Lung Cancer Disease Pathway Management
Priorities for Action

The cancer journey
Better cancer services every step of the way

- prevention
- screening
- diagnosis
- treatment
- recovery
- palliative & end-of-life care
Lung Cancer – Priorities for Action

Preamble:

In this report, we outline Cancer Care Ontario’s Disease Pathway Management (DPM) strategy for identifying priorities for action across all phases of the lung cancer patient journey. We address each phase of the lung cancer journey describing the current state of Ontario’s cancer system in order to develop the case for action.

We list the priorities for action identified by the Lung Cancer DPM working groups, the case for action against the priorities and specific quality improvement project concepts relevant to each phase of the cancer journey. This report represents one part of Cancer Care Ontario's lung cancer disease pathway management regional engagement strategy.

The second major component of the strategy is a set of roadshows held in each region of the province to engage clinicians and cancer program administrators in identifying specific regional opportunities with respect to lung cancer quality improvement. The sessions are meant to link the priorities for action with the current state and specific needs of each Regional Cancer Program. We will present region-specific lung cancer data for each phase of the cancer journey, lead discussions around the priorities for action most relevant to the individual regions, and explore tailored regional solutions. The discussion will be focused on identifying opportunities rather than an evaluation of current performance.

We intend to clearly describe the case for action in improving lung cancer care, the excellent progress that has been made, and the outstanding work available to build upon.

Please take the opportunity to contact your colleagues listed in this report or the disease pathway management team, as your region moves toward implementing initiatives to further improve lung cancer care across the journey.
Thank You

On behalf of lung cancer Disease Pathway Management, we look forward to continued and accelerated progress toward improving all aspects of the lung cancer journey.

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Goals and Objectives

Objectives of this Report

This report is one component of the regional engagement strategy for lung cancer disease pathway management, which is a provincial quality improvement initiative carried out by Cancer Care Ontario’s Disease Pathway Management team. It is intended as a companion to the regional engagement sessions held in each local health integration network (LHIN).

The content of this report is intended to:

1. Provide a call to action for lung cancer quality improvement by detailing the current issues
2. Provide an overview of the Disease Pathway Management strategy
3. Detail the progress to date of the lung cancer DPM team
4. Set provincial and regional focus on the priorities for action
5. Provide suggestions for how to address the identified priorities

Objectives of the Regional Engagement Sessions

Together, this report and the regional engagement sessions are intended to encourage and guide local and regional collaboration and action in the development of improvement projects to address issues identified across the Ontario lung cancer journey.

The engagement sessions held in each LHIN will provide the opportunity to:

1. Share select region-specific data for each phase of the lung cancer patient journey in a provincial context
2. Suggest and discuss specific opportunities for improvement and action
The Call for Action in Lung Cancer

Lung cancer continues to be one of the most commonly occurring cancers in Canada

Lung cancer is one of the most commonly occurring cancers in Canada with approximately 24,200 new cases diagnosed in 2010 (Canadian Cancer Society's Steering Committee, 2010). In Ontario, approximately 7,600 cases of lung cancer were diagnosed in 2010 (Canadian Cancer Society's Steering Committee, 2010). In both men and women, lung cancer is the second-most common cancer after prostate and breast, respectively. While the incidence rate for lung cancer in males has been decreasing modestly, the overall number of incident cases of lung cancer is on the rise in Canada (Canadian Cancer Society's Steering Committee, 2010).

Lung cancers are typically diagnosed at a late stage

In addition to being one of the most commonly diagnosed cancers in Canada, lung cancers are typically more advanced than other cancers at the point of diagnosis. Most lung cancers are diagnosed as late stage with 60% of non-small cell and 84% of small cell lung cancers diagnosed as either stage III or IV in 2008 (CCO Informatics, 2010). Lung cancer patients diagnosed at stage III or IV are rarely cured.

Few patients diagnosed with lung cancer survive past five years

Lung cancer survival is much worse with respect to the survival rates of other common cancers. The five-year survival rate for lung cancer is 16.6%, for individuals observed between 2002 and 2006 (Cancer Quality Council of Ontario, 2010). In contrast, the five-year survival rates for breast and prostate cancers are 87% and 98% respectively (CQCO, 2010).

