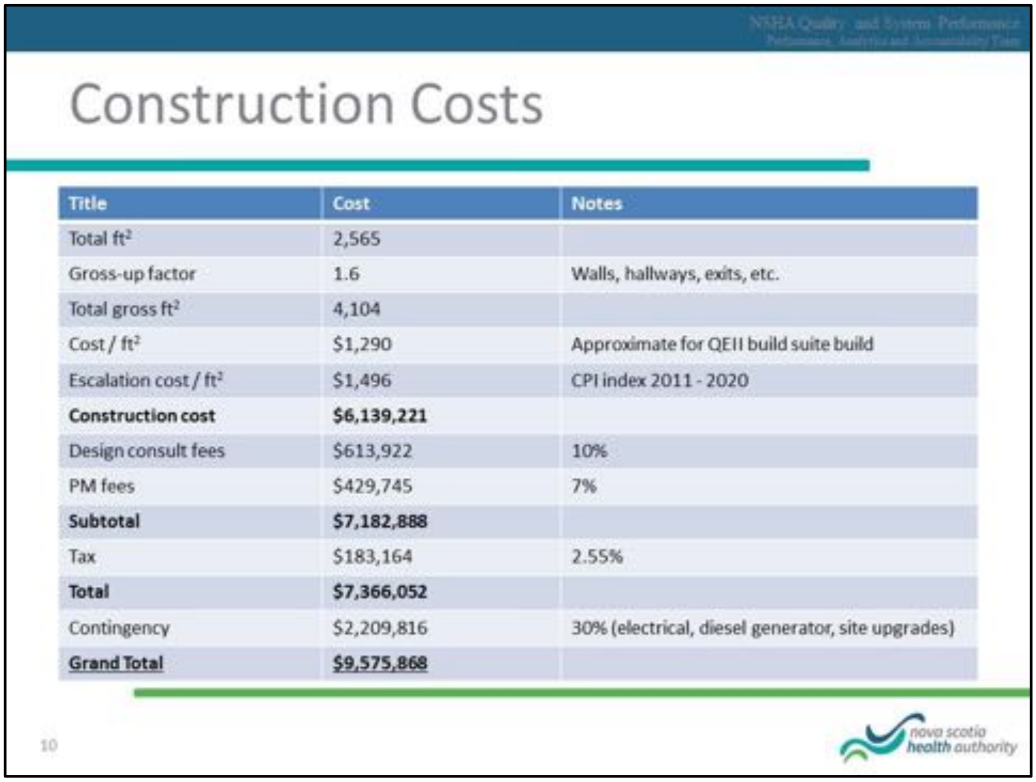


YRH Radiation Suite Space Planning

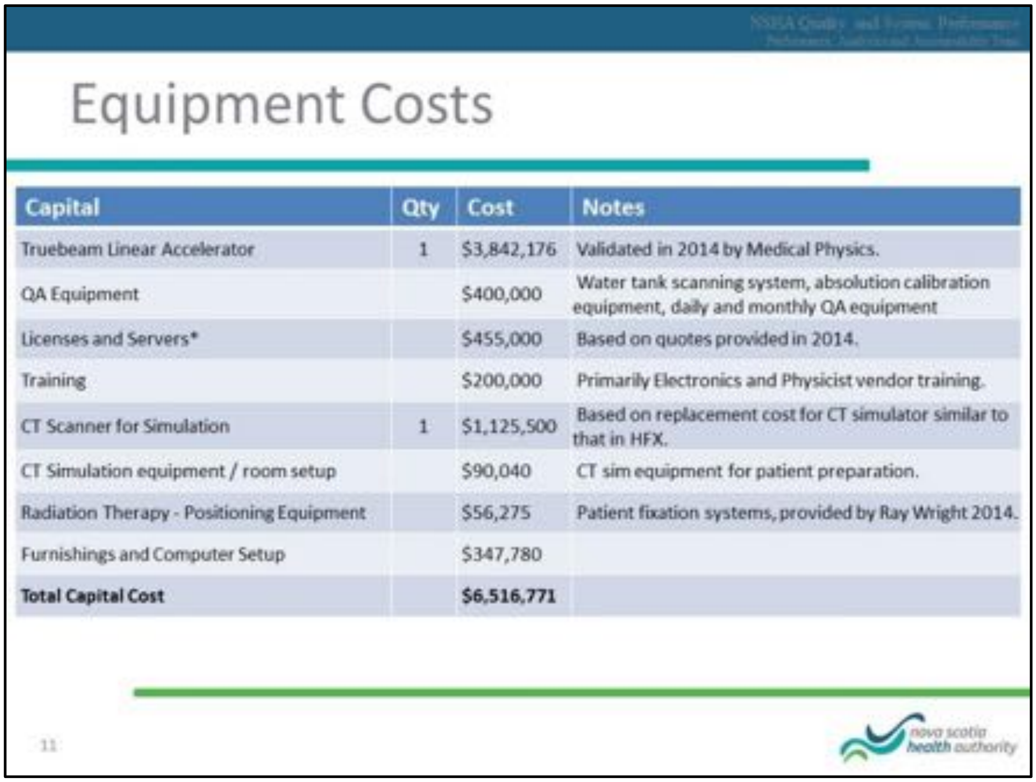
Area	Room	Qty	ft²	Total	Note
Located within new radiation suite (included in construction ft² estimate)	Reception File Storage	1	80	80	
	Electrical Room	1	90	90	
	Data Room	1	25	25	
	Patient education room	1	120	120	
	Waiting Room	1	150	150	
	Clean Utility'	1	70	70	
	Soiled Utility	1	70	70	
	Staff Washroom	1	60	60	
	Equipment Storage	1	150	150	
	Stretcher Storage	1	50	50	
	Patient Washroom	1	60	60	
	Patient Change Room #1	1	50	50	
	Patient Change Room #2	1	50	50	
	Radiation Room	1	940	940	Based on Rm 2310 + 2310a at VG
	Control Room	1	300	300	Based on Rm 2308 at VG
	Exam Room #1	1	100	100	
	Exam Room #2	1	100	100	
	Electronics Equipment storage	1	100	100	Based on Rm 2309+2013 at VG
Does not need to be located within new radiation suite (not included in construction ft² estimate)	Electronics Shop	1	150	150	Based on 1/3 of room 1035 at VG - could be located in existing space
	CT Sim (CT M/C + control rm + pt room)	1	670	670	Based on Rm 2044+2044A+2046 at VG - could be located in existing space
	CT Sim Mold Room	1	350	350	Based on Rm 2048 + 2048A at VG - could be locate din existing space
	Radiation Oncologist Office	1	100	100	Could be located in existing space
	Medical Physicist Office	1	100	100	Could be located in existing space
	RT Staff room	1	200	200	May already exist onsite

Total Departmental Gross ft²: 2,565



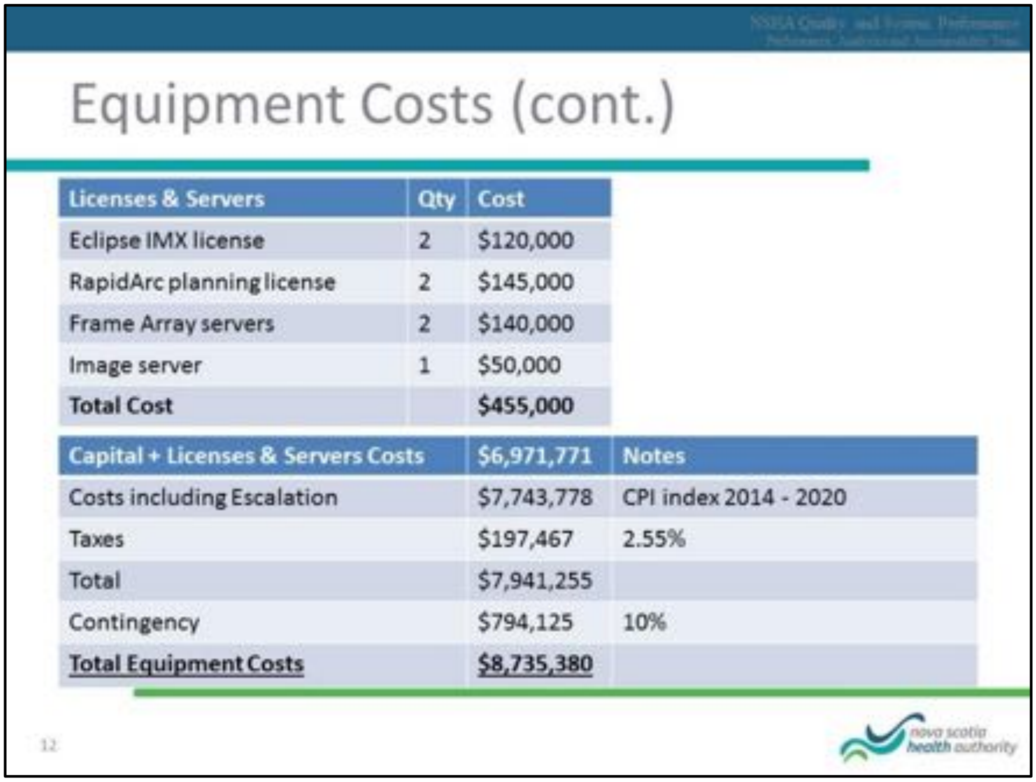
Construction Costs

Title	Cost	Notes
Total ft²	2,565	
Gross-up factor	1.6	Walls, hallways, exits, etc.
Total gross ft²	4,104	
Cost / ft²	$1,290	Approximate for QEII build suite build
Escalation cost / ft²	$1,496	CPI index 2011 - 2020
Construction cost	**$6,139,221**	
Design consult fees	$613,922	10%
PM fees	$429,745	7%
Subtotal	**$7,182,888**	
Tax	$183,164	2.55%
Total	**$7,366,052**	
Contingency	$2,209,816	30% (electrical, diesel generator, site upgrades)
Grand Total	**$9,575,868**	



Equipment Costs

Capital	Qty	Cost	Notes
Truebeam Linear Accelerator	1	$3,842,176	Validated in 2014 by Medical Physics.
QA Equipment		$400,000	Water tank scanning system, absolution calibration equipment, daily and monthly QA equipment
Licenses and Servers*		$455,000	Based on quotes provided in 2014.
Training		$200,000	Primarily Electronics and Physicist vendor training.
CT Scanner for Simulation	1	$1,125,500	Based on replacement cost for CT simulator similar to that in HFX.
CT Simulation equipment / room setup		$90,040	CT sim equipment for patient preparation.
Radiation Therapy - Positioning Equipment		$56,275	Patient fixation systems, provided by Ray Wright 2014.
Furnishings and Computer Setup		$347,780	
Total Capital Cost		**$6,516,771**	



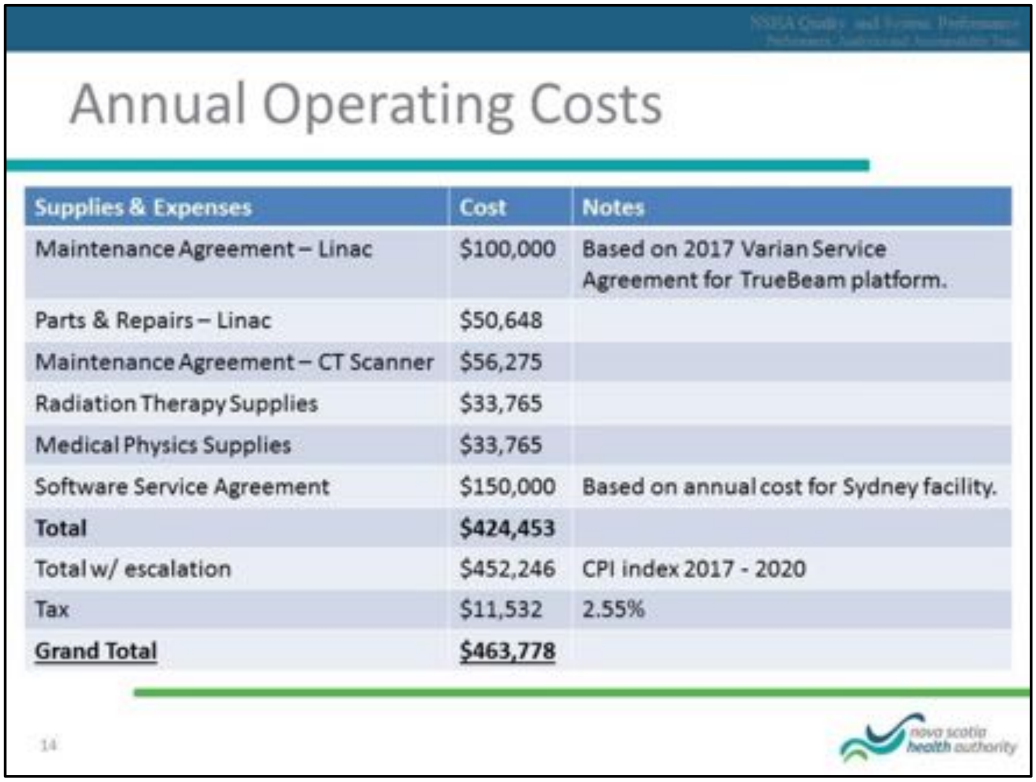
Equipment Costs (cont.)

Licenses & Servers	Qty	Cost
Eclipse IMX license	2	$120,000
RapidArc planning license	2	$145,000
Frame Array servers	2	$140,000
Image server	1	$50,000
Total Cost		**$455,000**

Capital + Licenses & Servers Costs	$6,971,771	Notes
Costs including Escalation	$7,743,778	CPI index 2014 - 2020
Taxes	$197,467	2.55%
Total	$7,941,255	
Contingency	$794,125	10%
Total Equipment Costs	**$8,735,380**	

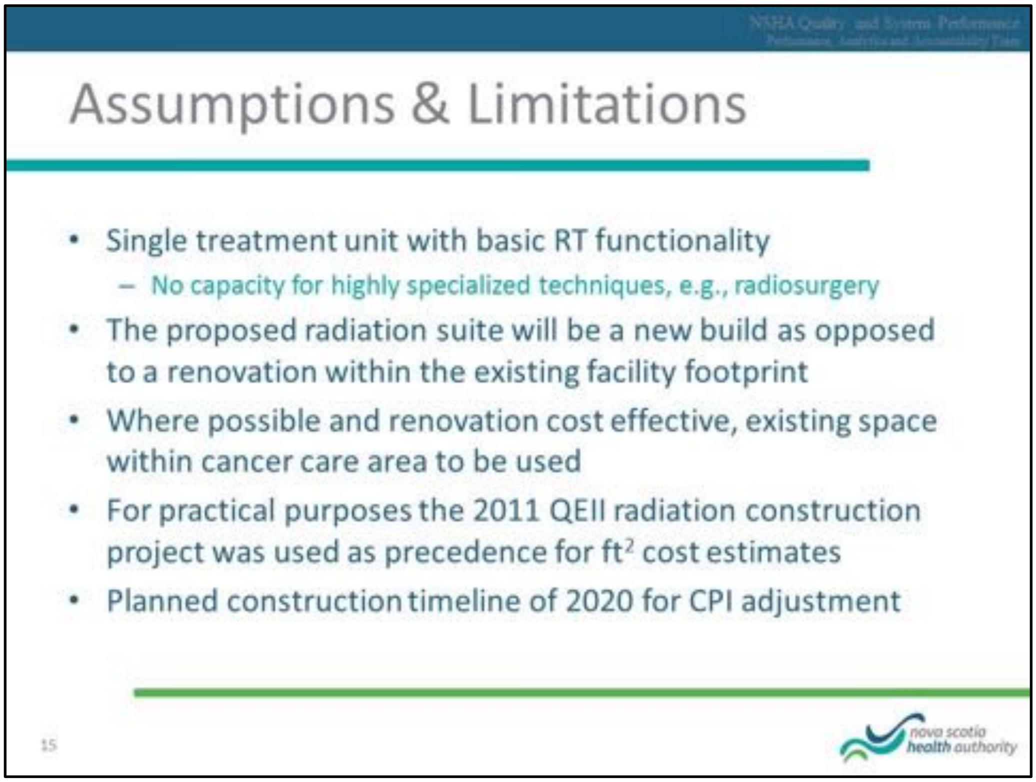
Health Human Resources Costs

Position	2018 Renum.	2018 FTE	FTE $	Notes
Radiation Onc	$416,208	2.0	$832,416	
Medical Phys III	$219,411	1.2	$263,293	Coverage provided by QEII site. Onsite Phys. does all QA, frontline elec support. No phys asst' required. Phys would be required 1 year in advance for training, then transition.
Dosimetrist	$106,362	1.0	$106,362	Service provided by QEII site, but budget allocation required for Dosimetrist workload.
Medical Onc	$351,275	0.5	$175,638	Add'tl Med Onc support for combined Chemo and Rad pat's.
Rad Therapist	$103,330	5.0	$516,650	
Electronics Tech	$90,979	1.2	$109,175	Coverage provided by QEII site.
RN	$94,362	2.0	$188,724	
Unit Aide	$45,363	1.2	$54,436	
Book & Reg Clerk	$47,715	1.0	$47,715	Clinic / radiation tx unit scheduling, support and sim prep, shared with other Cancer Services.
Referral Officer	$44,949	0	$0	Deemed not required for 2018 estimate by working group.
Med Secretary	$50,103	0.5	$25,065	Shared with other Cancer Services.
Health Serv Mgr	$109,324	0.5	$54,620	Shared with other Cancer Services.
Total Cost			**$2,374,093**	
Total Cost w/ Escalation			**$2,476,307**	CPI index 2018 - 2020



Annual Operating Costs

Supplies & Expenses	Cost	Notes
Maintenance Agreement – Linac	$100,000	Based on 2017 Varian Service Agreement for TrueBeam platform.
Parts & Repairs – Linac	$50,648	
Maintenance Agreement – CT Scanner	$56,275	
Radiation Therapy Supplies	$33,765	
Medical Physics Supplies	$33,765	
Software Service Agreement	$150,000	Based on annual cost for Sydney facility.
Total	**$424,453**	
Total w/ escalation	$452,246	CPI index 2017 - 2020
Tax	$11,532	2.55%
Grand Total	**$463,778**	



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Performance, Analytics and Accountability Team

Assumptions & Limitations

- Single treatment unit with basic RT functionality
  - No capacity for highly specialized techniques, e.g., radiosurgery
- The proposed radiation suite will be a new build as opposed to a renovation within the existing facility footprint
- Where possible and renovation cost effective, existing space within cancer care area to be used
- For practical purposes the 2011 QEII radiation construction project was used as precedence for ft^2 cost estimates
- Planned construction timeline of 2020 for CPI adjustment

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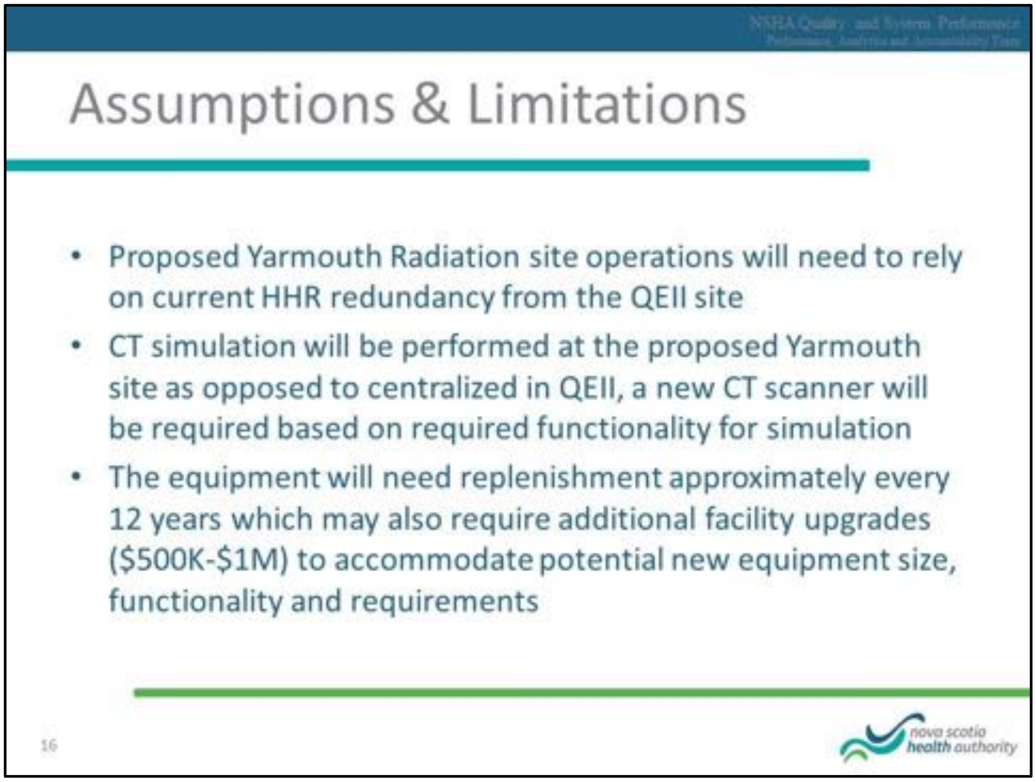

NSHA Quality and System Performance
Performance, Analytics and Accountability Team

Assumptions & Limitations

- Proposed Yarmouth Radiation site operations will need to rely on current HHR redundancy from the QEII site
- CT simulation will be performed at the proposed Yarmouth site as opposed to centralized in QEII, a new CT scanner will be required based on required functionality for simulation
- The equipment will need replenishment approximately every 12 years which may also require additional facility upgrades ($500K-$1M) to accommodate potential new equipment size, functionality and requirements

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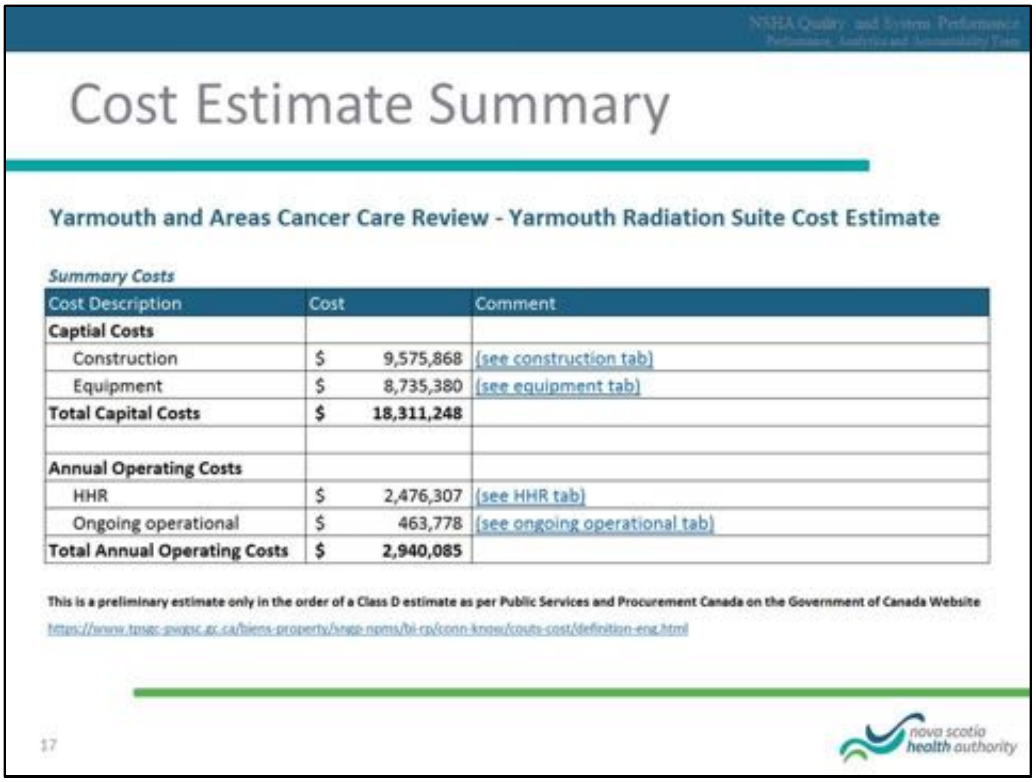

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Cost Estimate Summary

Yarmouth and Areas Cancer Care Review - Yarmouth Radiation Suite Cost Estimate

Summary Costs

Cost Description	Cost		Comment
Captial Costs			
Construction	$	9,575,868	(see construction tab)
Equipment	$	8,735,380	(see equipment tab)
Total Capital Costs	**$**	**18,311,248**	
Annual Operating Costs			
HHR	$	2,476,307	(see HHR tab)
Ongoing operational	$	463,778	(see ongoing operational tab)
Total Annual Operating Costs	**$**	**2,940,085**	

This is a preliminary estimate only in the order of a Class D estimate as per Public Services and Procurement Canada on the Government of Canada Website

https://www.tpsgc-pwgsc.gc.ca/biens-property/sngp-npms/bi-rp/conn-know/couts-cost/definition-eng.html

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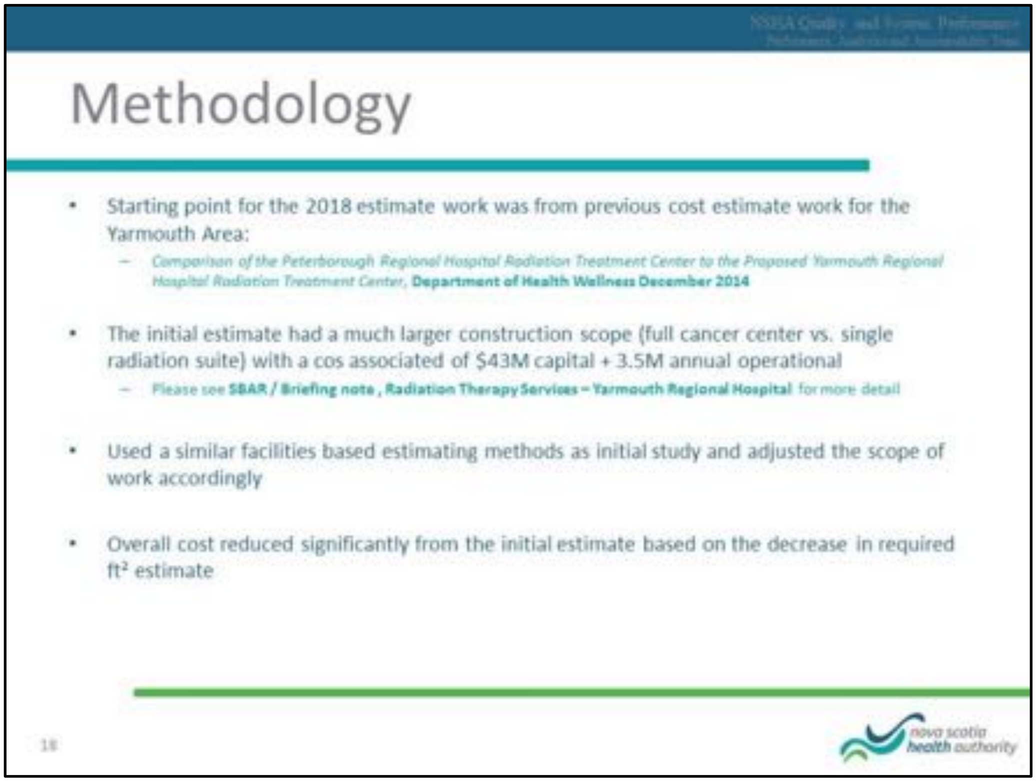

NSHA Quality and System Performance
Performance, Analytics and Accountability Team

Methodology

- Starting point for the 2018 estimate work was from previous cost estimate work for the Yarmouth Area:
  - *Comparison of the Peterborough Regional Hospital Radiation Treatment Center to the Proposed Yarmouth Regional Hospital Radiation Treatment Center*, **Department of Health Wellness December 2014**
- The initial estimate had a much larger construction scope (full cancer center vs. single radiation suite) with a cos associated of $43M capital + 3.5M annual operational
  - Please see **SBAR / Briefing note , Radiation Therapy Services – Yarmouth Regional Hospital** for more detail
- Used a similar facilities based estimating methods as initial study and adjusted the scope of work accordingly
- Overall cost reduced significantly from the initial estimate based on the decrease in required ft² estimate

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Appendix L. Equity Enhancing Work Book - Summary

Cancer burden for long travel patients				Total Cost $2,085,642
Drive Time greater or equal to (mins):		150		
Nova Scotia cancer rate:		0.66%	Quick analysis using cancer counts over NS population 2015	
Radiation treatment rate for new cancer patient		43%		
Radiation treatment factor for returning patients		30%		
% of patients requiring treatment at QEII:		19.0%	Quick analysis of CB radiation travel pattern over cancer counts (could do more validation	
Driving				
Number of trips per patient:		6	1 consult trip + 1 Simulation trip + 4 weeks 5 days per week	
$ per km reimbursement:	$	0.41	Northern Health Travel Grant Rate / KM	
Drive Cost per treatment	$	1,232	KM x 6 (number of trips) x 2 (roundtrip) x KM rate	
Lodging				
Price per dependent per night at Lodge	$	75		
Percent of patients for Lodge		80%		
Required nights estimate		20	4 weeks 5 days per week	
Price for hotel per night	$	149		
Percent of patients for hotel		20%		
Required nights estimate		22	4 weeks 5 days per week	
Meals				
Per diem meals allowance	$	50		
Required days estimate	$	22	1 consult trip + 1 Simulation trip + 4 weeks (20/5) radiotherapy treatment	
Parking				
Per day cost	$	15		
Required days estimate	$	22	1 consult trip + 1 Simulation trip + 4 weeks (20/5) radiotherapy treatment	
Dependents				
Percent of patients w/ dependents		15%		
Subsidized cost per day	$	50		
Required days estimate		22	1 consult trip + 1 Simulation trip + 4 weeks 5 days per week	
HHR Enhancements				
Admin Support Resrouce for Navigator	$	50,000		
Telehealth Coordinator	$	50,000		
Clinical Psychologist	$	130,000		

	Estimating radiation Patients in scope of > travel threshold					
County	Pop > drive time threshold to Halifax	Pop > drive time threshold to closest rad. facility	Delta	Rad. Pop. drive time threshold to closest rad.	Rad. Pop > drive time threshold to Halifax	Total Rad. Pop in scope
Annapolis	1739	1739	0	7	0	7
Antigonish	1493	0	1493	0	2	2
Cape Breton	98905	0	98905	0	69	69
Colchester	0	0	0	0	0	0
Cumberland	826	0	826	0	1	1
Digby	10772	10772	0	40	0	40
Guysborough	8258	4587	3671	17	3	20
Halifax	0	0	0	0	0	0
Hants	0	0	0	0	0	0
Inverness	16473	0	16473	0	12	12
Kings	0	0	0	0	0	0
Lunenburg	0	0	0	0	0	0
Pictou	0	0	0	0	0	0
Queens	0	0	0	0	0	0
Richmond	9304	0	9304	0	7	7
Shelburne	6883	6883	0	26	0	26
Victoria	6828	0	6828	0	5	5
Yarmouth	24988	24988	0	92	0	92
	186469	**48969**	**137500**	**182**	**99**	**281**

	SELF TRAVEL		TAXI					MEALS	LODGING		DEPENDENTS
County	Drive Time Cost	Parking Cost	1 Way - Close	Return - Close	1 Way - QEII Rad	Return - QEII Rad	Total Cost	Total Cost	Cost for dependent accompaniment at	Hotel cost for Lodge overflow	Total Cost
Annapolis	$ 8,627	$ 2,310	257	354	$ 257	354	$ 14,849	$ 7,700	$ 8,400	$ 4,589	$ 1,155
Antigonish	$ 2,465	$ 660	269	370	$ 280	386	$ 4,628	$ 2,200	$ 2,400	$ 1,311	$ 330
Cape Breton	$ 85,040	$ 22,770	36	50	$ 570	784	$ 324,618	$ 75,900	$ 82,800	$ 45,236	$ 11,385
Colchester	$ -	$ -	160	219	$ 160	219	$ -	$ -	$ -	$ -	$ -
Cumberland	$ 1,232	$ 330	123	169	$ 250	344	$ 2,062	$ 1,100	$ 1,200	$ 656	$ 165
Digby	$ 49,298	$ 13,200	346	476	$ 346	476	$ 114,139	$ 44,000	$ 48,000	$ 26,224	$ 6,600
Guysborough	$ 24,649	$ 6,600	323	444	$ 489	672	$ 57,427	$ 22,000	$ 24,000	$ 13,112	$ 3,300
Halifax	$ -	$ -	49	68	$ 49	68	$ -	$ -	$ -	$ -	$ -
Hants	$ -	$ -	105	145	$ 105	145	$ -	$ -	$ -	$ -	$ -
Inverness	$ 14,790	$ 3,960	228	313	$ 426	586	$ 42,199	$ 13,200	$ 14,400	$ 7,867	$ 1,980
Kings	$ -	$ -	178	245	$ 178	245	$ -	$ -	$ -	$ -	$ -
Lunenburg	$ -	$ -	156	215	$ 156	215	$ -	$ -	$ -	$ -	$ -
Pictou	$ -	$ -	212	291	$ 212	291	$ -	$ -	$ -	$ -	$ -
Queens	$ -	$ -	197	270	$ 197	270	$ -	$ -	$ -	$ -	$ -
Richmond	$ 8,627	$ 2,310	185	255	$ 431	593	$ 24,914	$ 7,700	$ 8,400	$ 4,589	$ 1,155
Shelburne	$ 32,044	$ 8,580	316	435	$ 316	435	$ 67,851	$ 28,600	$ 31,200	$ 17,046	$ 4,290
Victoria	$ 6,162	$ 1,650	174	239	$ 545	749	$ 22,466	$ 5,500	$ 6,000	$ 3,278	$ 825
Yarmouth	$ 113,386	$ 30,360	400	550	$ 400	550	$ 303,600	$ 101,200	$ 110,400	$ 60,315	$ 15,180
	$ 346,321	**$ 92,730**					**$978,753**	**$ 309,100**	**$ 337,200**	**$ 184,224**	**$ 46,365**

Methodology

Transportation

The first step was to calculate the proportion of travel for all radiation treatment patients. This was achieved using the Statistics Canada 2011 Census of Population data from Nova Scotia Community Counts as it is stratified at the local community level and can allow for more accurate travel distance calculations. Google Maps was used to determine the travel time from the local community data set to both cancer care sites (Halifax and Sydney). The SC decided on a travel time cut-off of 2.5 hours to the nearest radiation treatment centre.

Consulting with the SC's radiation oncologist, the average number of round-trips per patient is six (one-day initial consultation, one-day simulation, four weeks of radiation treatment with one return trip each week).

The projected cost for travel was informed by the cost of taxi travel from Yarmouth to Halifax ($550) and applying a travel factor to each community count (see Equity-Enhancing workbook). The cost was also calculated based on $0.41/kilometer reimbursement cost for patients preferring to use their own vehicle and the cost for parking of $15 per day for required radiation treatment days (22 days average).

Lodging

Patients who require lodging in Halifax often stay at The Lodge That Gives if there is availability. The cost is free for patients, but a fee of $75 per night is charged for a support person. Working group members recommended that lodging be covered for one support person at a cost of $75 per night. When accommodation at The Lodge That Gives is unavailable, the cost for a hotel room near the cancer centre in Halifax is approximately $150 per night. Costing was based on the assumption that approximately 80% of radiation treatment patients and their support person can stay at The Lodge That Gives as opposed to a hotel.

Meals

The working group recommended that each radiation treatment patient and one support person be provided with a $50 per diem meal allowance for required treatment days (22 days average).

Home Support

The working group assumed that 15% of all affected radiation therapy patients would benefit from and apply for subsidized support for dependents who remain at home in Yarmouth during their course of treatment in Halifax.

Appendix M. Terms of Deliberative Engagement

(Approved on 27 February 2018)

A. Skilled Facilitation

- Facilitation of the deliberations is provided by a member of the working group (WG) who has:
    - Good/excellent facilitation skills
    - No or minimal vested interest(s) in the decision or recommendation to be made
    - A working knowledge of healthcare delivery/systems
- Other features:
    - Encouragement of respectful discourse
    - Enabling of voices of all WG members during the deliberations
    - ‘As you go’ capacity building regarding the deliberative approach to decision making
    - Paying of attention to keeping the deliberations focused, i.e., on track and on time

B. Adoption of an ‘Engaged Participation’ Role

- In the role of engaged participation, WG members are encouraged and supported by the facilitator and their fellow members to constructively bring their individual and professional perspectives, values and attitudes to the deliberations (in contrast to a traditional representational role in which a WG member may feel an obligation to protect and further the interests of the particular group that she/he is representing)

C. Approach to Deliberating Together

- Safe, non-confrontational communication
- Open consideration of all perspectives and points of view
- Collective application of relevant values and principles to the decision making
- Consideration, and optimal balancing, of any competing obligations that arise during the deliberations
- Collaborative development of ‘best arguments’ on all sides of relevant questions/issues
- Identification and comparison of the anticipated benefits and burdens of possible decision making options

D. ‘Consensus-seeking’ or Democratic Decision Making

- Decisions are made through a consensus-seeking process which encourages the development of a consensus that ‘all can live with’ and support outside of the WG; if such a consensus is not possible, decisions/recommendations are made by majority vote

Appendix N. Other Supporting Documents

i. Public Service Announcement, February 7, 2018

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Nova Scotia Cancer Care Program

Public Service Announcement

Nova Scotia Health Authority's Cancer Care Program will hold two community focus groups in Yarmouth as part of its review of cancer services. The focus groups are one way for patients, families and community members to share their thoughts on having to travel for specialty cancer services such as radiation therapy and to talk about the supports that would make travelling for treatment easier.

The focus groups will be held in the Bluenose Room at Yarmouth Regional Hospital on February 20:

- 3:30 – 5 p.m.
- 6:30 – 8 p.m.

Space is limited to 12 people per session. To register, please call or email Leslie Hill at 1-866-599-2267 or leslie.hill@nshealth.ca

Those unable to participate in a focus group will have an opportunity to share their thoughts by completing an electronic survey.

ii. Media Release/Advisory, June 11, 2018

nova scotia
health authority
Nova Scotia Cancer Care Program

MEDIA ADVISORY

Engagement session to be held as part of Yarmouth area cancer services review

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FOR IMMEDIATE RELEASE
June 11, 2018

HALIFAX, N.S. – An engagement session will be held June 13 in Yarmouth as part of the ongoing Nova Scotia Health Authority (NSHA) review of cancer services in the area.

As part of NSHA's review, 943 Nova Scotians completed surveys and 24 people from Yarmouth participated in two focus groups.

"We were very pleased with the interest and thoughtful responses we received from the community," said Dr. Drew Bethune, medical director of NSHA's Nova Scotia Cancer Care Program. "The information we learned from the survey and focus groups will be shared during the upcoming engagement session.

The June 13 meeting will be a full-day, facilitated in-camera discussion with 15 stakeholders, including three patient advisers and cancer health professionals from Yarmouth and Halifax. They will listen to and discuss information collected and shared through presentations, including summarized results from focus groups and surveys, as well as demographic information and cancer data.

NSHA's review of cancer services got underway last fall. It is expected to be complete this summer.

-30-

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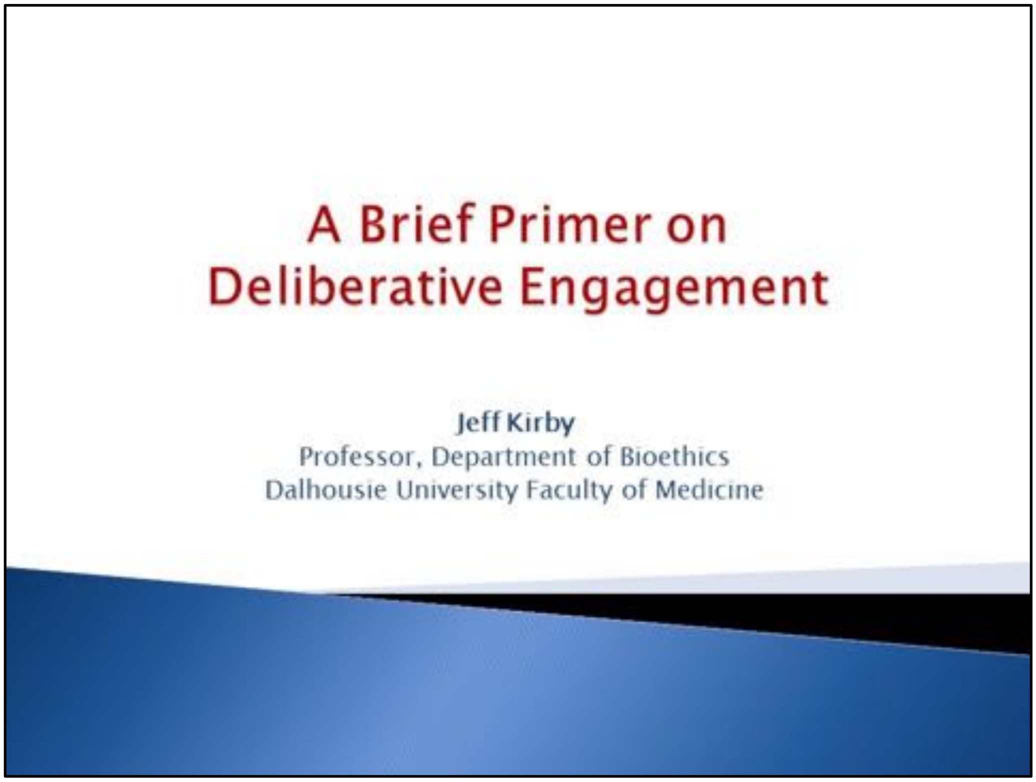
Provincial Media Line: 1-844-483-3344

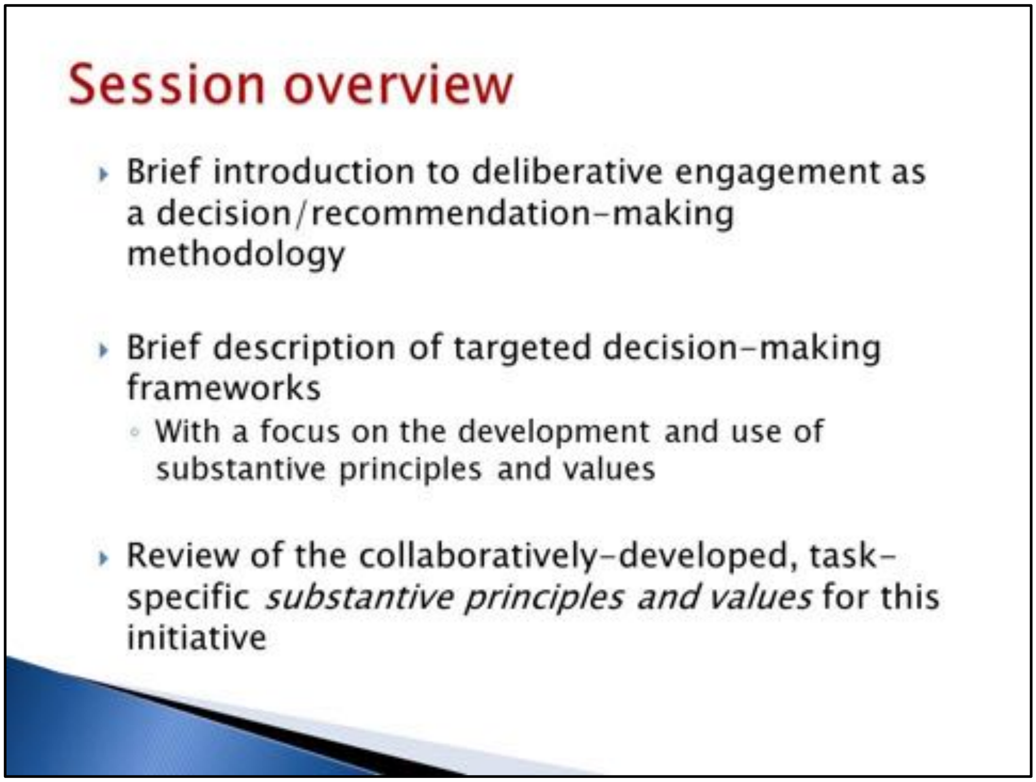
About Nova Scotia Health Authority
Nova Scotia Health Authority (NSHA) provides health services to Nova Scotians and a wide array of specialized services to Maritimers and Atlantic Canadians. NSHA operates hospitals, health centres and community-based programs across the province. Our team of health professionals includes employees, doctors, researchers, learners and volunteers. We work in partnership with community groups, schools, governments, foundations and auxiliaries and community health boards. Visit www.nshealth.ca for more.

iii. DES Presentation – A Brief Primer on Deliberative Engagement



A Brief Primer on Deliberative Engagement

Jeff Kirby
Professor, Department of Bioethics
Dalhousie University Faculty of Medicine



Session overview

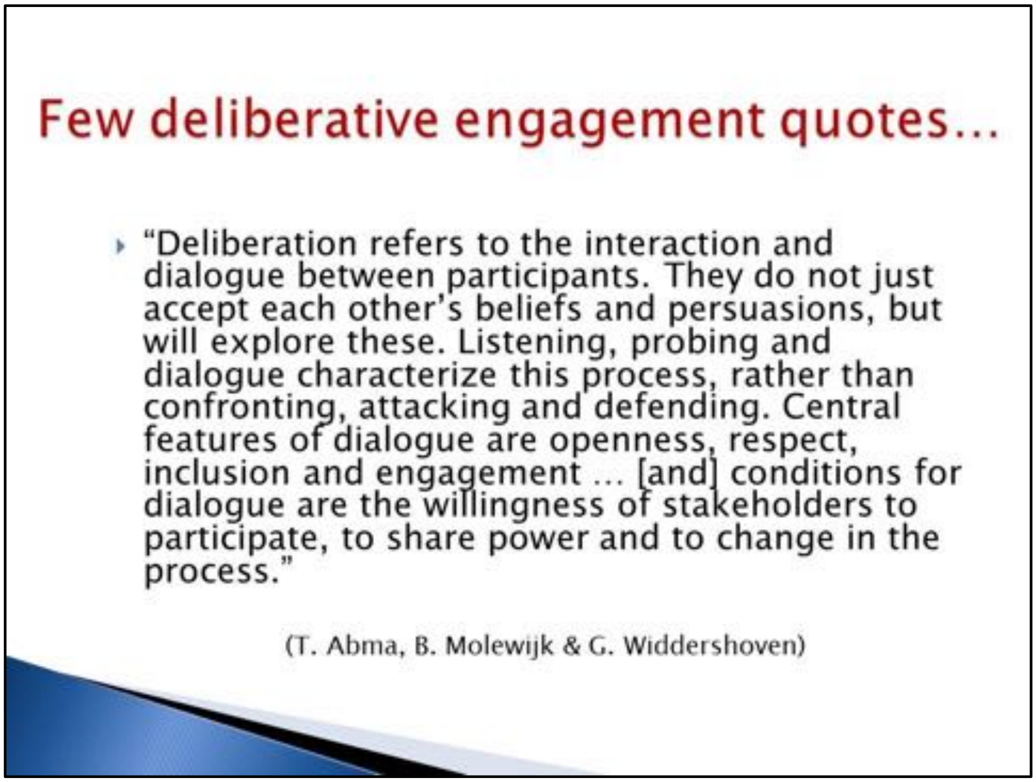
- Brief introduction to deliberative engagement as a decision/recommendation-making methodology
- Brief description of targeted decision-making frameworks
  - With a focus on the development and use of substantive principles and values
- Review of the collaboratively-developed, task-specific *substantive principles and values* for this initiative

Deliberative engagement

- Influence of social justice theorists…
  - Who have advocated for the use of structured, stakeholder-driven processes that are deliberative in nature and informed by collaboratively-chosen principles and values to: 1) make system-level healthcare decisions, and 2) develop health policies
  - According to Margaret Urban Walker, the relevant goals are to: 1) create a "moral-reflective space …where a sound and shared process of deliberation and negotiation can go on", and 2) develop a legitimate and dynamic means to "deliberate so that we may act justifiably, in a way we can convincingly account for in moral terms."