There is no recognized method of screening for lung cancer

An important factor contributing to the high incidence and mortality rates in lung cancer is the absence of effective screening methods for population-based screening. Research to support earlier detection of lung cancer is underway worldwide, however the work is still in progress. Only one trial has reported positive results. These results are still in the early stages of interpretation, but provide optimism for screening in the future, particularly for those at increased risk.

Lung cancer is not a main focus of research in Canada

Although it is one of the most common cancers in Canada, lung cancer receives comparatively fewer research dollars than other cancers. In 2007, lung cancer research in Canada received $13.8 million, compared to $54.7 million for breast cancer (CCRC and CPAC, 2009). While attempts to address low lung cancer research funding have been made, such as the Canadian Cancer Society’s 2009 grant competition for lung cancer research, more can be done to encourage research in this field.

Patients with lung cancer experience a stigma unlike other cancers

In addition to the lack of screening or early detection methods currently available, lung cancer patients are subjected to a stigma that is not associated with many other cancers: that it is caused by smoking. One in five Canadians admit to feeling less sympathetic to lung cancer patients compared to other types of cancer patients (Ipsos Mori, 2010). While the majority of lung cancer patients are, or were, smokers, many are in fact lifelong non-smokers or former smokers who quit many years before they were diagnosed. Possibly, as a result of the guilt and shame associated with lung cancer, patients are often less demanding or active in their cancer journey than other types of cancer patients.
What has been done in Ontario?

Although lung cancer remains a commonly diagnosed cancer characterized by poor survival rates and difficult patient challenges, positive steps to build improvement upon have been taken across the province.

Smoking rates continue to decline, which will ultimately translate into fewer new cases

Smoking continues to be the number one contributing factor to the development of lung cancer. Overall smoking rates across the province have been steadily declining over time (approximately 20% from 1960s to 2000) (Holowaty et al., 2002). Efforts to eradicate smoking in public places have also helped to reduce exposure to second-hand smoke.

Diagnostic Assessment Programs ensure an efficient diagnostic process

Diagnostic Assessment Programs (DAPs) aim to coordinate the various elements involved in the assessment and diagnosis of an individual patient with the goals of improving the coordination of care, reducing wait times, improving the patient experience and minimizing disease progression wherever possible. In 2008, Cancer Care Ontario began supporting pilot projects for DAPs in lung and colorectal cancers and saw great success with wait time reduction by 50% or greater in some cases. Currently there are 11 lung cancer DAPs and two under development, leading Cancer Care Ontario closer to its goal to establish a lung DAP in each region.

PET scanning helps establish a more accurate stage at diagnosis

Positron Emission Tomography, or PET scanning, is an imaging test used to diagnose and accurately stage certain lung cancers. Accurate staging leads to patients receiving the best treatment for their stage of disease. PET scans are now a publicly insured health service under certain conditions and have been available to patients under certain conditions since October 1, 2009. Currently, PET is insured for the following types of lung cancer, with specific parameters for each: limited disease small cell lung cancer; non-small cell lung cancer being considered for curative resection; clinical stage III non-small cell lung cancer where radical combined modality therapy is being considered; and solitary pulmonary nodules. For more information, visit www.petscansontario.ca.

Consolidation of thoracic surgery aims to improve treatment outcomes

Successful outcomes of thoracic surgery, such as lower mortality and decreased complications, are linked to the number of surgeries performed (minimum volumes), and to the availability of specialized surgical training and hospital resources. Cancer Care Ontario released the Thoracic Surgery Oncology Standards in 2005 and has worked with regions to designate thoracic surgery centres that are committed to implementing the Standards. As of December 2010, all non-designated centres in the province who were performing thoracic surgery have implemented plans to refer patients to designated centres, thus completing the consolidation.

The proportion of patients who have thoracic (lung and esophageal) surgery at a designated centre has increased over time from 79% in FY2006/07 to 85% in FY2008/09 for esophageal cancer and 76% to 81% for lung cancer over the same period. We expect this to continue to increase with the completion of consolidation in 2010. As well the percentage of patients who died in hospital or within 30 days following
pneumonectomy cancer surgery has improved from 10.9% in combined FY2003/04 and FY2004/05 across Ontario to 7.2% in combined FY2007/08 and FY2008/09.