Deliberative engagement

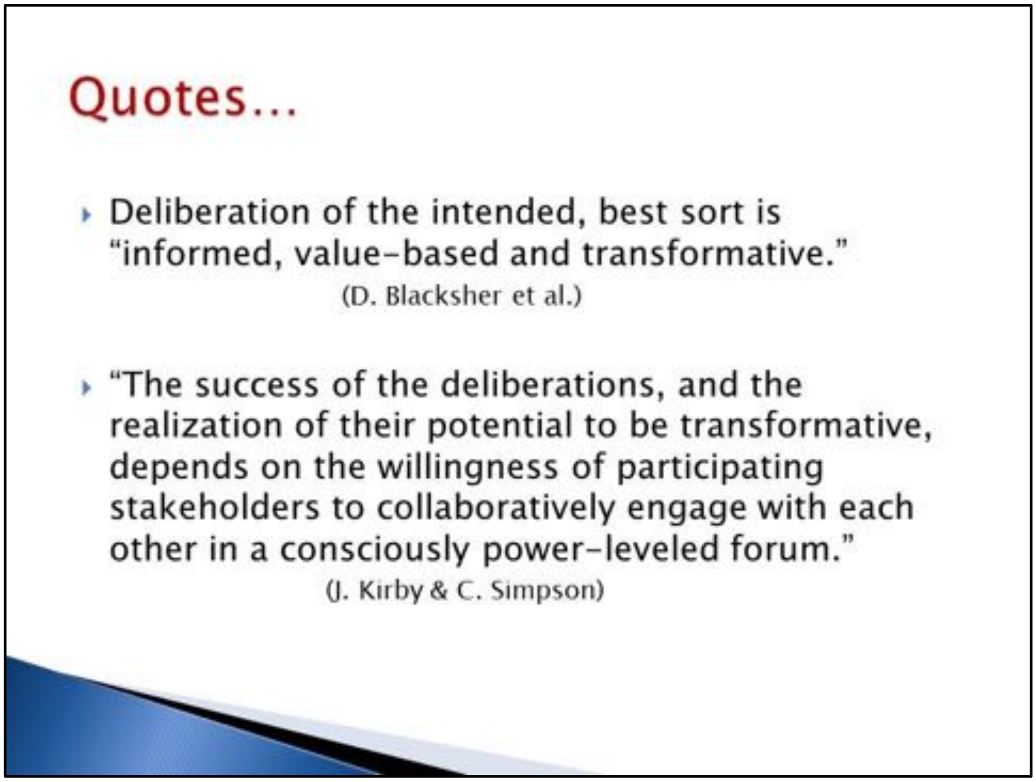
- Conception of healthcare decision making and health policy development as 'moral enterprises'
- According to Iris Marion Young, individuals who decide on behalf of affected others within collective institutions are obliged to demonstrate that <u>their deliberations and decisions have taken into meaningful account the interests and perspectives of all relevant stakeholders</u>



Few deliberative engagement quotes…

- "Deliberation refers to the interaction and dialogue between participants. They do not just accept each other's beliefs and persuasions, but will explore these. Listening, probing and dialogue characterize this process, rather than confronting, attacking and defending. Central features of dialogue are openness, respect, inclusion and engagement … [and] conditions for dialogue are the willingness of stakeholders to participate, to share power and to change in the process."

(T. Abma, B. Molewijk & G. Widdershoven)



Quotes…

- Deliberation of the intended, best sort is "informed, value-based and transformative."

(D. Blacksher et al.)

- "The success of the deliberations, and the realization of their potential to be transformative, depends on the willingness of participating stakeholders to collaboratively engage with each other in a consciously power-leveled forum."

(J. Kirby & C. Simpson)

Key elements of deliberative engagement

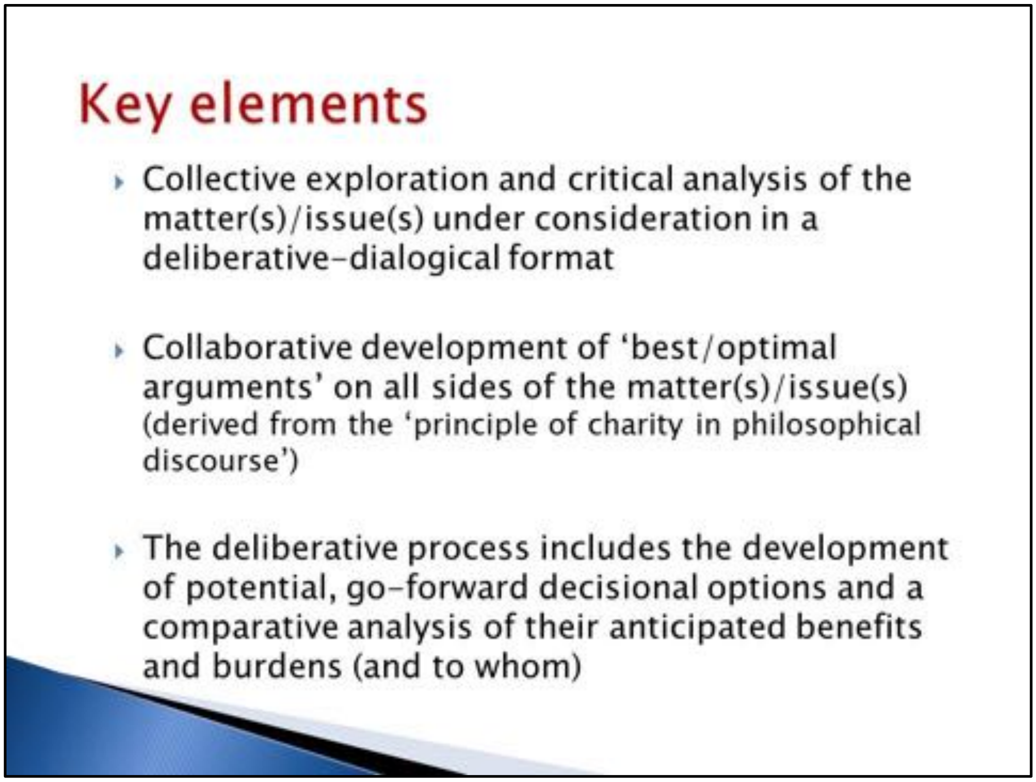
- Gathering of the ‘right’ deliberators including participants from core stakeholder groups and relevant resource persons
- Development and use of a relevantly-targeted decision/recommendation-making framework

Key elements

- Competent facilitation
  - Ideally, the facilitator(s) has a working knowledge of healthcare systems and no particular, vested interests in the decisional outcome(s)
  - Roles/functions of the facilitator include:
    - Enabling all ‘voices’
    - Paying careful attention to proactive, dynamic management of relevant power dynamics
    - Mitigating non-constructive conflict and extended ‘flights of fancy’

Key elements

- Encouragement, as possible, of deliberators' adoption of an 'engaged participation' role
- Agreement on, and collectively endorsed use of, *terms of deliberative engagement*
- Collaborative development and use of relevant, task-specific *substantive principles and values*
- Potential sharing during the deliberative engagement session of: 1) 'gut responses' to the matter(s)/issue(s) at hand, and 2) starting positions (in a safe space for expression of the legitimate, affective dimensions of the work)

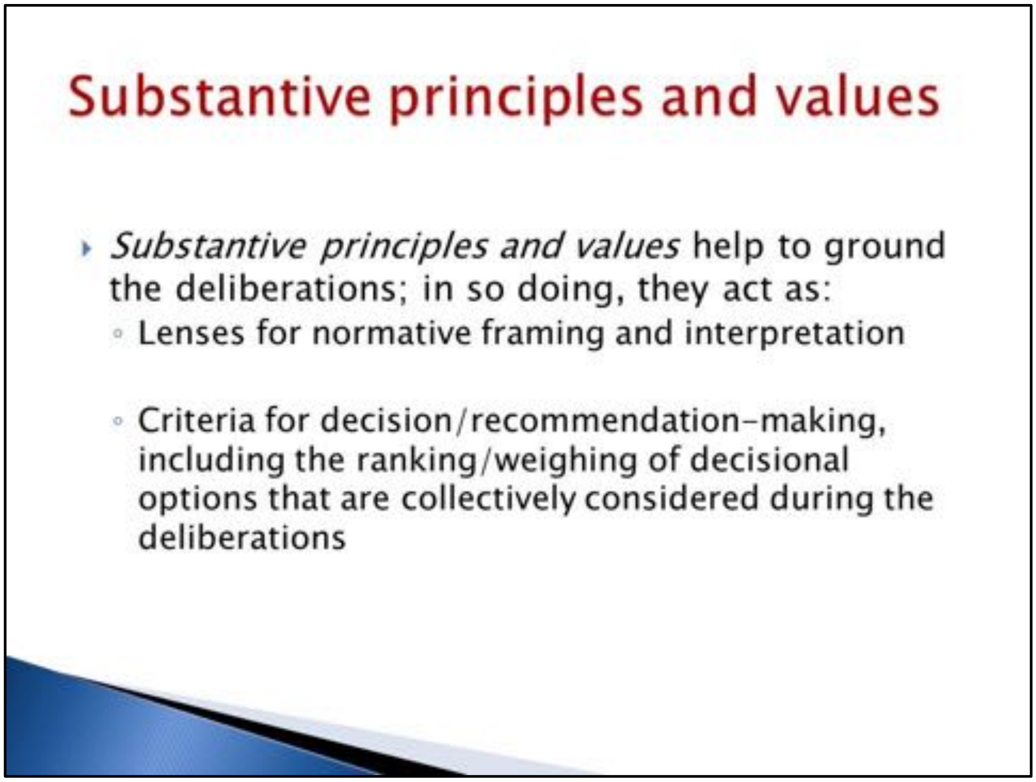


Key elements

- Collective exploration and critical analysis of the matter(s)/issue(s) under consideration in a deliberative-dialogical format
- Collaborative development of 'best/optimal arguments' on all sides of the matter(s)/issue(s) (derived from the 'principle of charity in philosophical discourse')
- The deliberative process includes the development of potential, go-forward decisional options and a comparative analysis of their anticipated benefits and burdens (and to whom)

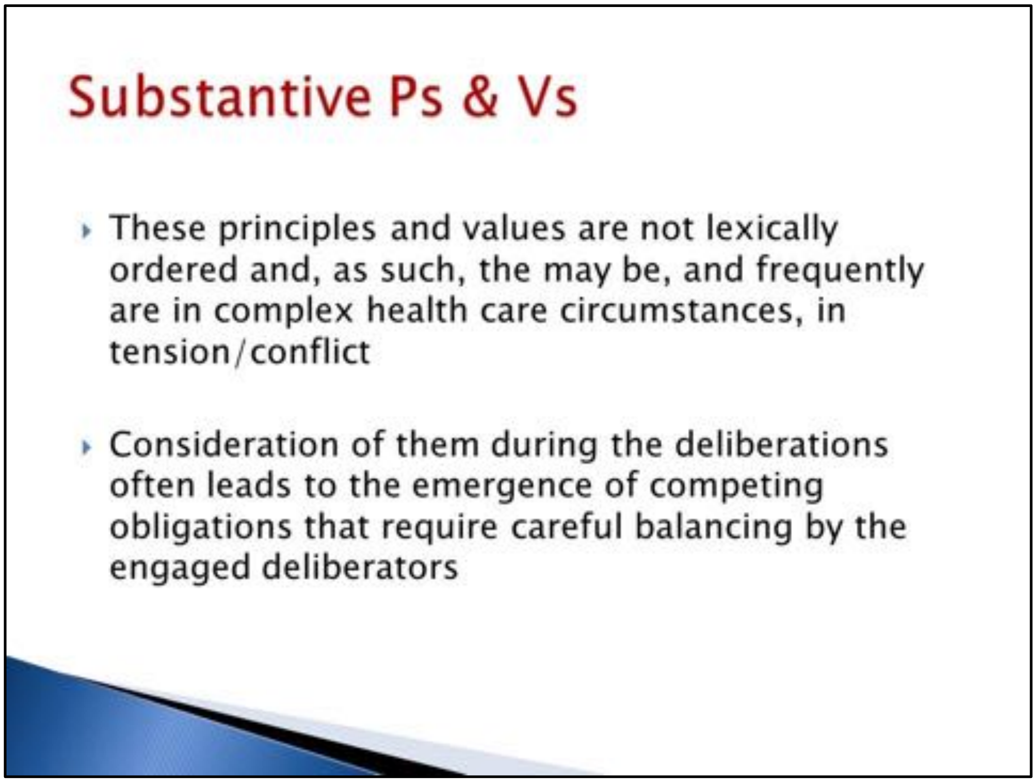
Recommendation-making frameworks

- Targeted decision/recommendation-making frameworks aim to facilitate the balanced application of multiple relevant 'lenses' to decision- and recommendation-making within healthcare organizations



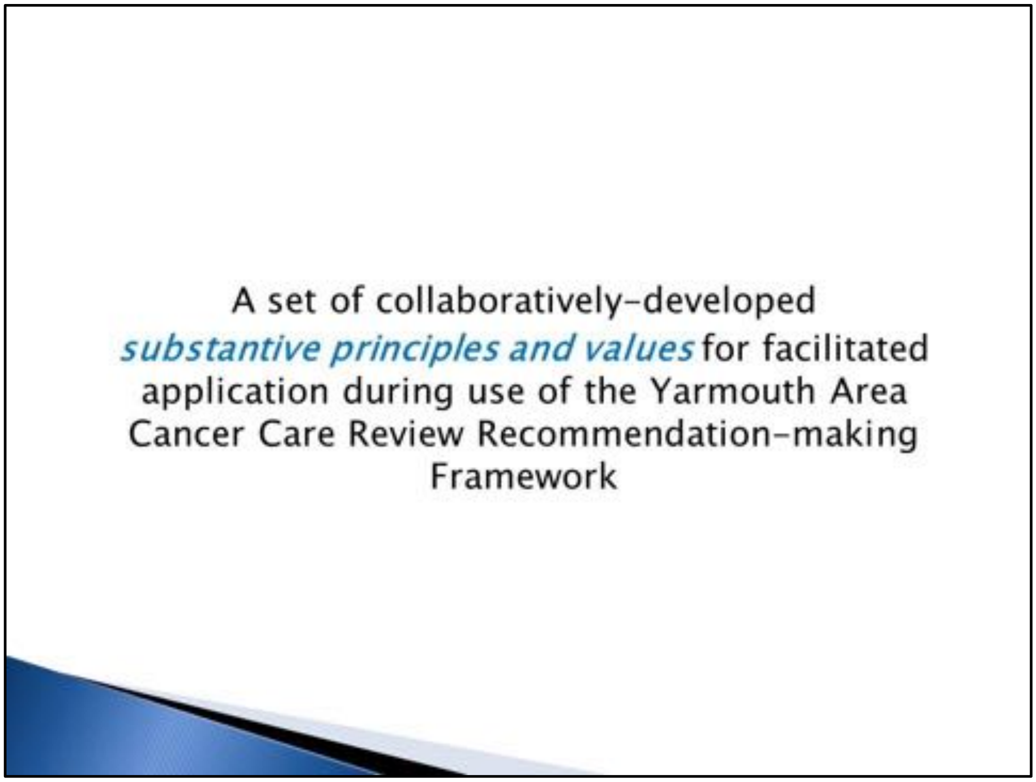
Substantive principles and values

- *Substantive principles and values* help to ground the deliberations; in so doing, they act as:
  - Lenses for normative framing and interpretation
  - Criteria for decision/recommendation-making, including the ranking/weighing of decisional options that are collectively considered during the deliberations

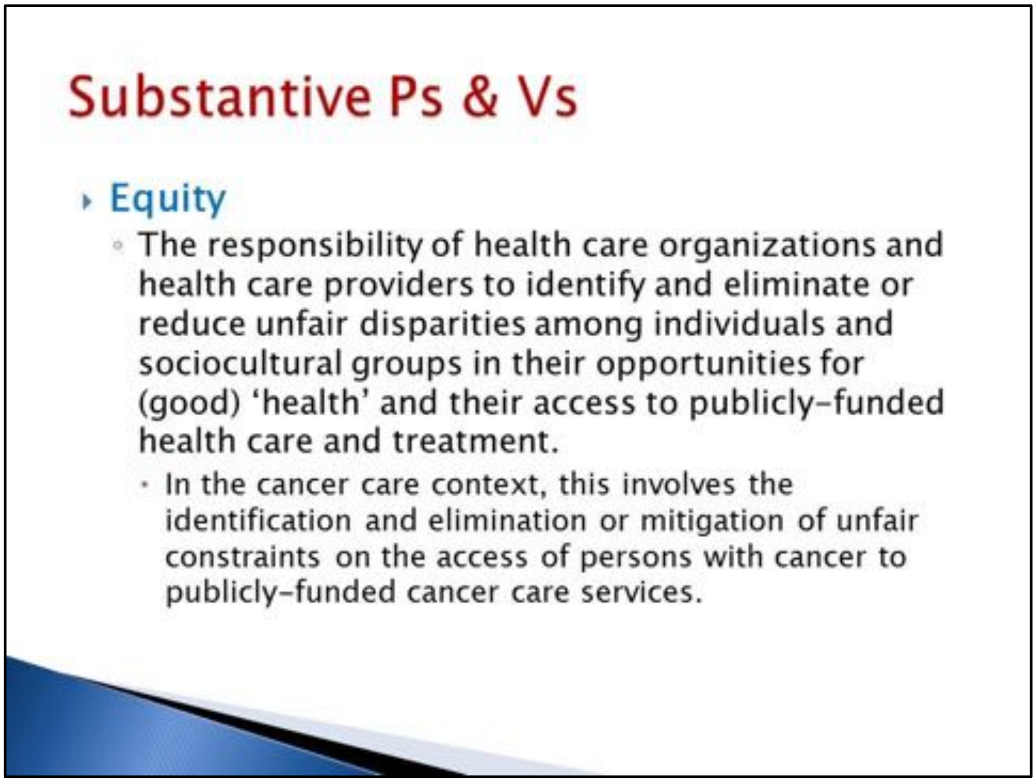


Substantive Ps & Vs

- These principles and values are not lexically ordered and, as such, the may be, and frequently are in complex health care circumstances, in tension/conflict
- Consideration of them during the deliberations often leads to the emergence of competing obligations that require careful balancing by the engaged deliberators

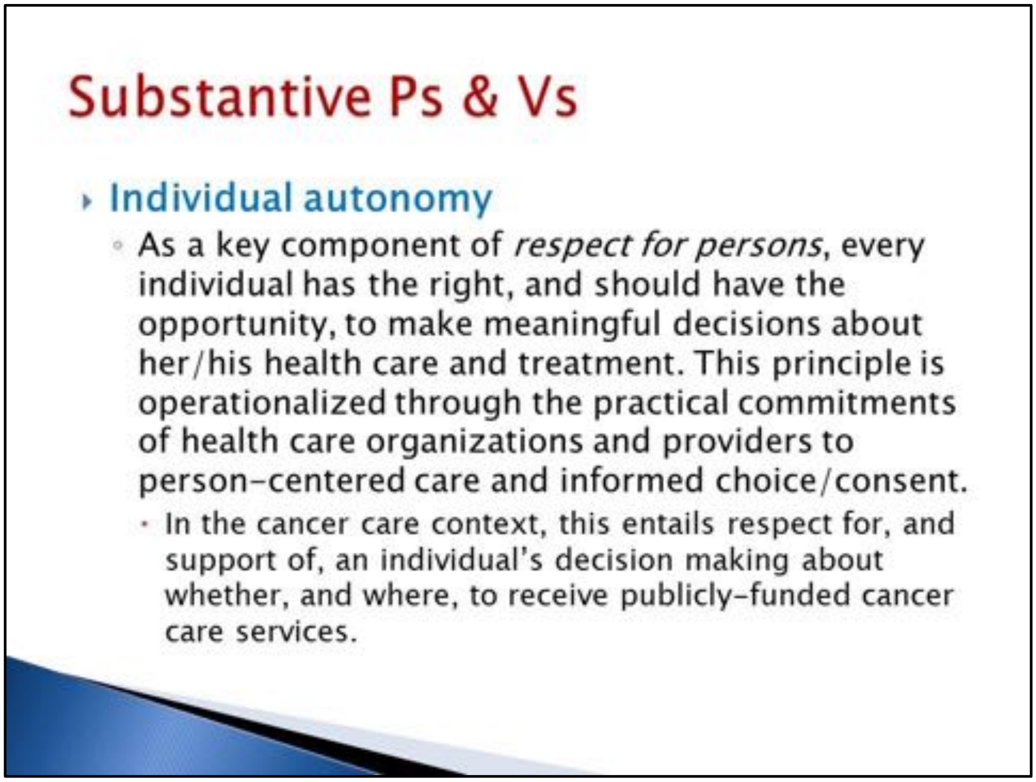


A set of collaboratively-developed *substantive principles and values* for facilitated application during use of the Yarmouth Area Cancer Care Review Recommendation-making Framework



Substantive Ps & Vs

- Equity
  - The responsibility of health care organizations and health care providers to identify and eliminate or reduce unfair disparities among individuals and sociocultural groups in their opportunities for (good) 'health' and their access to publicly-funded health care and treatment.
    - In the cancer care context, this involves the identification and elimination or mitigation of unfair constraints on the access of persons with cancer to publicly-funded cancer care services.

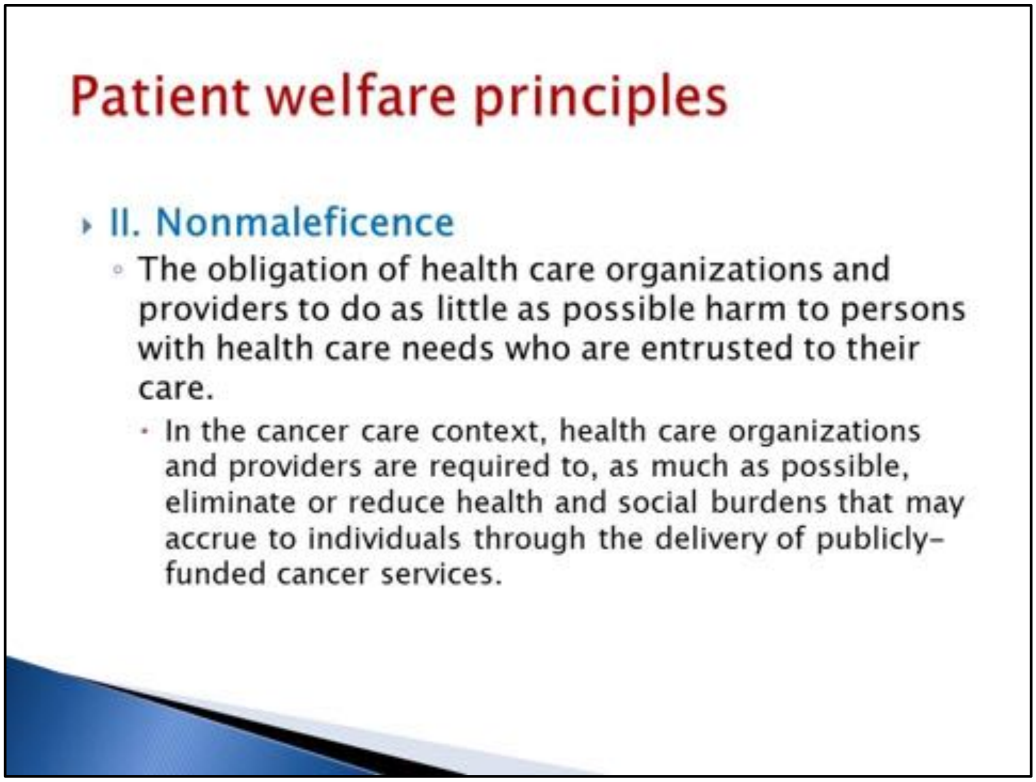


Substantive Ps & Vs

- Individual autonomy
  - As a key component of *respect for persons*, every individual has the right, and should have the opportunity, to make meaningful decisions about her/his health care and treatment. This principle is operationalized through the practical commitments of health care organizations and providers to person-centered care and informed choice/consent.
    - In the cancer care context, this entails respect for, and support of, an individual's decision making about whether, and where, to receive publicly-funded cancer care services.

Patient welfare principles

- I. Beneficence and duty-of-care
  - The obligation of health care providers and organizations to provide compassionate, nonjudgmental, dignity-promoting and culturally-sensitive care to persons who have health care needs.
    - In the cancer care context, this includes the responsibility of health care organizations and providers to deliver quality care and therapeutic benefits (through the provision of publicly-funded cancer care services) to persons with cancer.



Patient welfare principles

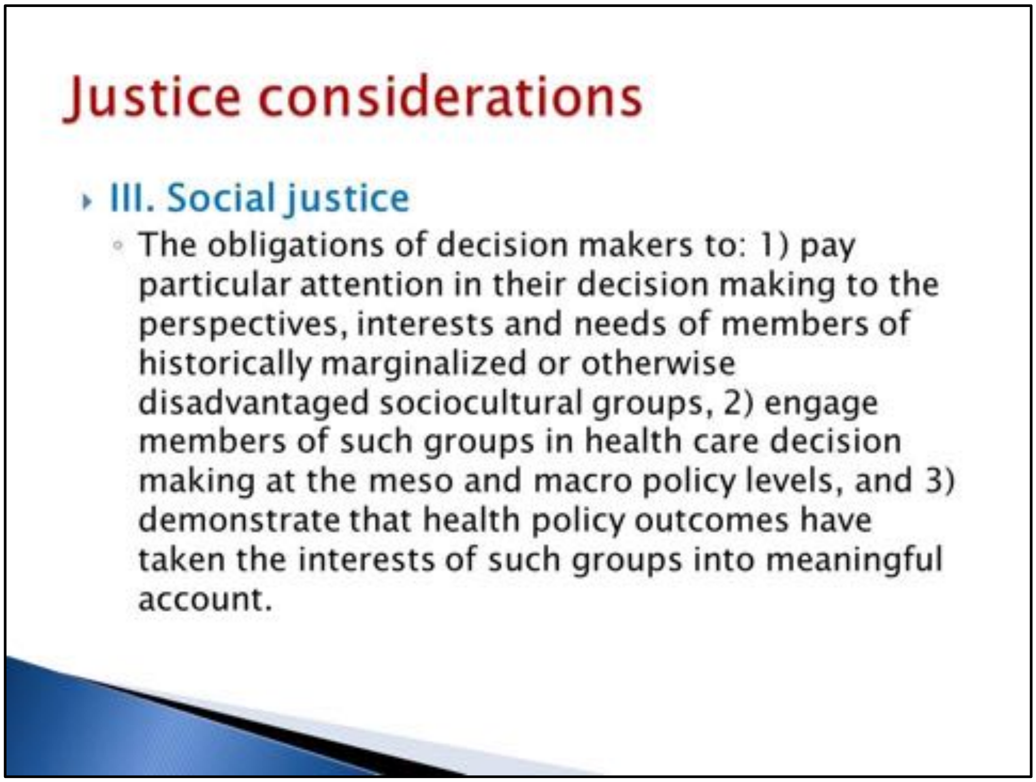
- II. Nonmaleficence
  - The obligation of health care organizations and providers to do as little as possible harm to persons with health care needs who are entrusted to their care.
    - In the cancer care context, health care organizations and providers are required to, as much as possible, eliminate or reduce health and social burdens that may accrue to individuals through the delivery of publicly-funded cancer services.

Relevant Justice forms/types…

- I. Traditional distributive justice
  - Social benefits, including health care and treatment, are to be fairly distributed/allocated within a given jurisdiction on a specified basis(es), e.g., in the case of publicly-funded health care delivery, on the bases of health care needs and available health resources.
    - Concept of a ‘fixed pot’ of limited health resources in the jurisdiction of Nova Scotia (NSHA)…

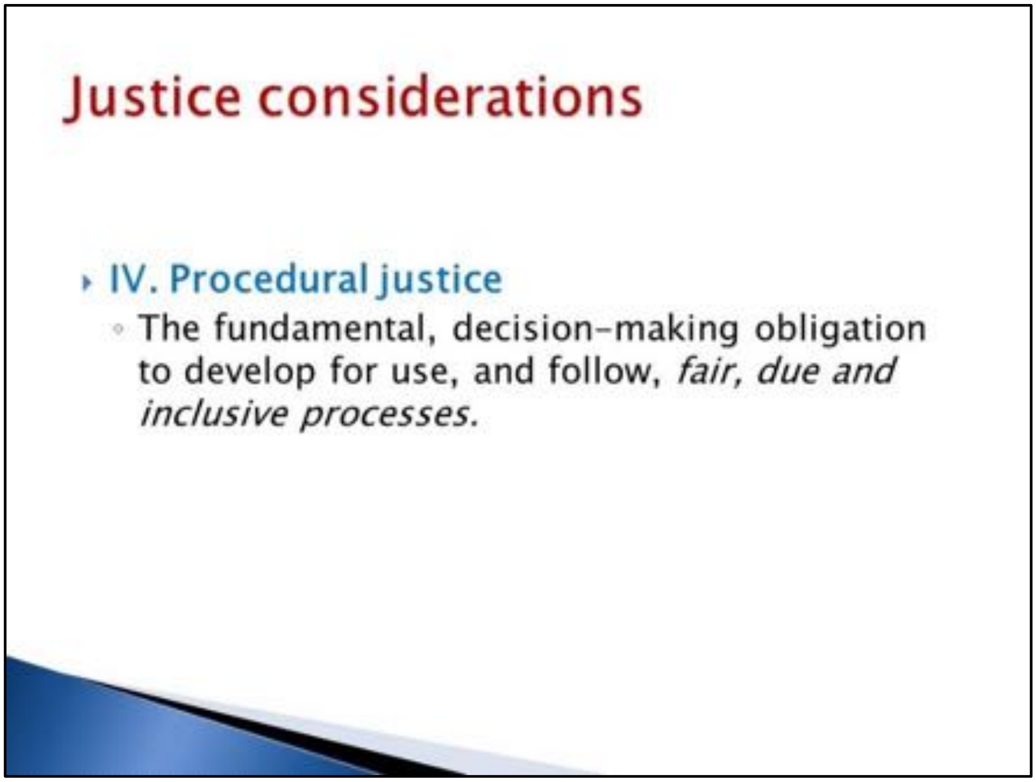
Justice considerations

- II. Formal justice
  - Like individuals and sociocultural groups should be treated alike, and dissimilar individuals and sociocultural groups should be treated dissimilarly, i.e., individuals and groups of persons are to be treated alike unless there is a demonstrable, *relevant* difference between/among them that would justify different treatment.



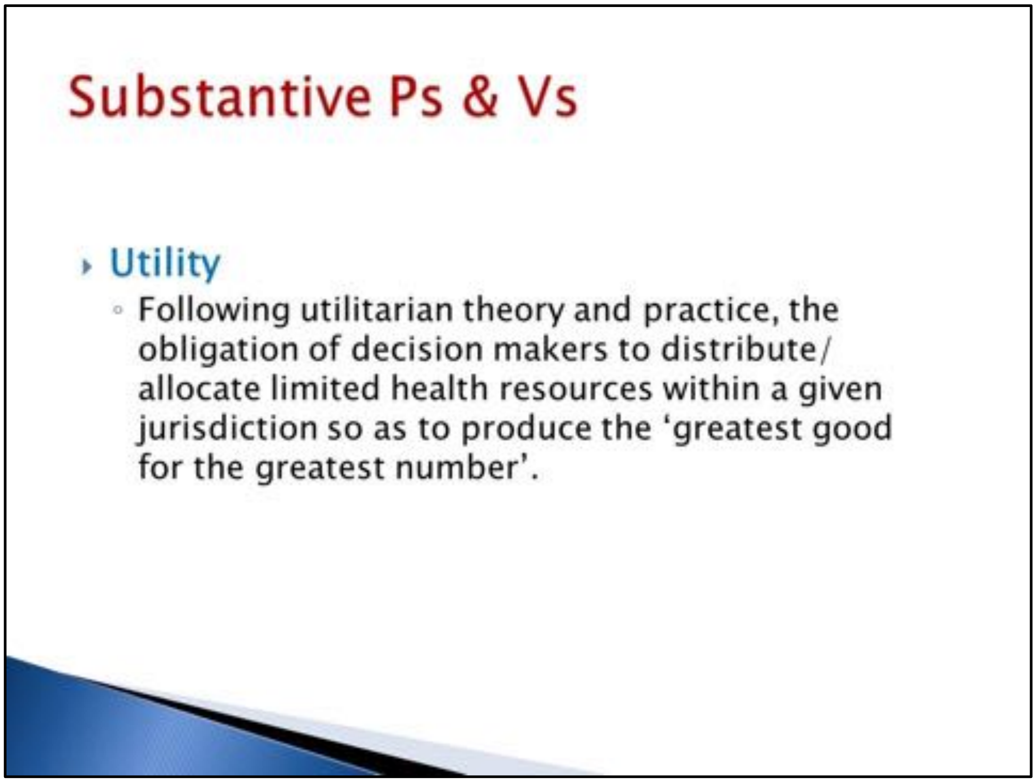
Justice considerations

- III. Social justice
  - The obligations of decision makers to: 1) pay particular attention in their decision making to the perspectives, interests and needs of members of historically marginalized or otherwise disadvantaged sociocultural groups, 2) engage members of such groups in health care decision making at the meso and macro policy levels, and 3) demonstrate that health policy outcomes have taken the interests of such groups into meaningful account.



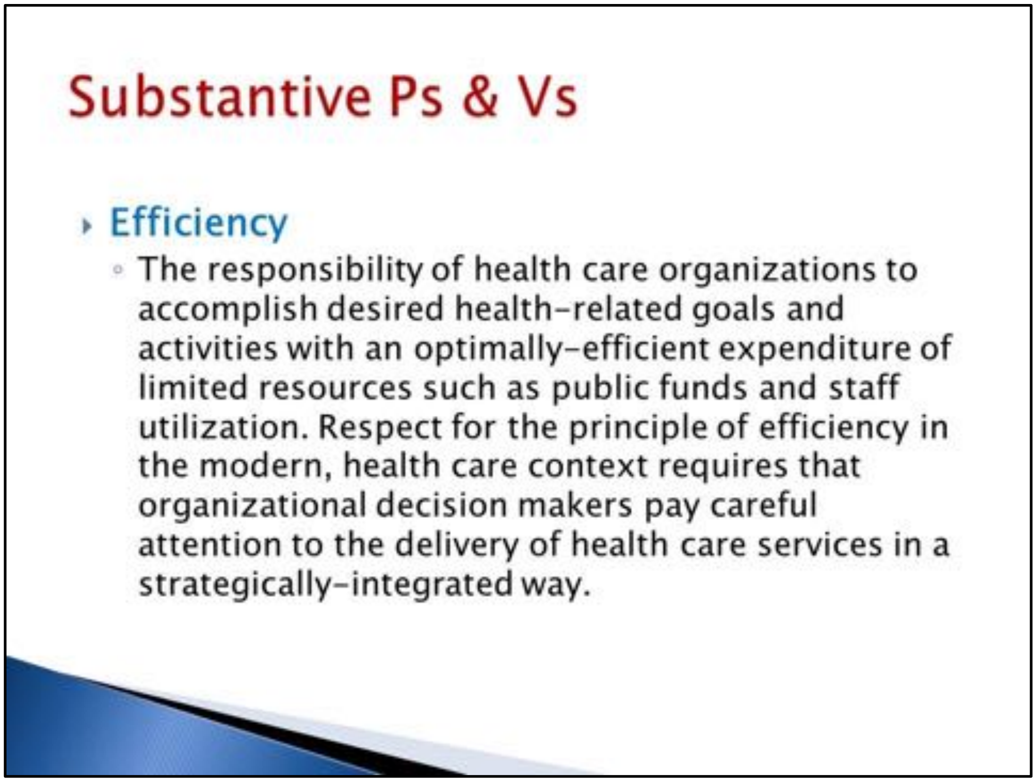
Justice considerations

- IV. Procedural justice
  - The fundamental, decision-making obligation to develop for use, and follow, *fair, due and inclusive processes.*



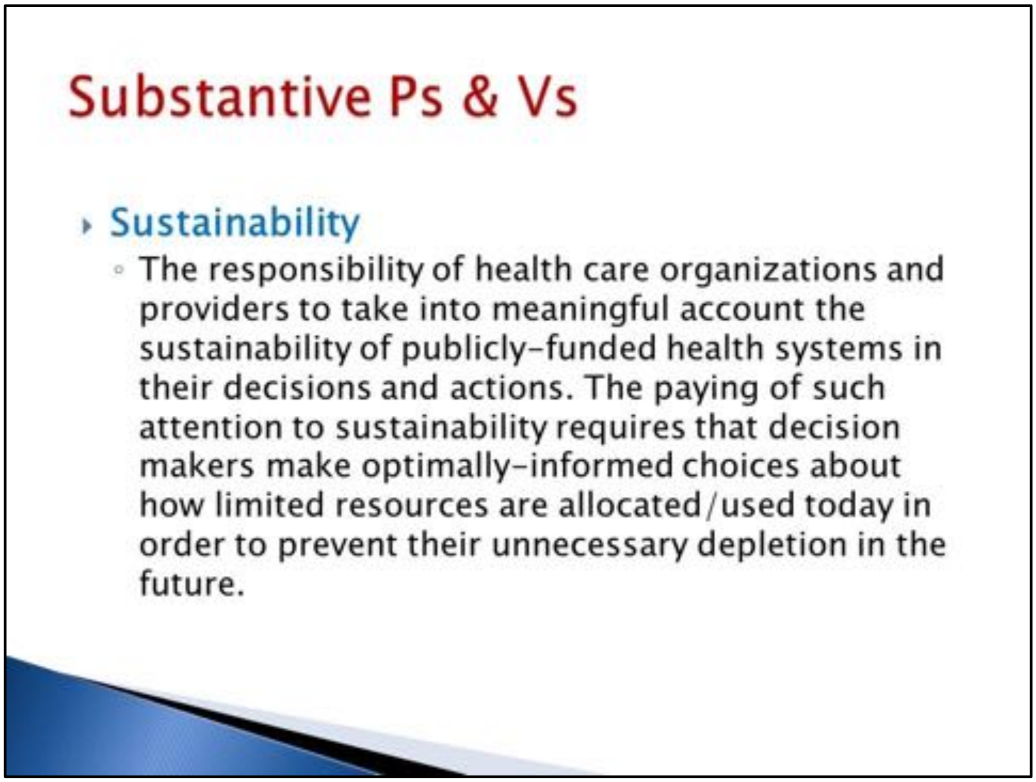
Substantive Ps & Vs

- Utility
  - Following utilitarian theory and practice, the obligation of decision makers to distribute/ allocate limited health resources within a given jurisdiction so as to produce the 'greatest good for the greatest number'.



Substantive Ps & Vs

- Efficiency
  - The responsibility of health care organizations to accomplish desired health-related goals and activities with an optimally-efficient expenditure of limited resources such as public funds and staff utilization. Respect for the principle of efficiency in the modern, health care context requires that organizational decision makers pay careful attention to the delivery of health care services in a strategically-integrated way.



Substantive Ps & Vs

- Sustainability
  - The responsibility of health care organizations and providers to take into meaningful account the sustainability of publicly-funded health systems in their decisions and actions. The paying of such attention to sustainability requires that decision makers make optimally-informed choices about how limited resources are allocated/used today in order to prevent their unnecessary depletion in the future.

iv. DES Presentation – Communications and Engagement

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Communications and Engagement –
Yarmouth Area Cancer Services Review

June 13, 2018

Communication and Engagement Activities

- Steering Committee established in late fall 2017
- Members included cancer health professionals from Yarmouth and Halifax and three patient/public advisors
- Members work established a project charter, outlining the scope of the work and broad timelines
- Communication and engagement plan developed and fine-tuned, focusing on an open and transparent process with community input.

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Engaging with stakeholders

- Recruited public advisors to join Steering Committee (Fall 2017)
- January 18th visit to Yarmouth for meetings with cancer care program staff and community leaders to share the review process, its scope and to listen to concerns and answer questions
- Team met with cancer program staff, board members of Yarmouth Hospital Foundation, municipal councilors, and Derek Lesser, the organizer of a Facebook group advocating for radiation therapy in Yarmouth
- Following meetings, a media release was issued; it summarized the information shared, and Dr. Bethune was interviewed by a reporter from the Yarmouth Vanguard

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Information shared:

- Government and NSHA have heard the community's concerns about having to travel long distances for radiation treatment
- Cancer Program established a steering committee with patient advisors and health professionals from Yarmouth and Halifax to conduct a thorough review
- Review to consider: cancer statistics, cost estimates to design, build and operate a radiation therapy facility in Yarmouth, other cancer priorities and needs across the province and feedback from the community
- Invited community groups to select an individual as their representative on the Steering Committee

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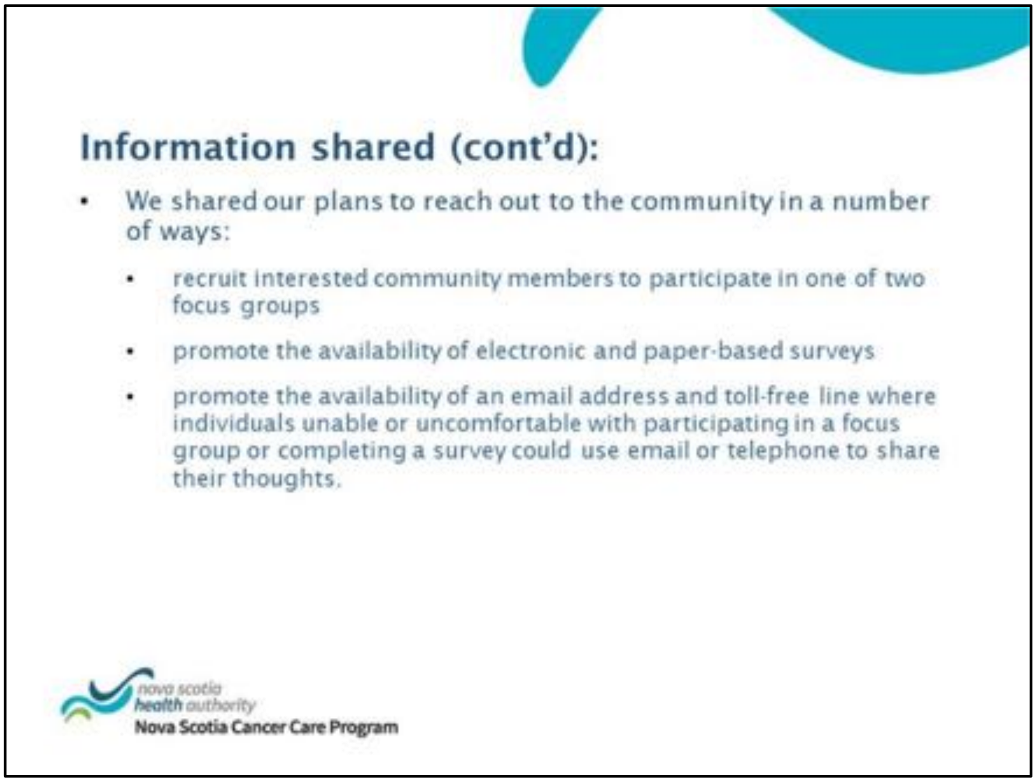

Information shared (cont'd):

- We shared our plans to reach out to the community in a number of ways:
  - recruit interested community members to participate in one of two focus groups
  - promote the availability of electronic and paper-based surveys
  - promote the availability of an email address and toll-free line where individuals unable or uncomfortable with participating in a focus group or completing a survey could use email or telephone to share their thoughts.

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Community Interest

- Two focus groups with 12 people registered in each group, were held on February 20 in Yarmouth (the opportunity was promoted with a public service announcement, posting on social media, by sharing with our Cancer Patient Family Network, cancer health professionals in Yarmouth and area and community leaders)
- Electronic and paper-based surveys were made available in early April (promoted through the same channels as the focus groups). We received 943 responses.

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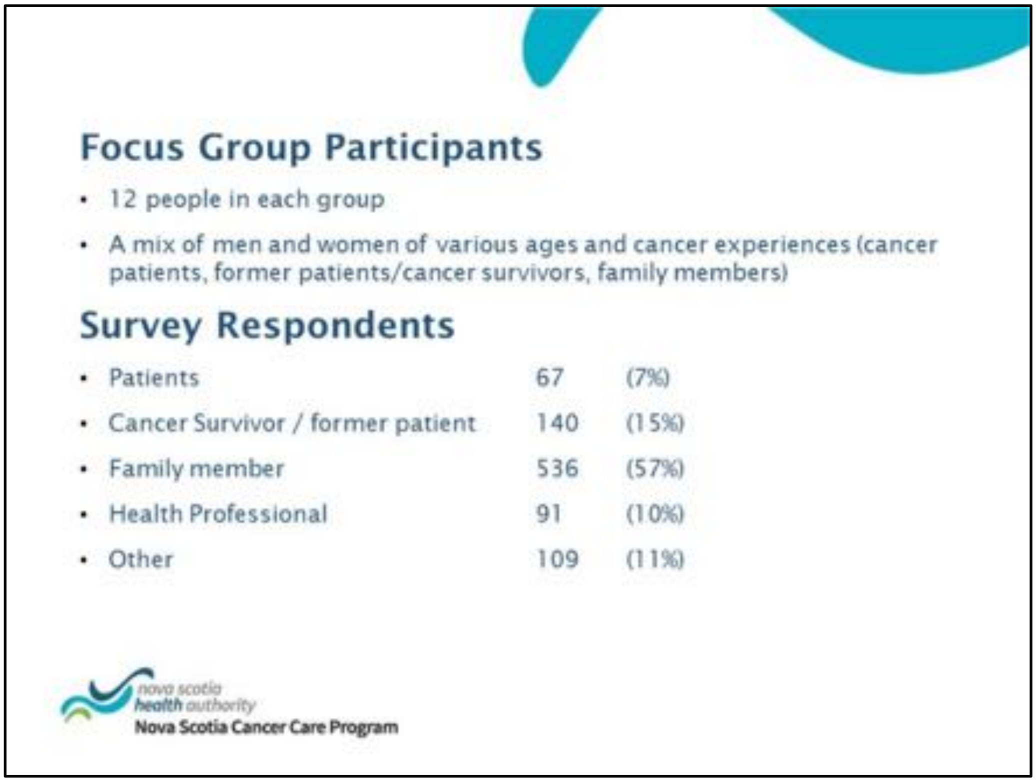

Focus Group Participants

- 12 people in each group
- A mix of men and women of various ages and cancer experiences (cancer patients, former patients/cancer survivors, family members)

Survey Respondents

Patients	67	(7%)
Cancer Survivor / former patient	140	(15%)
Family member	536	(57%)
Health Professional	91	(10%)
Other	109	(11%)

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What we learned:

Survey respondents noted four key challenges in traveling to Halifax for cancer treatment

- Travel
  - traveling in poor weather
  - when someone is ill
- Emotional toll of being away from home
- Emotional toll of travel to, and being in Halifax for treatment
- Out of pocket expenses

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What we learned:

Quotes from the survey

"An elderly family friend actually had to decline treatment in Halifax because he just would not know how to manage alone in such a foreign place and no one could go and stay for the weeks needed."