**Symptom screening helps proactively manage side effects**

Recognizing that appropriately identifying the presence of symptoms is integral to addressing them, Cancer Care Ontario launched the Ontario Cancer Symptom Management Collaborative (OCSMC), which collects patient-reported scores on nine common cancer symptoms using the Edmonton Symptom Assessment System (ESAS). The overall goal of the OCSMC is to promote a model of care enabling earlier identification, communication and documentation of a patient’s symptoms, optimal symptom management and coordinated care planning. Lung cancer patients have been highlighted as a priority for this program and the target is 90% of all lung cancer patients should be screened using ESAS; currently, approximately 60% of lung cancer patients are screened.

**Follow-up guidelines are in development to guide patients and physicians after cancer treatment**

Once lung cancer patients have completed their treatment, they are followed-up by their oncologist and continue to receive general medical care from their family physician. Ontario follow-up guidelines for lung cancer patients are in development to provide guidance to healthcare providers regarding recommended follow-up testing, follow-up intervals and general cancer screening activities. These guidelines will also include a patient-oriented component that will help patients identify potential symptoms of recurrence and inform them of when they should contact their physician.
Disease Pathway Management – An Overview

Disease Pathway Management (DPM) is a new approach to examining the cancer journey from start to finish for a specific disease site, with the objective of improving the cancer system and experience.

Goals of Disease Pathway Management

Supporting the mission and mandate of Cancer Care Ontario, the goal of Disease Pathway Management is to develop, implement and evaluate an integrated program of activity aimed at advancing system-wide improvements for Ontarians across the cancer continuum.

Specifically, DPM focuses on ways to improve: the quality of care, processes and the patient experience for a given type of cancer. For a given disease site, DPM serves as a catalyst to identify current strengths, recommend priority areas for improvement and promote action against those priorities.

Working Process

Disease Pathway Management uses a multidisciplinary approach to bring together experts including physicians, nurses, support staff, patients and advocates for a specific type of cancer. Divided into working groups by phase of the cancer journey, these teams work using their experience and the support of Cancer Care Ontario staff to:

- characterize the patient journey by developing pathway maps of the ideal state;
- identify and prioritize gaps in the cancer system;
- present these issues to the Ontario cancer community for discussion and action;
- measure the resulting impact of actions taken against the priorities.

The formal DPM cycle for a given disease site consists of three phases:

- **Phase 1** Detail the ‘ideal state’ patient journey; identify areas for improvement; prioritize areas for improvement; seek feedback on these priorities from additional stakeholders
- **Phase 2** Regional engagement: sharing issues with the regions, promoting and supporting action
- **Phase 3** Implementation and measurement of impact

Benefits

Disease Pathway Management provides a unique opportunity to bring together multidisciplinary experts who are involved with a particular cancer. By providing a forum for interdisciplinary discussion that is informed by data, these groups have the potential to identify disease-specific issues and priorities for a specific cancer that may have otherwise been overlooked. Using this approach will help Cancer Care Ontario ensure that patients are provided the best care and cancer experience possible.
Lung Cancer DPM – Progress To Date

In June 2009, the lung cancer DPM team, consisting of 48 clinicians, patients and system stakeholders, was formed under the leadership of Dr. Bill Evans and Dr. Yee Ung (see Appendix 1 – Listing of Lung Cancer DPM Team Members). Care was taken to select a geographically diverse, multidisciplinary team with varying experience and expertise spanning the entire lung cancer journey. Based on each member’s area of expertise, the team was divided into five working groups representing the phases of the patient journey:

- Prevention and Screening/Early Diagnosis
- Diagnosis
- Treatment
- Palliative Care, End-of-Life and Survivorship
- Patient and Family Advisory Group

Over the course of the year, each team met on a monthly basis with the goals of mapping the patient journey, identifying priorities for improvement and generating initial concepts to address the identified areas where there was opportunity for improvement. The teams met for a total of 50 hours and yielded 17 improvement project concepts.

Symposium

The efforts from the first year of the lung DPM team culminated in a symposium of diverse lung cancer stakeholders held in March 2010. The purpose of this event was to bring together a wider group of stakeholders in the lung cancer community for discussion about the work to date, to engage stakeholders on the project concepts and to provide a forum for feedback on implementation.

In total, approximately 115 people attended the event, including front-line clinical representatives, health administrators, ministry representatives and the end users: patients and caregivers.