"The loneliness of being away from family and friends at a time when you need them the most, fear of spending your limited time left ALONE and scared."

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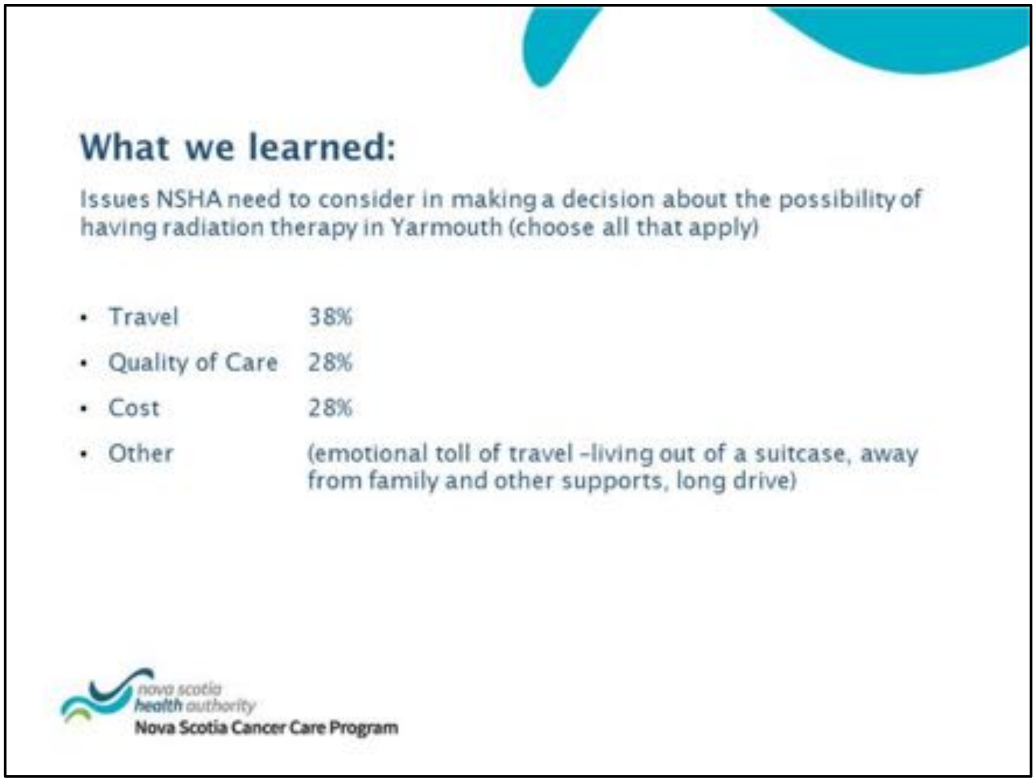

What we learned:

Issues NSHA need to consider in making a decision about the possibility of having radiation therapy in Yarmouth (choose all that apply)

• Travel	38%
• Quality of Care	28%
• Cost	28%
• Other	(emotional toll of travel -living out of a suitcase, away from family and other supports, long drive)

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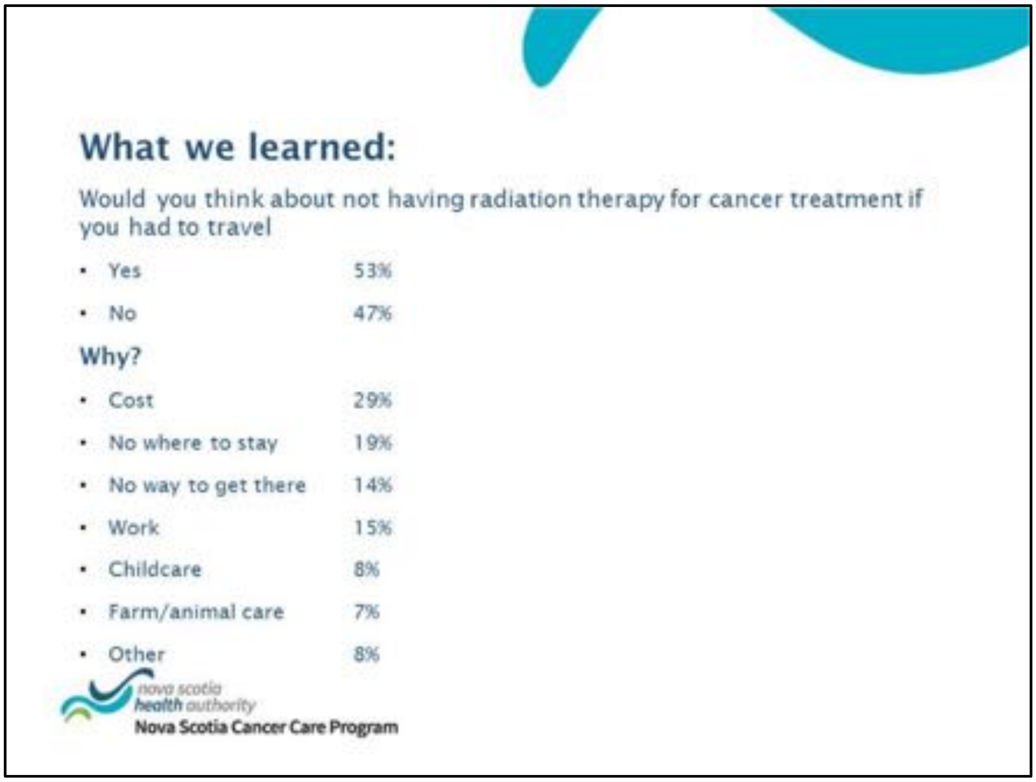

What we learned:

Would you think about not having radiation therapy for cancer treatment if you had to travel

Yes	53%
No	47%

Why?

Cost	29%
No where to stay	19%
No way to get there	14%
Work	15%
Childcare	8%
Farm/animal care	7%
Other	8%

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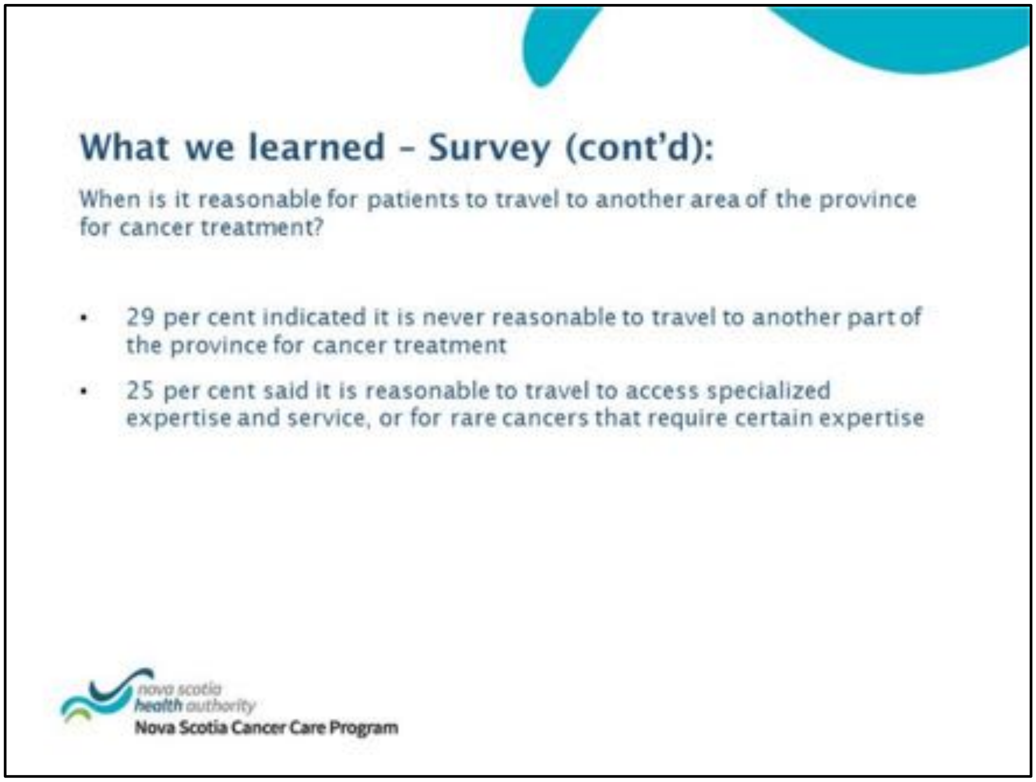

What we learned – Survey (cont'd):

When is it reasonable for patients to travel to another area of the province for cancer treatment?

- 29 per cent indicated it is never reasonable to travel to another part of the province for cancer treatment
- 25 per cent said it is reasonable to travel to access specialized expertise and service, or for rare cancers that require certain expertise

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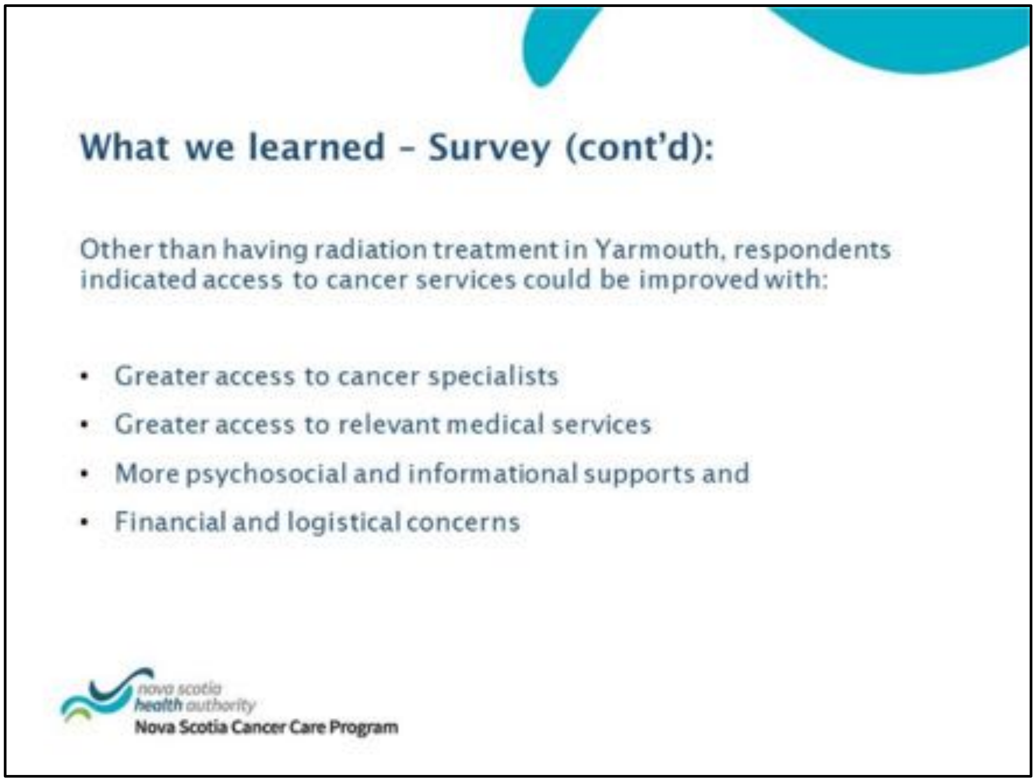

What we learned – Survey (cont'd):

Other than having radiation treatment in Yarmouth, respondents indicated access to cancer services could be improved with:

- Greater access to cancer specialists
- Greater access to relevant medical services
- More psychosocial and informational supports and
- Financial and logistical concerns

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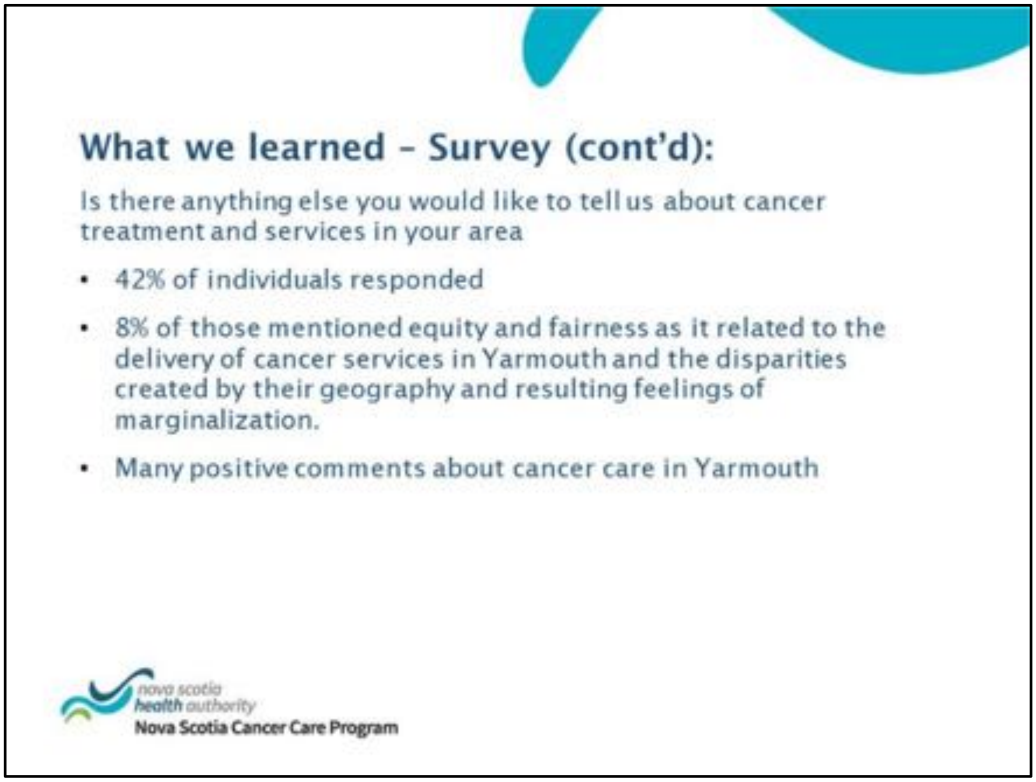

What we learned – Survey (cont'd):

Is there anything else you would like to tell us about cancer treatment and services in your area

- 42% of individuals responded
- 8% of those mentioned equity and fairness as it related to the delivery of cancer services in Yarmouth and the disparities created by their geography and resulting feelings of marginalization.
- Many positive comments about cancer care in Yarmouth

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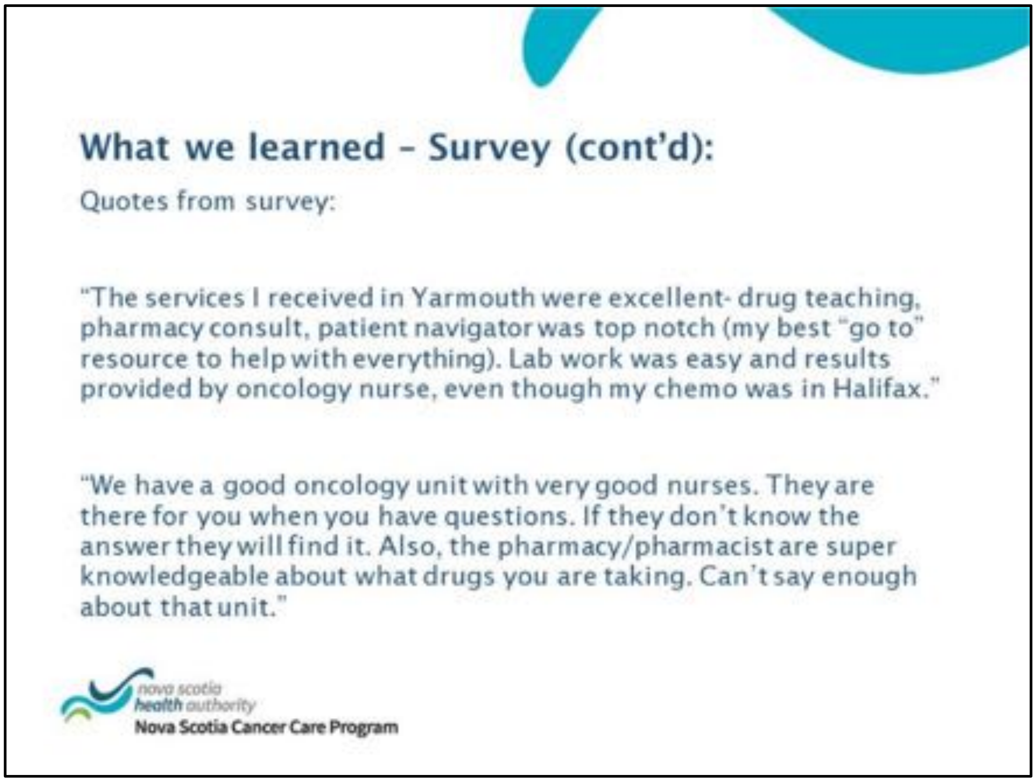

What we learned – Survey (cont'd):

Quotes from survey:

"The services I received in Yarmouth were excellent- drug teaching, pharmacy consult, patient navigator was top notch (my best "go to" resource to help with everything). Lab work was easy and results provided by oncology nurse, even though my chemo was in Halifax."

"We have a good oncology unit with very good nurses. They are there for you when you have questions. If they don't know the answer they will find it. Also, the pharmacy/pharmacist are super knowledgeable about what drugs you are taking. Can't say enough about that unit."

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What we learned – Focus Groups

Shared similar thoughts and concerns as those shared by survey respondents

They spoke of the challenges of being away from home and family for a period of time, noting the impact on family, children, work, lifestyle, and emotional wellbeing

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Additional communication with stakeholders

- A focus group report was developed and shared with participants, to ensure the content included represented the discussion, before being finalized (March 2018)
- Media Advisory regarding next steps in the review process was issued to media south western Nova Scotia on June 11.
- The Media Advisory was also share with steering committee members, cancer care program staff and community leaders

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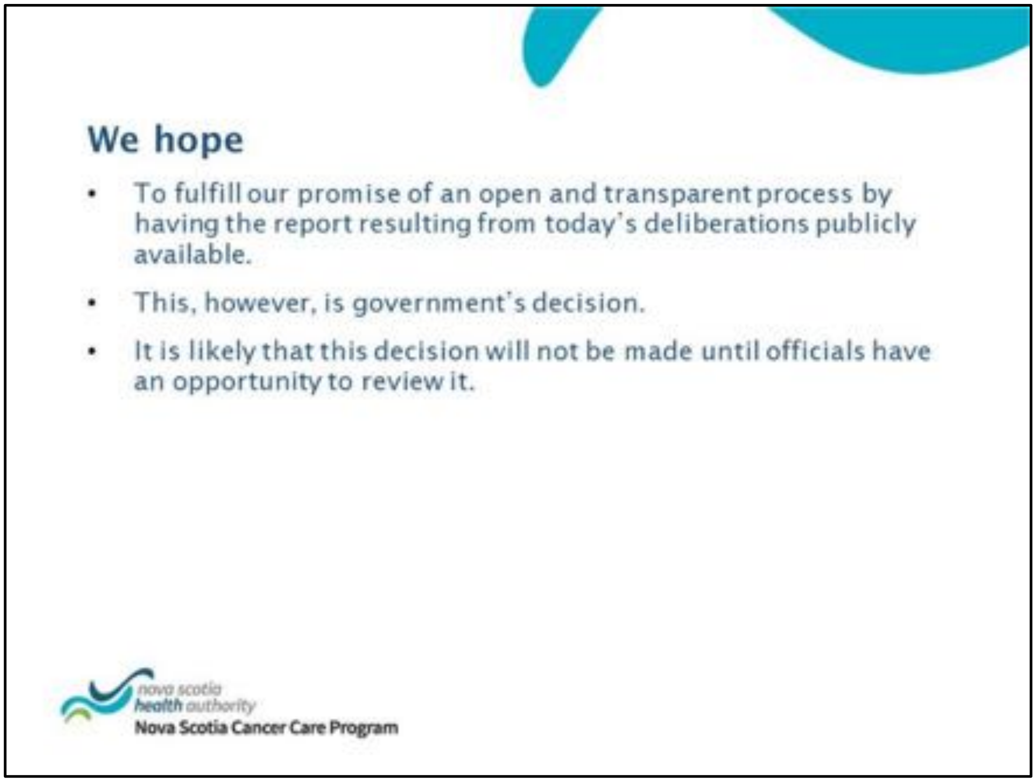

We hope

- To fulfill our promise of an open and transparent process by having the report resulting from today's deliberations publicly available.
- This, however, is government's decision.
- It is likely that this decision will not be made until officials have an opportunity to review it.

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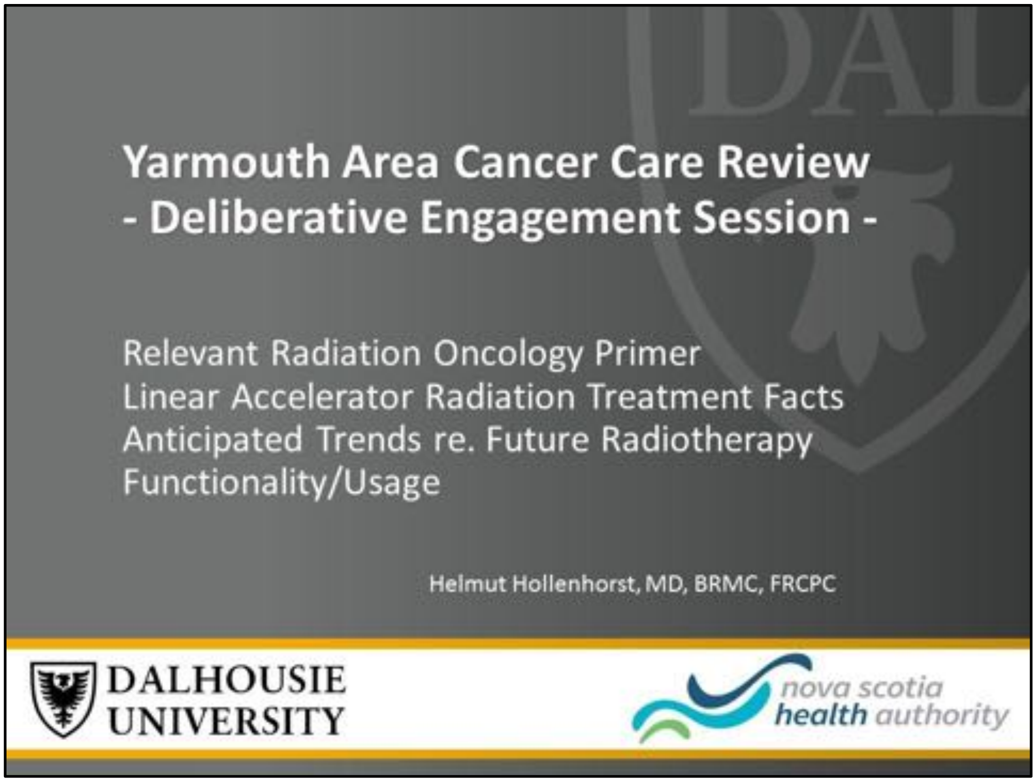
v. DES Presentation - Radiation Oncology Primer – Linear Accelerator Radiation Treatment Facts



Yarmouth Area Cancer Care Review
- Deliberative Engagement Session -

Relevant Radiation Oncology Primer
Linear Accelerator Radiation Treatment Facts
Anticipated Trends re. Future Radiotherapy Functionality/Usage

Helmut Hollenhorst, MD, BRMC, FRCPC

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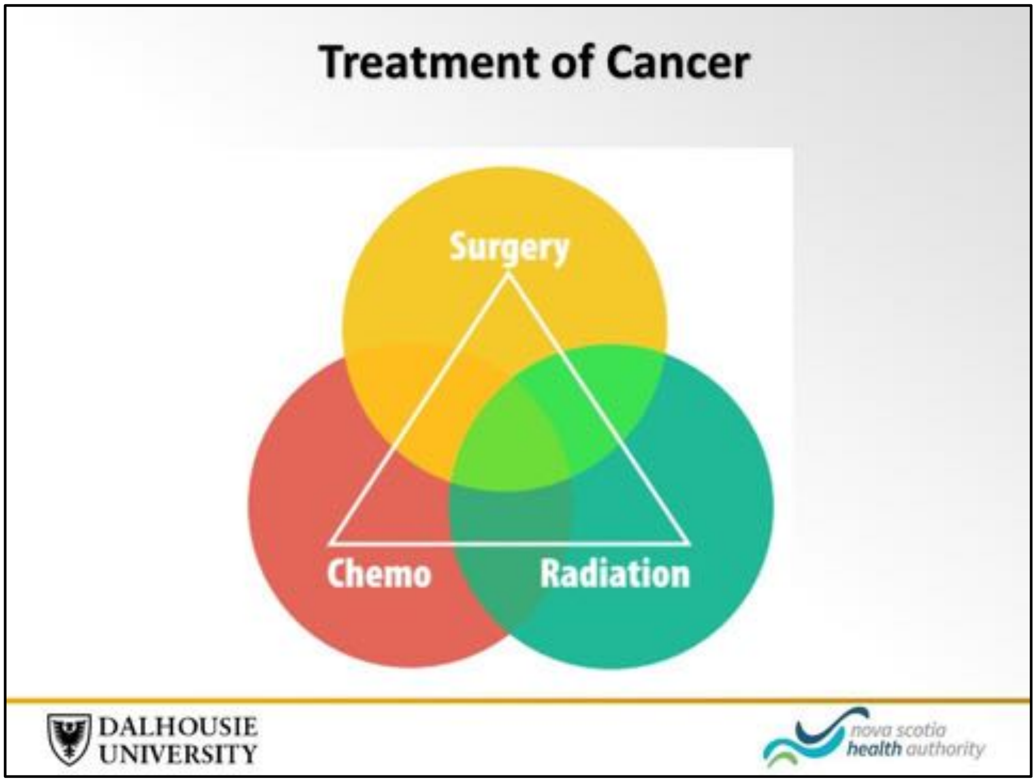

Treatment of Cancer

Surgery

Chemo

Radiation

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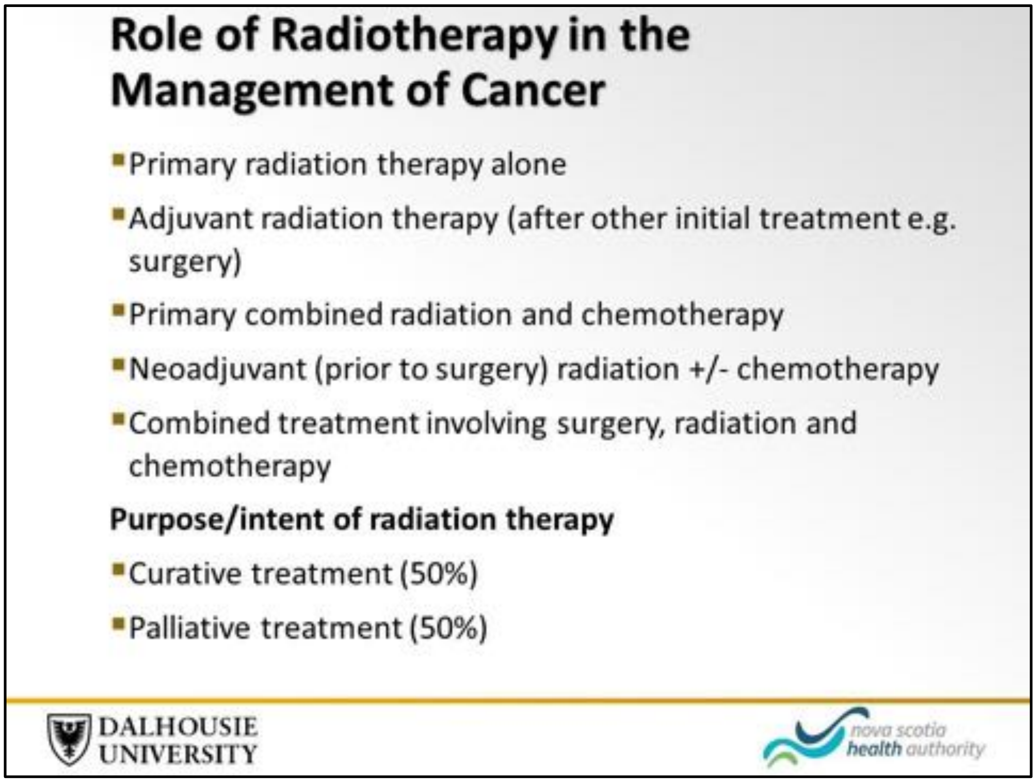

Role of Radiotherapy in the Management of Cancer

- Primary radiation therapy alone
- Adjuvant radiation therapy (after other initial treatment e.g. surgery)
- Primary combined radiation and chemotherapy
- Neoadjuvant (prior to surgery) radiation +/- chemotherapy
- Combined treatment involving surgery, radiation and chemotherapy

Purpose/intent of radiation therapy

- Curative treatment (50%)
- Palliative treatment (50%)

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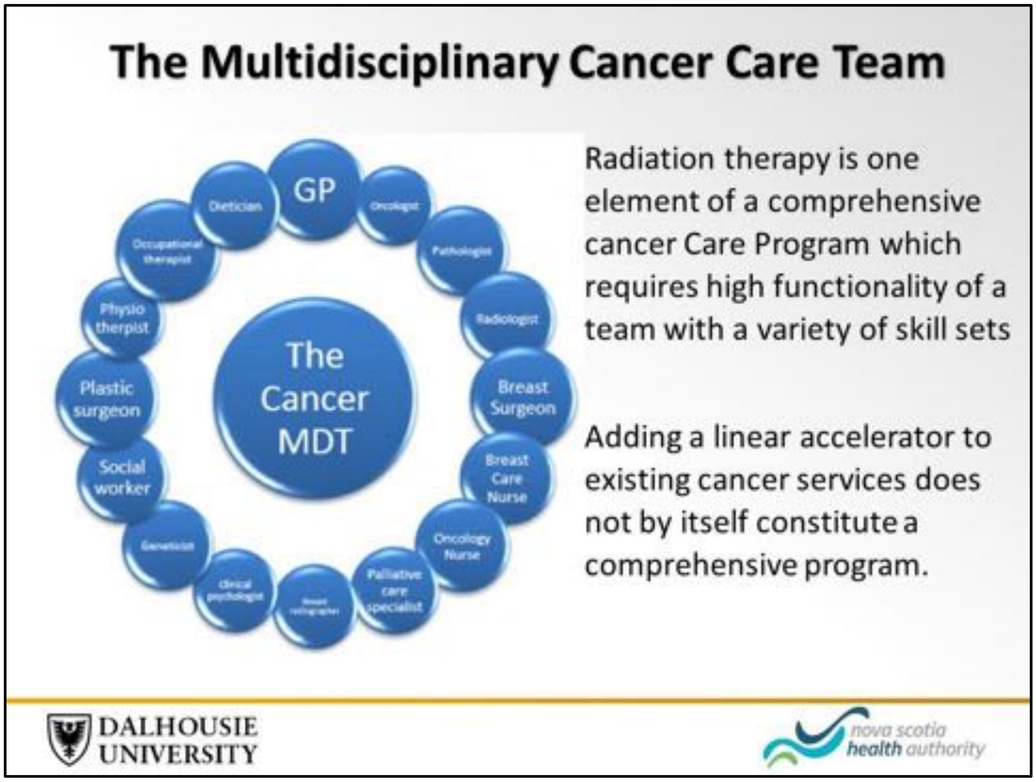

The Multidisciplinary Cancer Care Team

Radiation therapy is one element of a comprehensive cancer Care Program which requires high functionality of a team with a variety of skill sets

Adding a linear accelerator to existing cancer services does not by itself constitute a comprehensive program.

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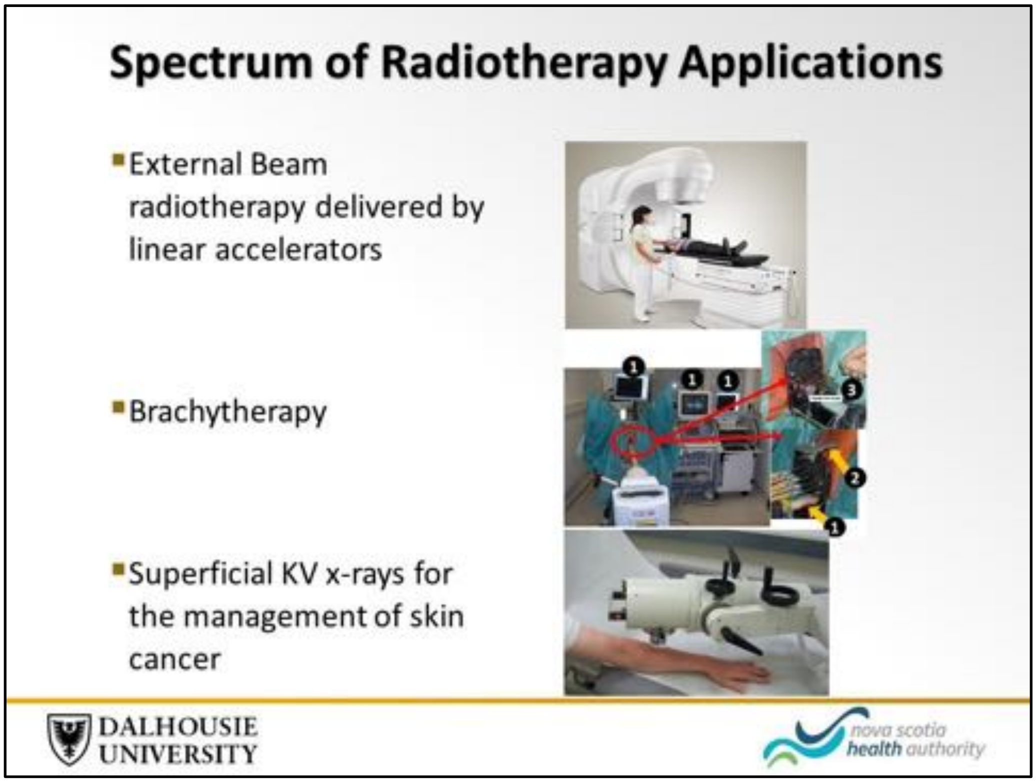

Spectrum of Radiotherapy Applications

- External Beam radiotherapy delivered by linear accelerators
- Brachytherapy
- Superficial KV x-rays for the management of skin cancer

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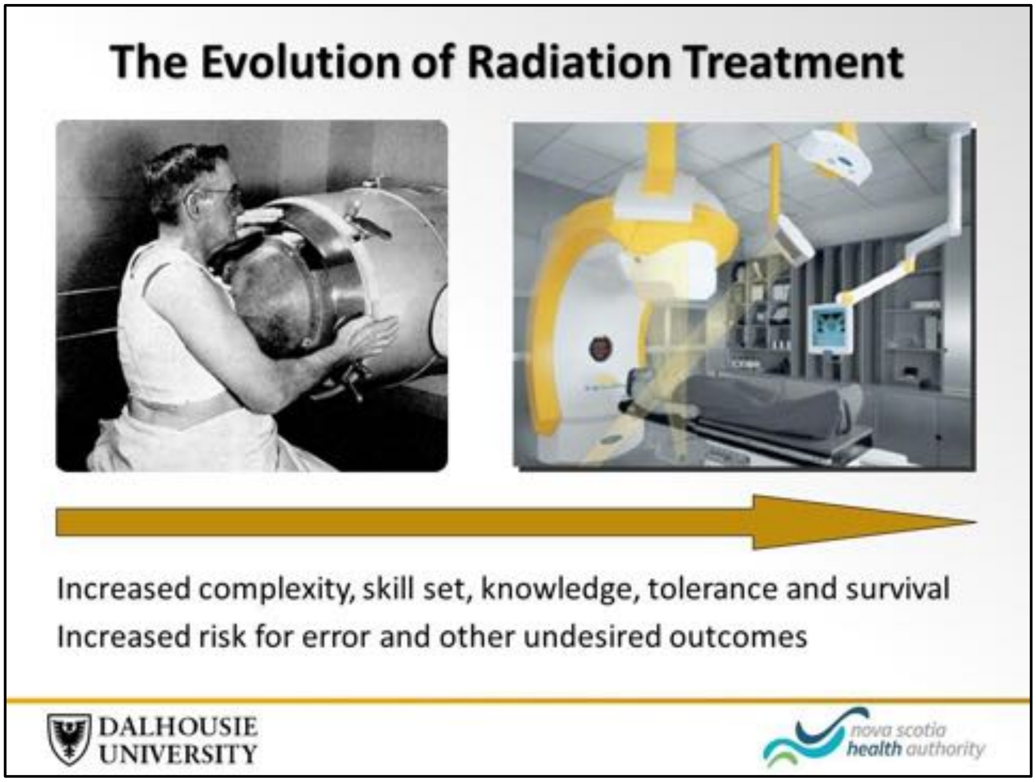

The Evolution of Radiation Treatment

Increased complexity, skill set, knowledge, tolerance and survival
Increased risk for error and other undesired outcomes

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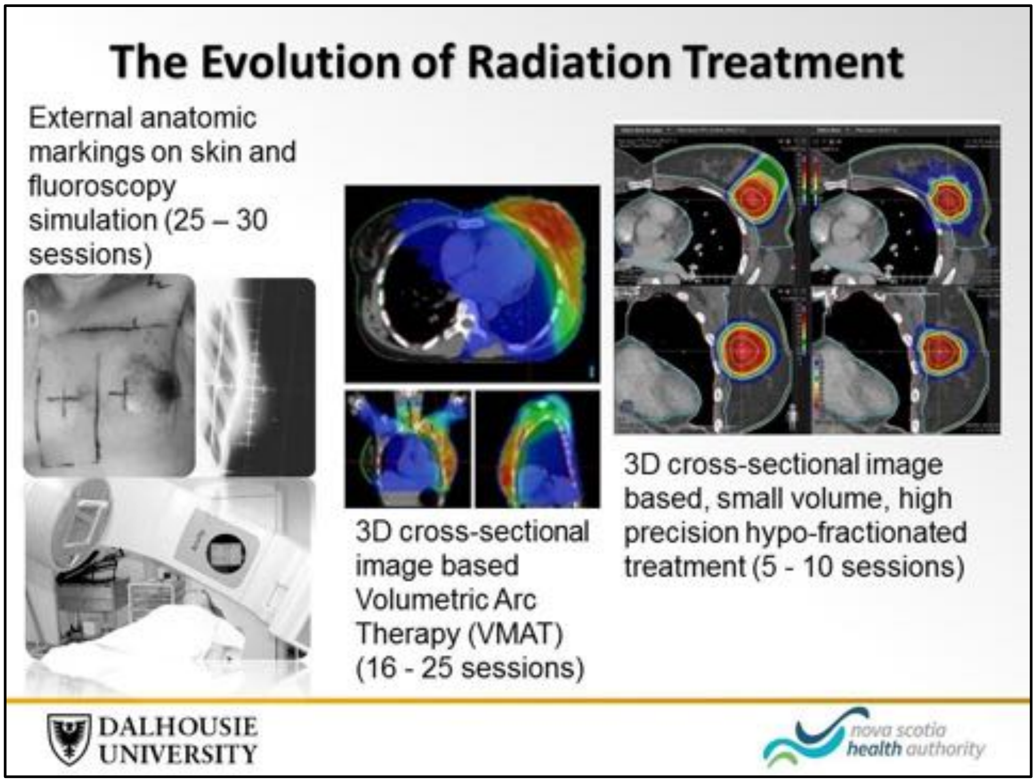

The Evolution of Radiation Treatment

External anatomic markings on skin and fluoroscopy simulation (25 – 30 sessions)

3D cross-sectional image based Volumetric Arc Therapy (VMAT) (16 - 25 sessions)

3D cross-sectional image based, small volume, high precision hypo-fractionated treatment (5 - 10 sessions)

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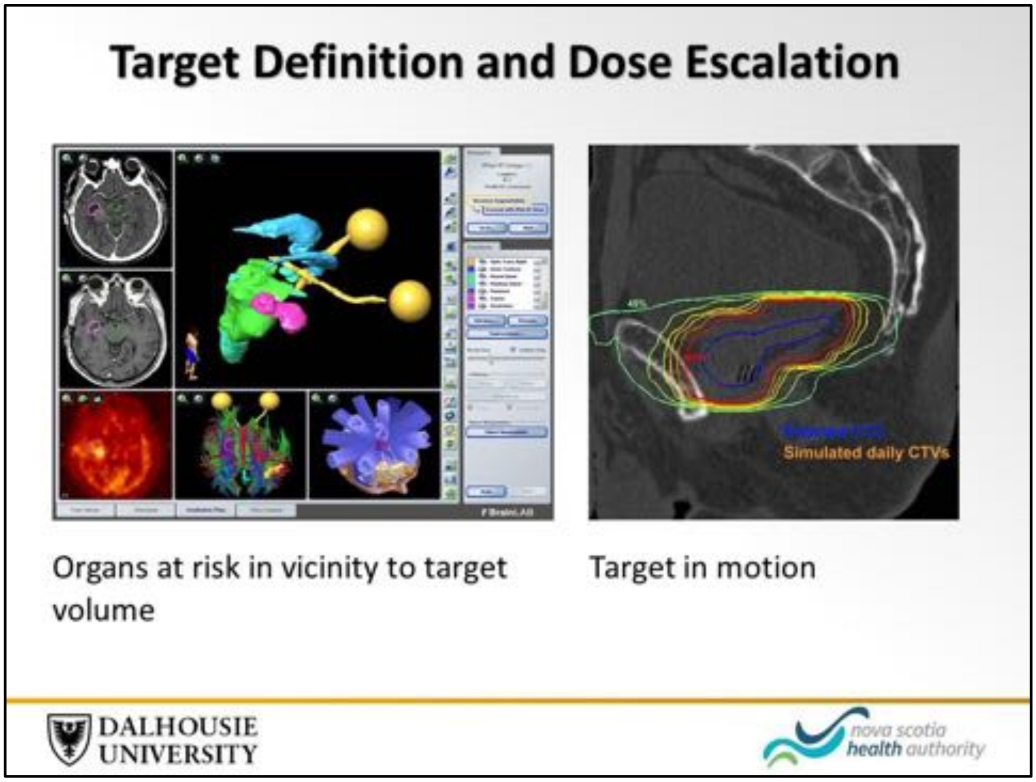

Target Definition and Dose Escalation

Organs at risk in vicinity to target volume

Target in motion

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Utilization of Radiotherapy in Cancer Treatment

- Current estimates of the proportion of cancer patients who will require radiotherapy are based almost entirely on expert opinion
- Range around 50%, varies widely
- Wide range of utilization rate depending on cancer site
- Utilization along the cancer journey trajectory varies largely
- Utilization is also dependent on other factors, e.g.:
  - Distance from Cancer Center
  - Patient age
  - Awareness of services and degree of collaboration with centralized services

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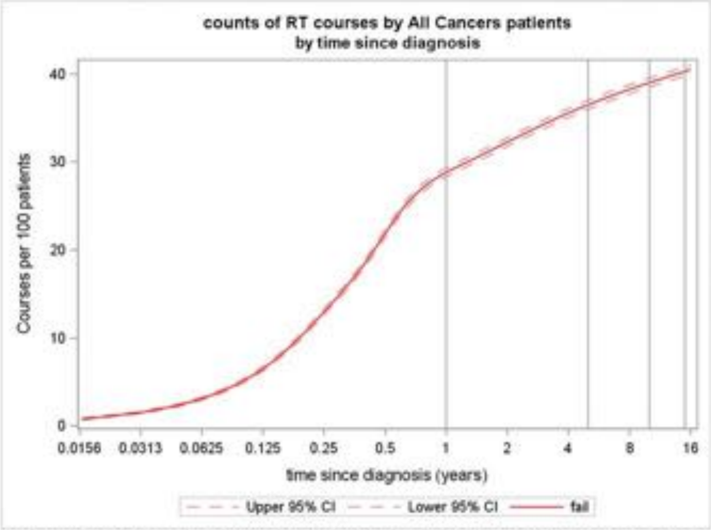
Nova Scotia Life Time Use of RT Profile



Analysis: NSCCP Registry & Analytics Team April 2018 – data source Nova Scotia Cancer Registry Information System

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Quality & Safety in Radiation Therapy

SUN 24

IN TOMORROW'S PAPER:

News Ottawa & Region

Staff shortage led to radiation error: report

Wrong dosage given to 326 Civic Hospital cancer patients

Overdose cancer girl dies

A teenage cancer patient who was given a massive overdose of radiation has died.

Lisa Norris, 16, was given 17 overdoses of radiation therapy during her treatment for a brain tumour at the Beatson Oncology Centre in Glasgow in January.

It was reported she died yesterday at her home in Ayrshire surrounded by her family.

Radiation Offers New Cures, and Ways to Do Harm

As Scott Jerome-Parks lay dying, he clung to this wish: that his fatal radiation overdose — which left him deaf, struggling to see, unable to swallow, burned, with his teeth falling out, with ulcers in his mouth and throat, nauseated, in severe pain and finally unable to breathe — be studied and talked about publicly so that others might not have to live his nightmare.

Sensing death was near, Mr. Jerome-Parks summoned his family for a final Christmas. His friends sent two buckets of sand from the beach where they had played as children so he could touch it, feel it and remember better days.

Mr. Jerome-Parks died several weeks later in 2007. He was 43.

A New York City hospital treating him for tongue cancer had failed to detect a computer error that directed a linear accelerator to blast his brain stem and neck with errant beams of radiation. Not once, but on three consecutive days.

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The Canadian Approach to Quality in Radiation Therapy –CPQR (since 2010)

CPQR is a leader in quality improvement initiatives for radiation treatment.