As a result of a review of data and patient and provider input, eight initiatives, collectively spanning all phases of the patient journey, were selected from a larger list of 17 improvement projects generated by the Lung Cancer DPM working groups (see Appendix 2 for expanded list).

<table>
<thead>
<tr>
<th>Project</th>
<th>Working Group</th>
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<tbody>
<tr>
<td>1 Smoking Cessation in Regional Cancer Centres (RCCs)</td>
<td>Prevention &amp; Screening</td>
</tr>
<tr>
<td>2 Occupational and Environmental Risks at the Primary Care Level</td>
<td>Prevention &amp; Screening</td>
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<tr>
<td>Promoting awareness, connecting symptoms with exposure and promoting swift action.</td>
<td></td>
</tr>
<tr>
<td>3 De-stigmatizing Lung Cancer</td>
<td>Prevention &amp; Screening</td>
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<tr>
<td>How to reduce the stigma associated with lung cancer – from a patient and healthcare professional perspective.</td>
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The symposium served to engage and connect stakeholders involved in the lung cancer journey. The interactive and multidisciplinary day yielded fruitful discussions and concrete considerations for moving forward on the eight priorities discussed.

Table 1 - Improvement Projects Discussed

<table>
<thead>
<tr>
<th>Priority</th>
<th>Description</th>
<th>Domain</th>
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<tbody>
<tr>
<td>4</td>
<td>Optimizing the Use of Diagnostic Imaging in Lung Cancer</td>
<td>Diagnosis</td>
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<tr>
<td></td>
<td>Standardizing imaging and implementing synoptic reporting.</td>
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<td>5</td>
<td>Improving the Referral Process</td>
<td>Treatment</td>
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<td></td>
<td>Ensuring appropriate and efficient referrals both into and within the cancer system.</td>
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<td>6</td>
<td>Managing Transitions Between Care Providers</td>
<td>Palliative Care, End of Life Care (EOL), Survivorship (cross-journey)</td>
</tr>
<tr>
<td></td>
<td>How to best manage transitions between providers along the cancer journey – maximizing opportunities.</td>
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<td>7</td>
<td>Standardizing Patient Information</td>
<td>Patient and Family Advisory</td>
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<td></td>
<td>Ensuring that patients have access to and are provided with the right information at the right time across the journey.</td>
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<tr>
<td>8</td>
<td>Educating Healthcare Professionals outside the Cancer System on Lung Cancer</td>
<td>Palliative Care, EOL, Survivorship</td>
</tr>
<tr>
<td></td>
<td>Improving understanding of lung cancer to help leverage care provided by non-oncology health professionals during the journey.</td>
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Pilot Projects

**Dyspnea Management**

Improving the management of dyspnea – shortness of breath – in lung cancer patients was a key issue identified in year one of Lung DPM. The DPM working groups noted that dyspnea is both a priority symptom for many lung cancer patients with approximately 60% of patients who visit the clinic reporting some level of dyspnea. Evidence has shown that counselling patients about dyspnea and providing practical tips for managing the activities day-to-day can help improve a patient’s functional outcomes and quality of life.

In response, Cancer Care Ontario’s DPM team held a funding competition and funded six cancer treatment centres across the province for the development and implementation of one-year pilot projects in dyspnea management. Each centre uses a different approach to dyspnea management and is required to measure impact of their project on quality of life, functional outcomes and patient satisfaction. The results of these pilot projects will be made available in mid-2011.
Lung Cancer DPM: Priorities for Action

The following pages detail the specific output of each Disease Pathway Management working group.

The information is presented as follows:

**Identified Priorities for Action**

This section details the priorities for action within the journey phase of the working group at a high level.

**Case for Action**

This section outlines the background information regarding each priority.

** Proposed Improvement Projects**

This section details the improvement project concepts proposed to address each priority. These projects are suggestions; the concepts shared here are not the only way to address each issue identified.
Prevention, Screening & Early Diagnosis

Identified Priorities for Action

1. Increasing support and resources for smoking cessation
2. Linking historical exposure to awareness of increased risk at the primary care level
3. Raising awareness of lung cancer and its causes to reduce stigma for patients
4. Mobilizing for action as a result of research advancements in screening and tobacco control

Case for Action on Prevention, Screening & Early Diagnosis

Smoking is the leading cause of lung cancer

Not only does cigarette smoking cause 87% of all lung cancers, but smoking is also associated with increased complications and morbidity levels in lung cancer patients undergoing treatment, decreased survival, development of a second primary cancer, and increased risk in developing other serious medical conditions such as Chronic Obstructive Pulmonary Disease (COPD), coronary heart disease, stroke, etc. (Cox, 2002). Despite this knowledge, not all of Ontario’s regional cancer programs have a formalized, coordinated approach to addressing smoking cessation.