ABOUT THE CPQR

OUR ACTIVITIES

OUR STEERING COMMITTEE

Focus of Activities:

1. Quality Assurance Guidelines
2. Technical Quality Control Guidelines
3. Radiation Treatment Incidents
4. Patient Engagement
5. Patient Reported Outcomes

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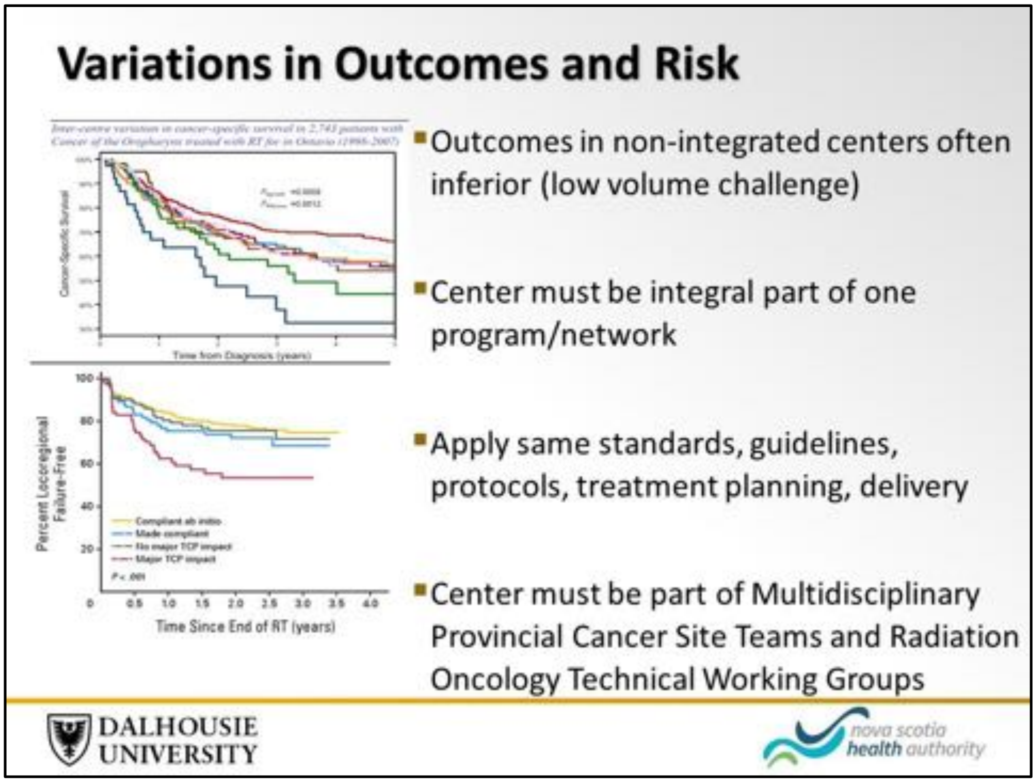

Variations in Outcomes and Risk

- Outcomes in non-integrated centers often inferior (low volume challenge)
- Center must be integral part of one program/network
- Apply same standards, guidelines, protocols, treatment planning, delivery
- Center must be part of Multidisciplinary Provincial Cancer Site Teams and Radiation Oncology Technical Working Groups

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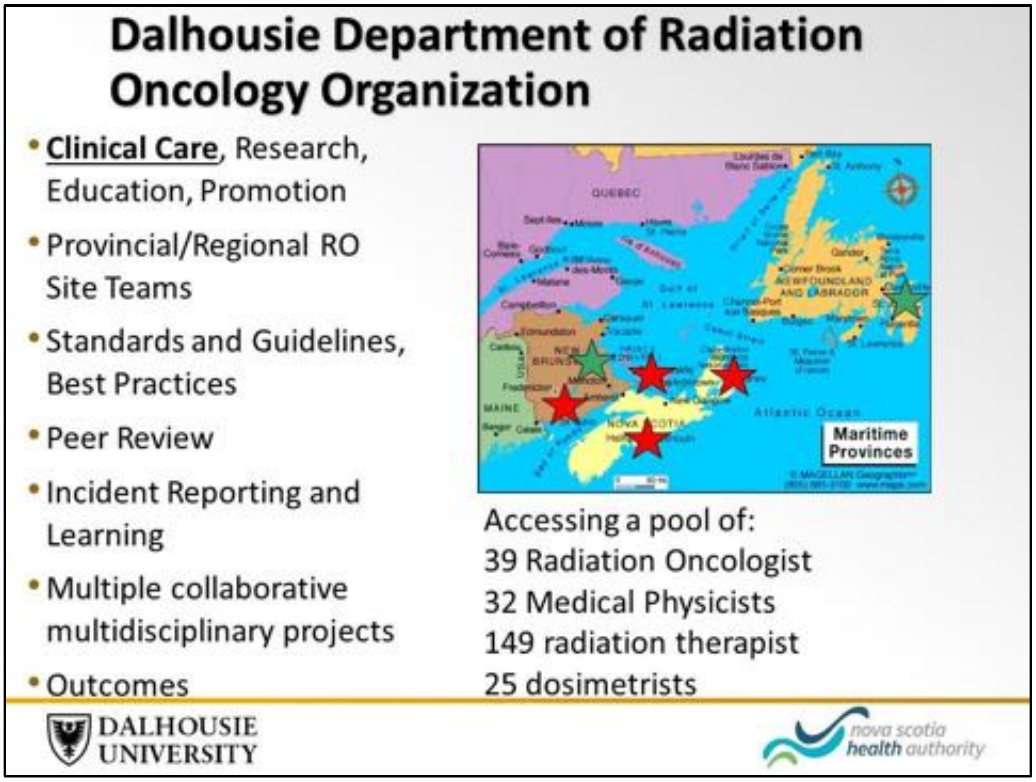

Dalhousie Department of Radiation Oncology Organization

- **Clinical Care**, Research, Education, Promotion
- Provincial/Regional RO Site Teams
- Standards and Guidelines, Best Practices
- Peer Review
- Incident Reporting and Learning
- Multiple collaborative multidisciplinary projects
- Outcomes

Accessing a pool of:
39 Radiation Oncologist
32 Medical Physicists
149 radiation therapist
25 dosimetrists

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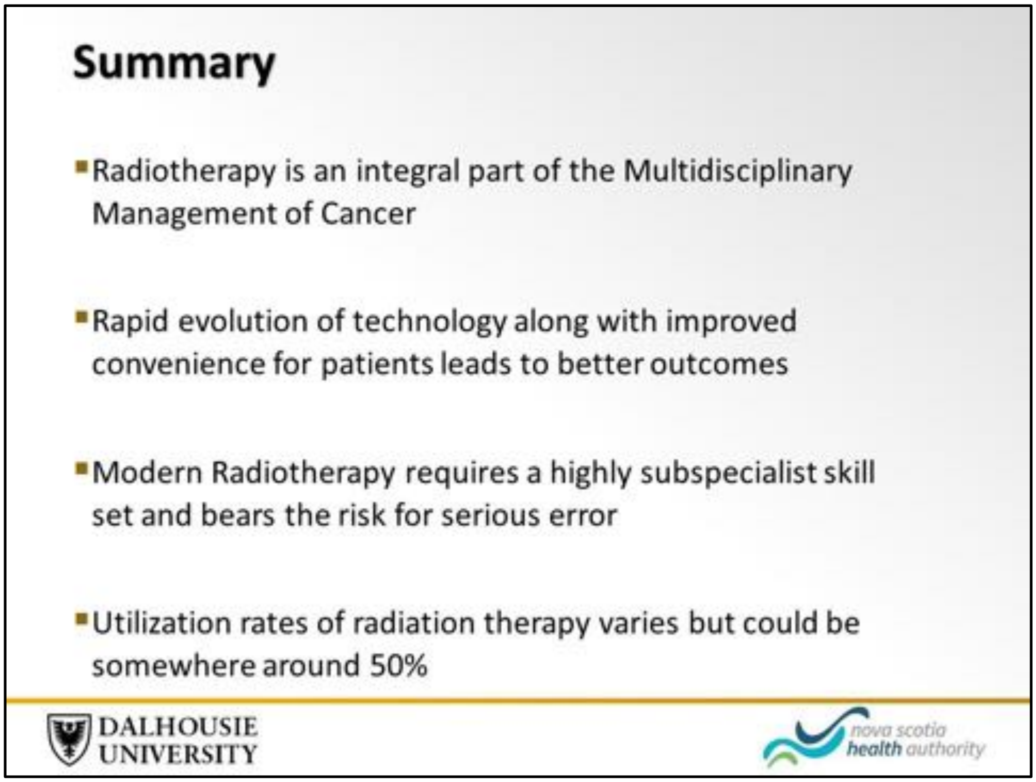

Summary

- Radiotherapy is an integral part of the Multidisciplinary Management of Cancer
- Rapid evolution of technology along with improved convenience for patients leads to better outcomes
- Modern Radiotherapy requires a highly subspecialist skill set and bears the risk for serious error
- Utilization rates of radiation therapy varies but could be somewhere around 50%

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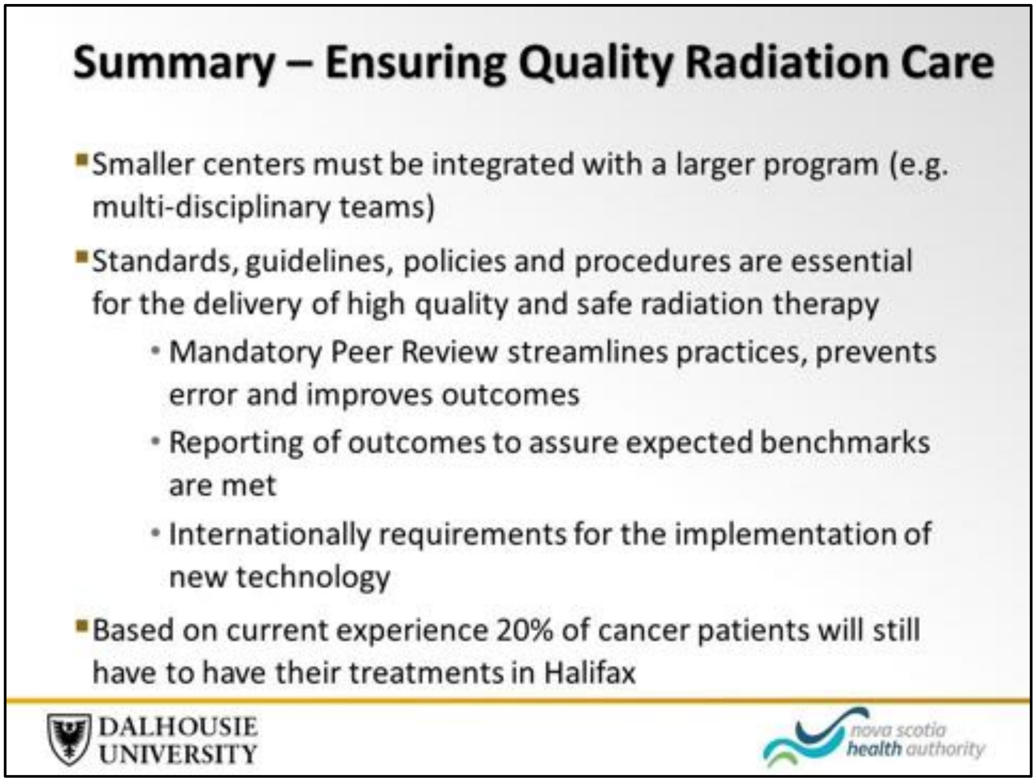

Summary – Ensuring Quality Radiation Care

- Smaller centers must be integrated with a larger program (e.g. multi-disciplinary teams)
- Standards, guidelines, policies and procedures are essential for the delivery of high quality and safe radiation therapy
    - Mandatory Peer Review streamlines practices, prevents error and improves outcomes
    - Reporting of outcomes to assure expected benchmarks are met
    - Internationally requirements for the implementation of new technology
- Based on current experience 20% of cancer patients will still have to have their treatments in Halifax

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vi. DES Presentation - Comparator Cases

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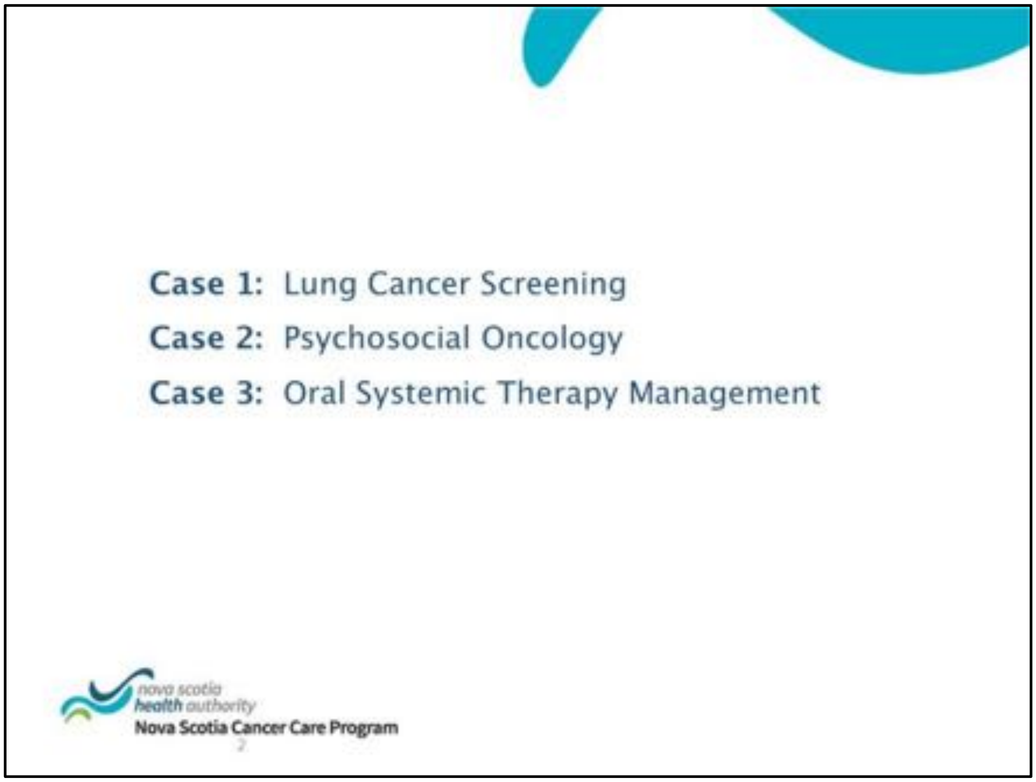
Comparator Cases

Yarmouth Deliberative Engagement Session
June 13, 2018



Case 1: Lung Cancer Screening

Case 2: Psychosocial Oncology

Case 3: Oral Systemic Therapy Management

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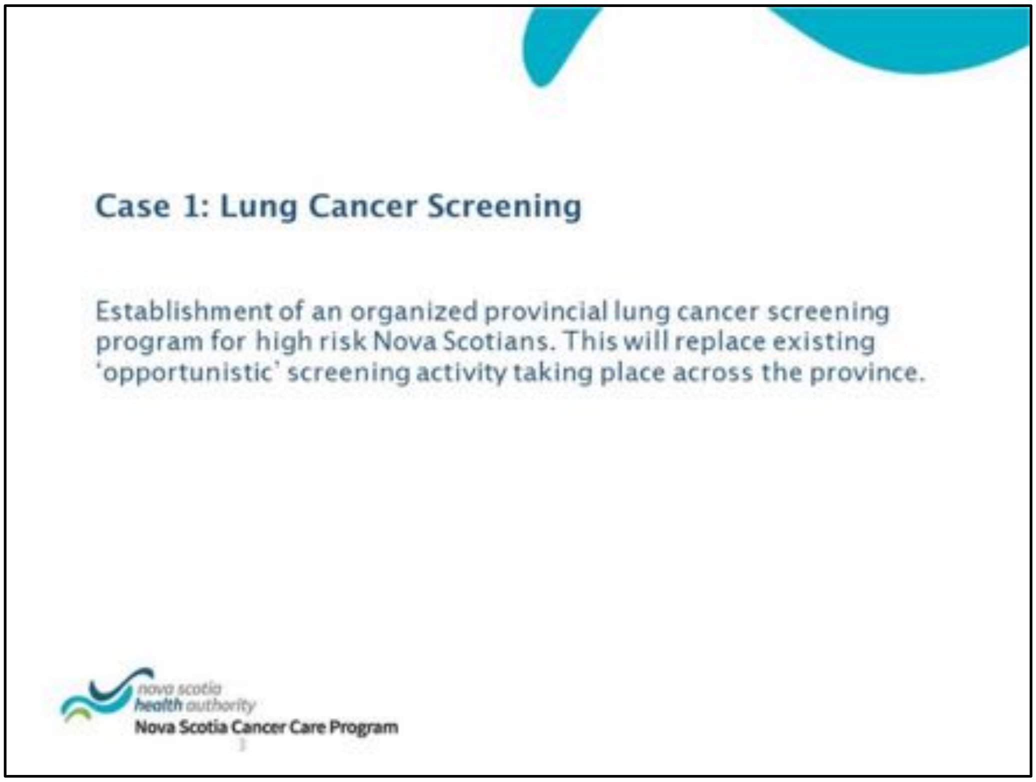

Case 1: Lung Cancer Screening

Establishment of an organized provincial lung cancer screening program for high risk Nova Scotians. This will replace existing 'opportunistic' screening activity taking place across the province.

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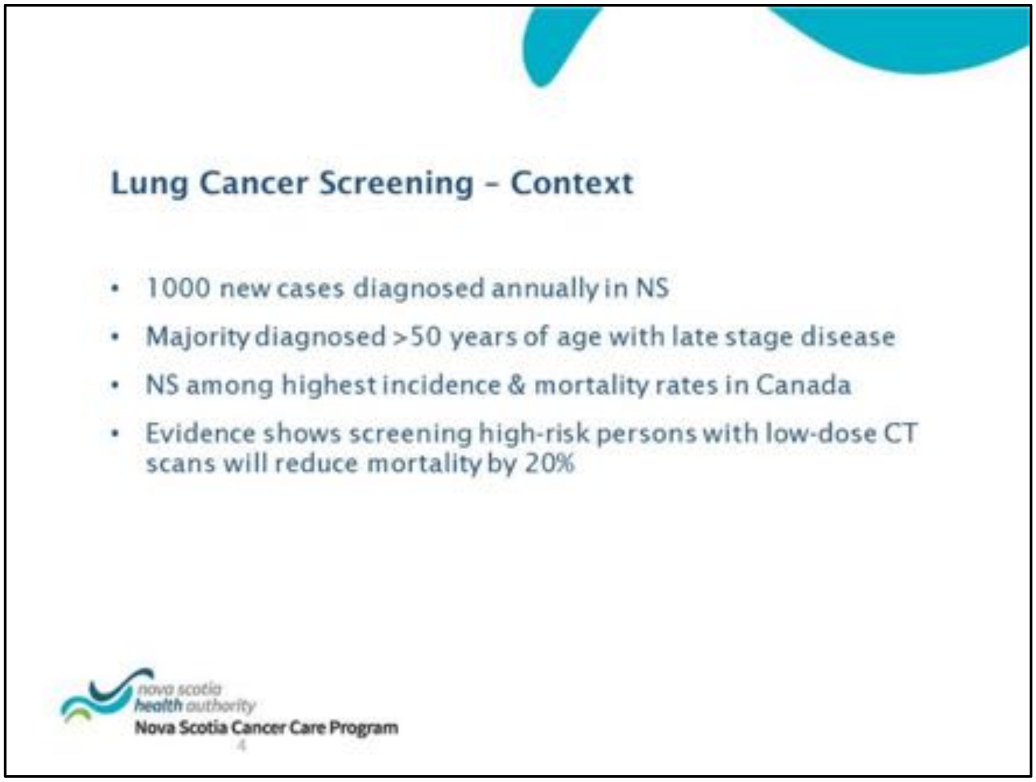

Lung Cancer Screening – Context

- 1000 new cases diagnosed annually in NS
- Majority diagnosed >50 years of age with late stage disease
- NS among highest incidence & mortality rates in Canada
- Evidence shows screening high-risk persons with low-dose CT scans will reduce mortality by 20%

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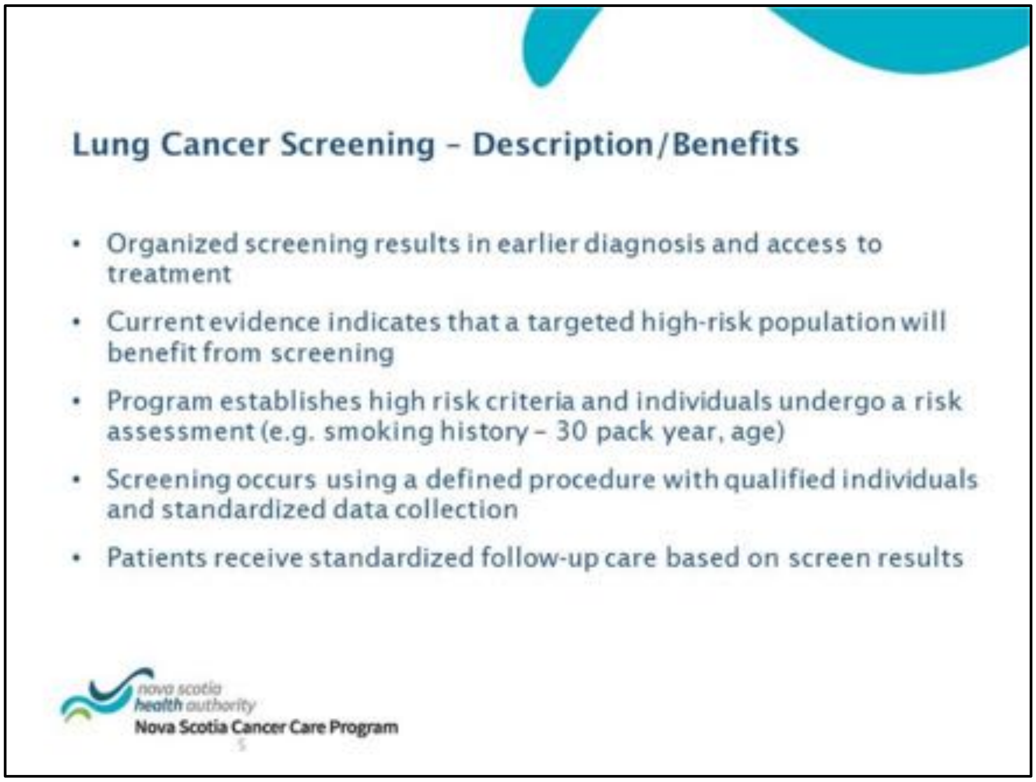

Lung Cancer Screening – Description/Benefits

- Organized screening results in earlier diagnosis and access to treatment
- Current evidence indicates that a targeted high-risk population will benefit from screening
- Program establishes high risk criteria and individuals undergo a risk assessment (e.g. smoking history – 30 pack year, age)
- Screening occurs using a defined procedure with qualified individuals and standardized data collection
- Patients receive standardized follow-up care based on screen results