Occupational and environmental exposures lead to increased risk for lung cancer

It is known that certain occupational and environmental exposures (such as exposure to asbestos in manufacturing or radon in the home) can lead to increased risk for lung cancer. In the United States, 10-15% of lung cancer deaths are due to radon exposure (Cancer Care Ontario: Population Studies & Surveillance, 2006); in Ontario, 4-10% of cancer deaths are a result of workplace exposure (Occupational Cancer Research Centre, 2009). Understanding a patient’s history and level of risk is therefore important for identifying potential lung cancers as early in the disease process as possible, when treatment can be most effective.

Lack of understanding attaches a stigma to lung cancer patients

There is a stigma associated with lung cancer: that it is the ‘self-inflicted’ cancer that only happens to smokers. In Canada, 22% of individuals have less sympathy for lung cancer patients than patients with other cancers (Ipsos Mori, 2010).

The majority of people diagnosed with lung cancer in Canada are elderly, with a mean age at diagnosis in 2008 of 70 years old. This means that many patients started smoking at a time when smoking was not only acceptable, but promoted by the medical community. Although these individuals made the decision to smoke, they did so at a time where the ramifications of that choice were not well understood. Many current patients had quit smoking, but still developed lung cancer later on in life.

Research on early detection is underway

The detection of lung cancer when it is at an early stage and surgically resectable is key to the best possible outcome for patients, yet effective screening methods for lung cancer do not yet exist for population-based screening. Research is underway, including two major North American trials: the National Lung Screening Trial in the United States and Early Detection of Lung Cancer study in Canada. Early results from the National Lung Screening Trial indicate a positive outcome for those at increased risk, while results from the Early Detection of Lung Cancer study are expected in subsequent years.
Translating study results into a lung screening program, however, is expected to take a significant amount of time.

**Proposed Improvement Projects: Prevention, Screening & Early Diagnosis**

1. **Smoking Cessation Programs in Regional Cancer Programs**

   Such a project would take advantage of the resources of the regional cancer centres and their networks to reach out to cancer patients, their families, and staff, regarding smoking cessation.

   At its core, this project would consist of the implementation of evidence-based smoking cessation programs within the cancer program. Options for implementation could include existing approaches such as those offered by the Ottawa Heart Institute, or could involve a simpler approach such as promoting the use of Registered Nurses’ Association of Ontario (RNAO) best practices for counselling patients regarding smoking cessation.

2. **Raising Awareness of Occupational and Environmental Risks at the Primary Care Level**

   This project concept would promote the discussion of a patient’s prior occupational and environmental exposures with their family healthcare provider in order to heighten awareness of the potential risk of lung cancer and promote early attention to any symptoms suggestive of lung cancer.

   Patients with a history of exposure could be educated about potential symptoms to watch for. Physicians would be refreshed on the links between exposure and developing a lung cancer, and would be provided with tools to flag patients at risk should related symptoms present.

3. **Promoting Awareness and Reducing Stigma: a Public Education Campaign**

   This project would help change public attitudes and beliefs about lung cancer. It could take the form of a public awareness campaign designed to improve understanding of lung cancer, including:

   - Who gets lung cancer (all people, all ages – not just smokers)
   - Statistics for lung cancer (incidence, deaths, types and number of treatments, funding)
   - Awareness around (lack of) screening and the importance of early detection
   - The other risk factors for developing lung cancer (occupational and environmental exposures, including second-hand smoke)

   The Campaign would create greater awareness of the causes of lung cancer, which could translate into reduced stigma for patients and a greater demand for attention to ensure optimal care and research funding. Additionally, by improving awareness of lung cancer, it is possible that more individuals could present at primary care with symptoms and be referred to DAPs earlier on in the disease trajectory.

4. **Research Briefs: Early Detection of Lung Cancer**

   As the ongoing research in this field (including early detection techniques, screening trials and biomarker development work), has yet to be published, this series of briefs would aim to keep the stakeholders relevant to decision-making regarding screening programs informed in a timely manner. Doing so would promote swifter decisions and/or implementation of a widespread lung screening program once conclusive results are published.
Lung Cancer DPM – Priorities for Action

Diagnosis

Identified Priorities for Action

1. Developing synoptic reporting for diagnostic imaging
2. Supporting the ongoing training and education of radiologists
3. Ensuring physicians receive sufficient contextual information about a patient in a timely fashion

Case for Action on Diagnosis

Imaging Plays an Important Role in the Diagnosis of Lung Cancer

Imaging is an integral part of arriving at a diagnosis of lung cancer: from identifying an initial problem via chest x-ray or CT scan, to characterizing the location of a tumour for appropriate biopsy, to staging the extent of the disease.

In Ontario, the target wait time for CT scans is 28 days from the point of requisition. With these wait times and with CTs playing a role at up to three different timepoints along the journey to diagnosis, it is important that CTs are performed and interpreted appropriately. Equally important is that the results are communicated clearly to practitioners who make decisions based on them to avoid further time delays for the patient or inappropriate further investigation.

Contextual Patient Information Up Front Ensures a Smoother Journey

The physicians involved in diagnosis and treatment may not always receive enough information about the patient to perform their diagnostic assessments effectively. Lack of contextual information regarding a patient’s history and background may cause those involved in diagnostic imaging to make assumptions, or to spend unnecessary time contacting the referring physician to obtain the required information. Both of these may result in delays for the patient, which in some cases may allow for progression of the cancer.

Proposed Improvement Projects: Diagnosis

1. Improving Diagnostic Imaging via Synoptic Reporting

As imaging plays an important role in the initial diagnosis and subsequent staging of lung cancers, the communication of imaging results is of paramount importance. This project aims to improve the communication of radiological results to requesting physicians.

Reporting of radiology results currently takes place in prose format, which has the potential to create misunderstandings. Pieces of information may inadvertently be missed, or results and interpretation may be unclear. To add value to radiology, this project proposes adding a synoptic portion (similar in concept to synoptic reporting for pathology) to the radiology report. This portion could reflect information such as “index of suspicion for cancer” and “level of urgency”; physicians receiving the report could quickly scan the synoptic section for high level results and read the prose for more detail as required.

2. Supporting High Quality Diagnostic Imaging via Radiologist Education

Diagnostic imaging is critically important to arrive at a timely and accurate diagnosis of lung cancer and it is a field that has experienced a rapid advancement in technology. Lung cancer can be complicated, as is not always straightforward from a diagnostic perspective. This project aims to put processes and structures in place to support the radiology community in maintaining superior skill levels in performing
and interpreting diagnostic imaging via Continuing Medical Education (CME). By sharing best practices and collaborating on difficult sample cases through vehicles such as ListServs, Ontario radiologists can work together to continue to ensure the highest standard of quality in diagnostic imaging.

3. Standardized Requisition Form for all Modalities

A standardized requisition form for all modalities is proposed to provide more context surrounding the patient (including history, suspected diagnosis and co-morbidities). This is expected to improve efficiencies in referrals and ordering tests because receivers of the requisitions will have the necessary information to perform their functions and will not use time sourcing this information. This form would be customizable by institution to allow for specific information to be included. While this form could initially be developed as a paper-based resource, it should ultimately inform the creation of a centralized automated referral and requisition system.

Alternatively, an education program regarding the importance of flagging and communicating the background information about a patient as well as the level of suspicion of lung cancer should be put in place.
Treatment

Identified Priorities for Action

1. Educating and raising awareness regarding proper referrals
2. Developing standards of access to care for diagnosis and treatment
3. Developing a framework for how to prioritize patient care
4. Improving the management of urgent problems along the disease trajectory

Case for Action on Treatment

Referrals Represent an Opportunity for Increased Efficiencies

Currently, referrals for diagnosis and treatment can sometimes be characterized by: a lack of complete information for the consulting physician; inefficient processes; or, referrals to an inappropriate specialist. Inefficiencies in the transitions into and within the cancer system can cause delays, negatively impacting the experience of patients, and in some cases, allowing the cancer to progress to a higher stage.