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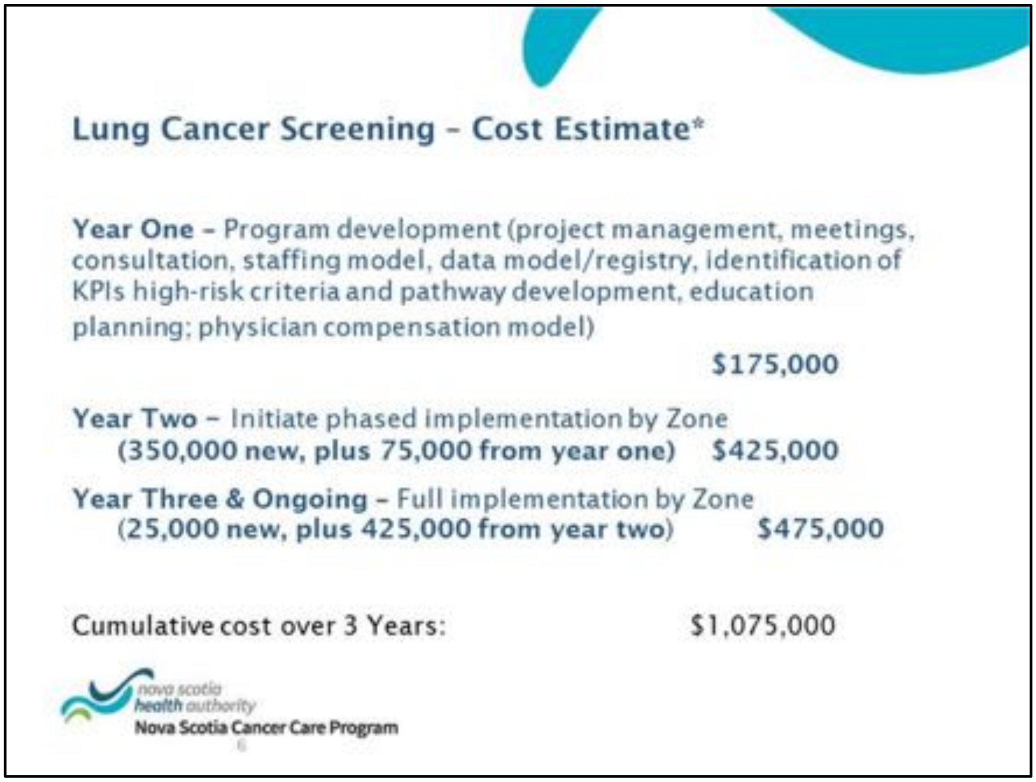

Lung Cancer Screening – Cost Estimate*

Year One – Program development (project management, meetings, consultation, staffing model, data model/registry, identification of KPIs high-risk criteria and pathway development, education planning; physician compensation model) **$175,000**

Year Two – Initiate phased implementation by Zone
(350,000 new, plus 75,000 from year one) $425,000

Year Three & Ongoing – Full implementation by Zone
(25,000 new, plus 425,000 from year two) $475,000

Cumulative cost over 3 Years: $1,075,000

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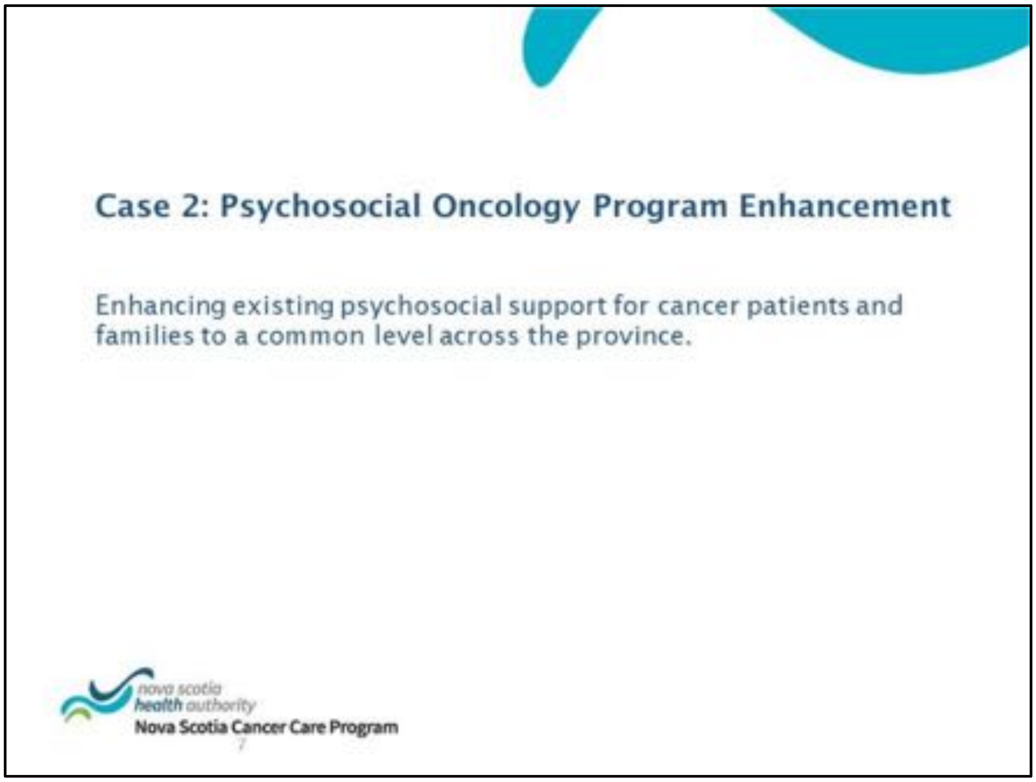

Case 2: Psychosocial Oncology Program Enhancement

Enhancing existing psychosocial support for cancer patients and families to a common level across the province.

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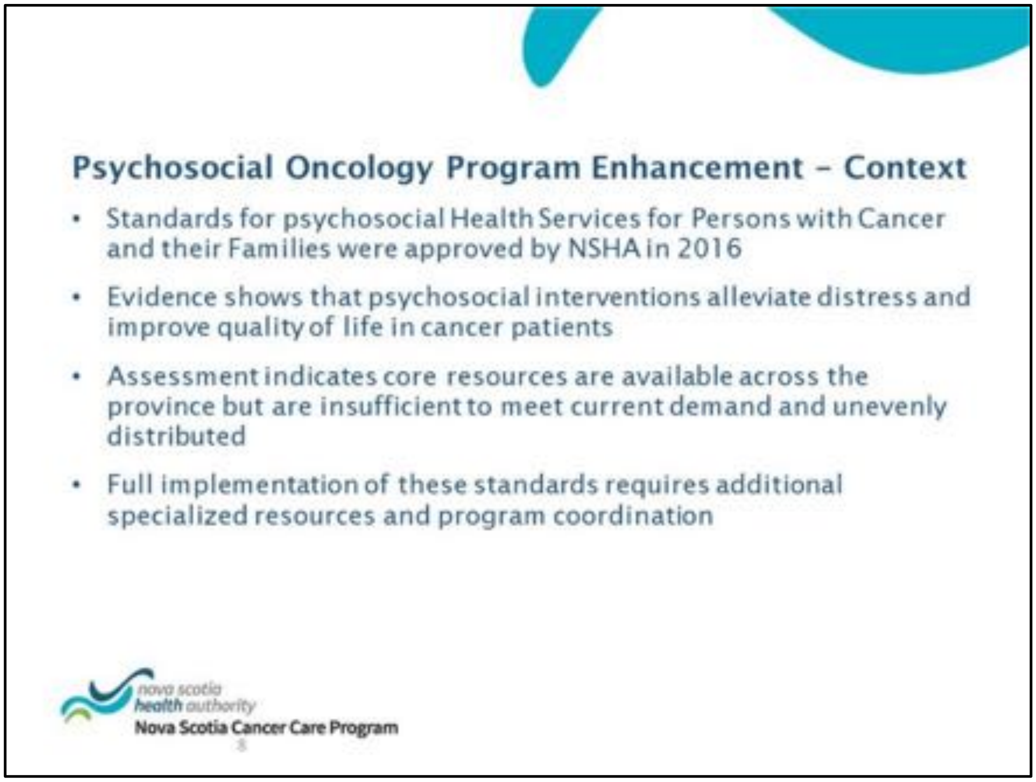

Psychosocial Oncology Program Enhancement – Context

- Standards for psychosocial Health Services for Persons with Cancer and their Families were approved by NSHA in 2016
- Evidence shows that psychosocial interventions alleviate distress and improve quality of life in cancer patients
- Assessment indicates core resources are available across the province but are insufficient to meet current demand and unevenly distributed
- Full implementation of these standards requires additional specialized resources and program coordination

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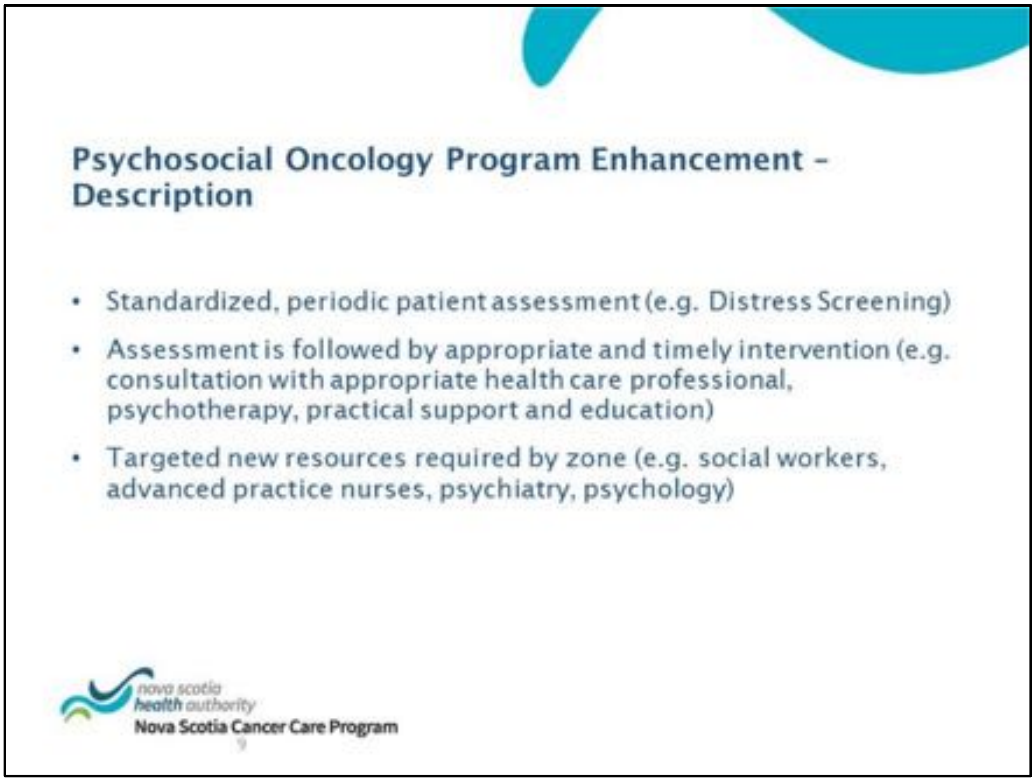

Psychosocial Oncology Program Enhancement – Description

- Standardized, periodic patient assessment (e.g. Distress Screening)
- Assessment is followed by appropriate and timely intervention (e.g. consultation with appropriate health care professional, psychotherapy, practical support and education)
- Targeted new resources required by zone (e.g. social workers, advanced practice nurses, psychiatry, psychology)

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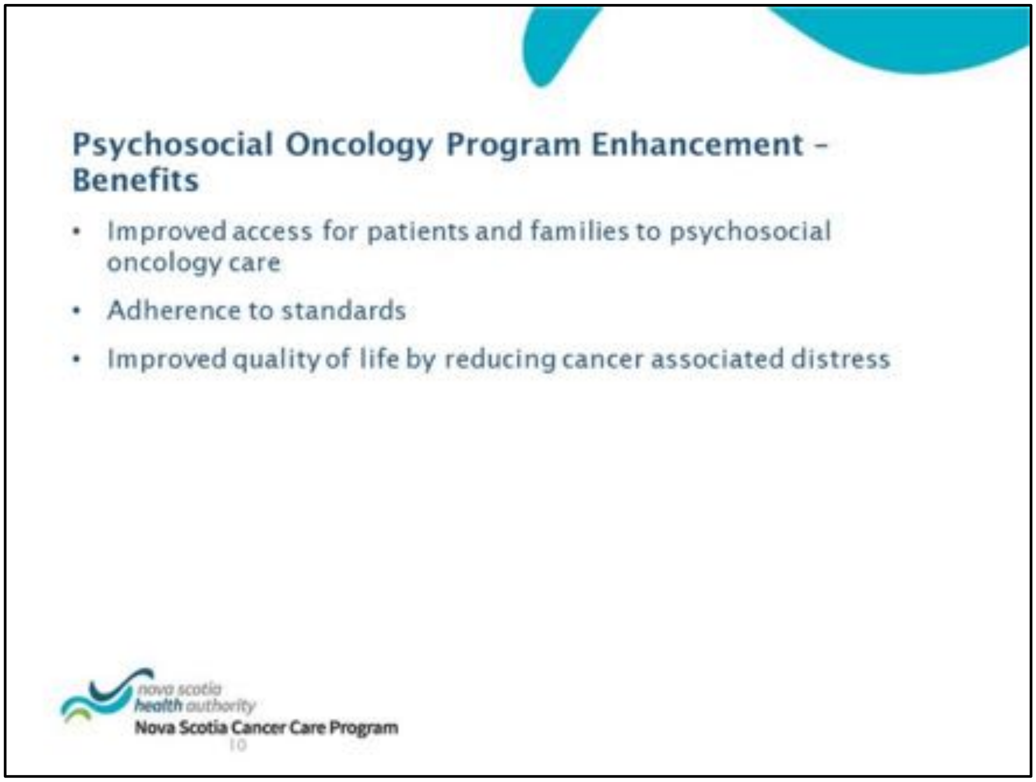

Psychosocial Oncology Program Enhancement – Benefits

- Improved access for patients and families to psychosocial oncology care
- Adherence to standards
- Improved quality of life by reducing cancer associated distress

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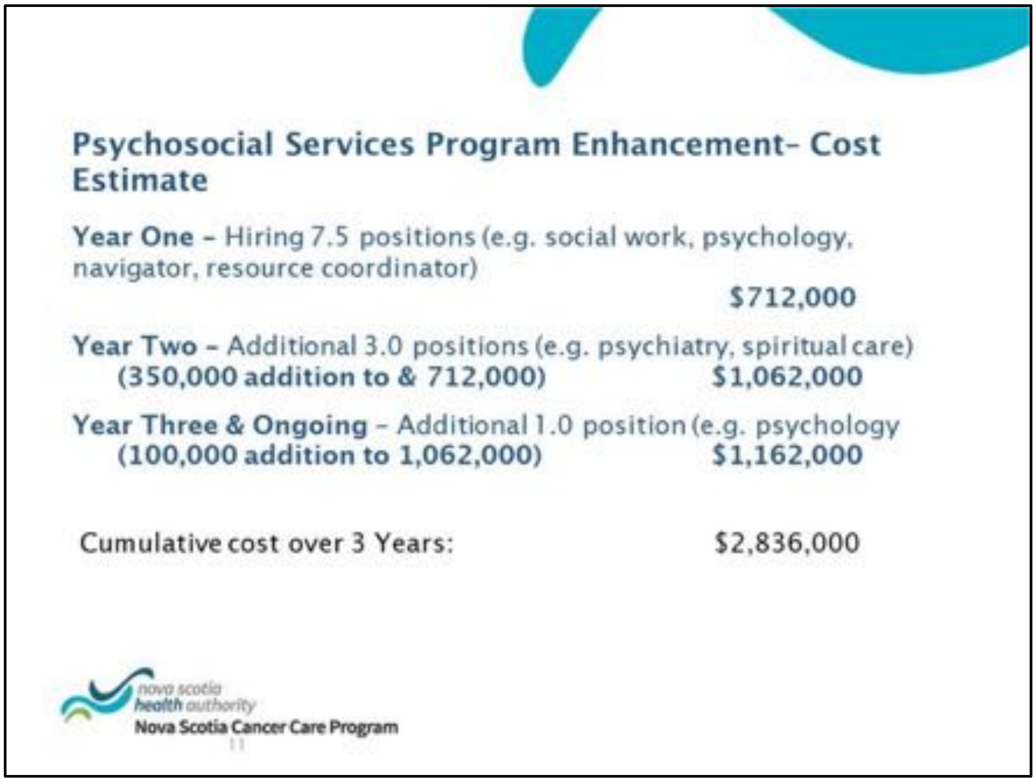

Psychosocial Services Program Enhancement- Cost Estimate

Year One - Hiring 7.5 positions (e.g. social work, psychology, navigator, resource coordinator)
$712,000

Year Two - Additional 3.0 positions (e.g. psychiatry, spiritual care)
(350,000 addition to & 712,000) **$1,062,000**

Year Three & Ongoing - Additional 1.0 position (e.g. psychology
(100,000 addition to 1,062,000) **$1,162,000**

Cumulative cost over 3 Years: $2,836,000

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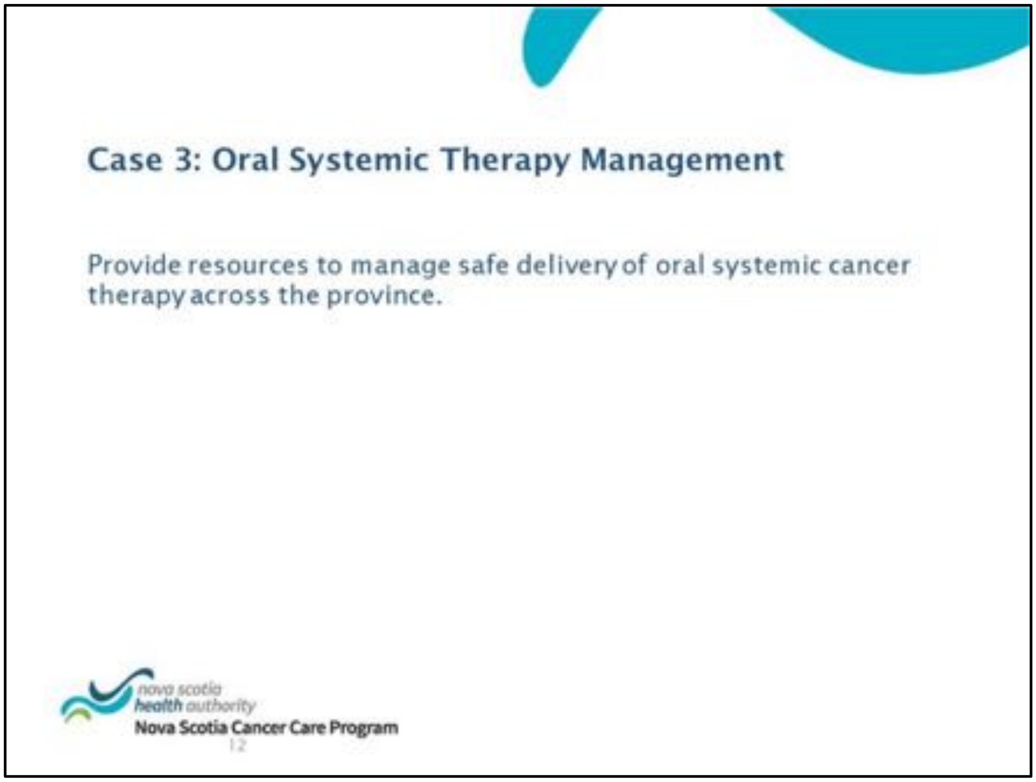

Case 3: Oral Systemic Therapy Management

Provide resources to manage safe delivery of oral systemic cancer therapy across the province.

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Oral Systemic Therapy – Context

- Systemic therapy (i.e. IV chemotherapy, injections, oral medications) is the treatment of choice for many cancers
- For many years the majority of treatments have been delivered in outpatient chemotherapy units
- An increasing number of systemic therapy agents are now given in oral form to be taken at home
- New supports and processes are needed to ensure the safe management of patients taking oral medications

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Oral Systemic Therapy – Description/Benefits

- Ensure standardized processes for oral systemic therapy management by appropriately trained professionals (e.g. timing, contact, education, adherence to care protocols such as adverse reaction management)
- Maintain current drug information
- Standardized training for health professionals (e.g. oncology pharmacists, pharmacy technicians, community pharmacists)
- Improved patient safety
- More efficient patient care
- Cost savings from appropriate prescription management

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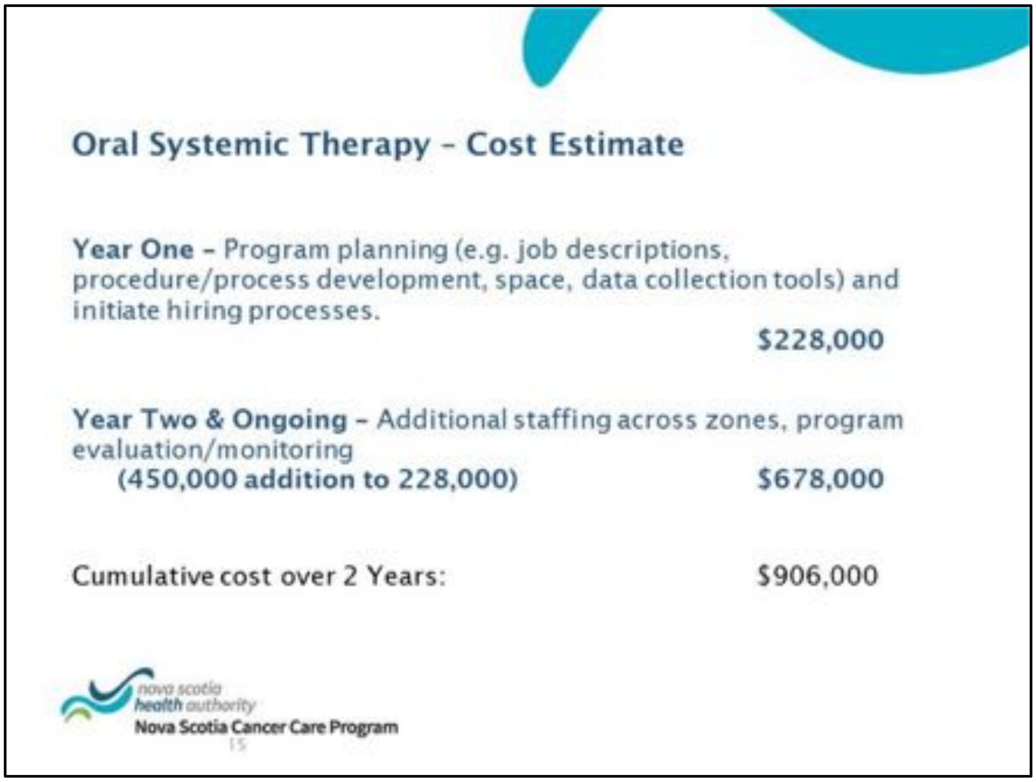

Oral Systemic Therapy – Cost Estimate

Year One – Program planning (e.g. job descriptions, procedure/process development, space, data collection tools) and initiate hiring processes.
$228,000

Year Two & Ongoing – Additional staffing across zones, program evaluation/monitoring
(450,000 addition to 228,000) **$678,000**

Cumulative cost over 2 Years: $906,000

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Nova Scotia Cancer Care Program

vii. DES Participants

Name	Title / Affiliation
Christine Smith	Communications Manager, NSCCP (Assistant Facilitator/non-voting member)
Jeff Kirby	Medical Ethicist, Dalhousie University Faculty of Medicine (Lead Facilitator/voting member)
Dr. Drew Bethune	Medical Director, NSCCP
Maureen MacIntyre	Director, Cancer System Integration, NSCCP
Krista Rigby	Director, Community & Population Oncology, NSCCP
Dr. James Robar	Chief of Medical Physics
Dr. Helmut Hollenhorst	Radiation Oncologist
Dr. Nathan Lamond	Medical Oncologist
Karen Jenkins	Interim NSHA Operations Executive Director, WZ
Dr. Lois Bowden	WZ Administrative Physician Lead
Maria Marshall	Patient Rep from WZ
Don Smith	Patient Rep from WZ
Sandy Dennis	Public Advisor from WZ
Margot Judge	Oncology Nurse
Darolyn Walker	Patient Navigator