The Length of the Patient Journey Varies Across the Province

A lack of current standards or expectations for how quickly patients should move through the lung cancer pathway translates into a prolonged patient journey in some parts of the province and potentially to poorer outcomes. Currently the median time from diagnosis to treatment is 35 days in Ontario; however, examining the 90th percentile of this same data shows that there are some patients who are waiting close to four months to receive their first treatment (Lung Cancer Disease Pathway Management, 2011). This variance in wait times indicates that some guidance with regard to what should be reasonable expectations for wait time intervals would be appropriate.

A Comprehensive Approach to Prioritizing Patients May Improve Outcomes

In a system often stretched to capacity, decisions regarding prioritization for treatment may need to be made. Currently, the system may work a first-come-first-serve or ‘negotiate for your patient’ basis, which may not result in optimal outcomes. With a high incidence and low five-year survival rate, optimal assessment and treatment is not only important to ensure optimal outcomes, but also to promote equitable and comparable approaches to patient management across the province.

The Approach to the Management of Acute Symptoms can be Improved

During treatment, patients can experience urgent problems or side effects. When this happens, the patients need to be able to access medical advice or attention from their oncology team quickly, or else they are likely to visit the Emergency Department (ED). Currently, a vast proportion of lung cancer patients access the ED with over 40% of patients diagnosed in 2009 accessing the ED within three months of diagnosis, and just under 75% of patients accessing the ED within three months of death (Lung Cancer Disease Pathway Management, 2011). Managing cancer patients’ problems in the ED is not an efficient use of resources, nor the best way to care for the needs of cancer patients.
Proposed Improvement Projects: Treatment

1. Educating and Raising Awareness of the Referral Process

Because many lung cancer patients may enter the cancer treatment system outside of an organized diagnostic process such as a DAP, it is recommended that a preferred process for how to refer patients into the cancer system be created and communicated to relevant clinical parties including family physicians, ED physicians and others. It is important that clinicians referring patients for assessment and treatment understand the type of physician to whom it is most appropriate to refer a patient presenting in a particular way with suspected lung cancer. It is also important to understand which required procedures (imaging, etc.) could be scheduled in parallel with the referral to make for a speedier patient transition.

As many Regional Cancer Programs already have established referral processes in place, a potential focus of this project could be to promote existing referral processes to the relevant parties involved. Suggested activities to support this include travelling or web-based community presentations led by key opinion leaders. These sessions could cover how to appropriately refer (in general), specific types of referral (e.g. metastatic patient), and what elements (e.g. CT) can be co-booked with the referral and by whom.

2. Developing Standards for Access to Care (including diagnosis and treatment)

This project would aim to identify provincial standards for access to care for selected portions of the lung cancer journey. The purpose of these standards would be to ensure that all Ontario lung cancer patients receive appropriate care in a timely manner and are provided with the best possible conditions for managing their disease. The development of standards would result in a resource that all regional cancer programs could refer to when planning and managing patient flow through the system.

3. Developing a Framework to Prioritize Patients for Treatment

To address this issue, it is proposed that an evidence-based framework on how to triage patients for treatment be developed for implementation in Ontario. This would provide provincial guidance to physicians and would help ensure that optimal outcomes are provided equitably to patients across the province. Such a project could take the form of an environmental scan of strategies currently used at various cancer centres for a subset of the lung population (i.e. SCLC), as well as a literature review. Once a smaller scale review has been conducted, a wider more comprehensive review of strategies for managing all lung cancer patients could be conducted. A recommendations document could be created and published on the CCO website.

4. Defining a Process for Managing Urgent Problems along the Cancer Continuum

This project would aim to clearly outline a defined process for managing urgent, unplanned problems along the cancer journey, including side effects and symptom management. This would require that each cancer program define who patients should approach for their issues and when; this process would be clearly communicated to all patients and caregivers as well as staff.

A program for the management of urgent problems could include aspects such as: an on-call physician for one hospital or multiple hospitals in an area; a clinic exclusively to manage acute problems; nurse-led clinics for awareness and education regarding treatment side effects. To support these aspects a patient-oriented list of symptoms with a clinician to contact for support in managing each symptom.
Palliative Care

Identified Priorities for Action

1. Identifying supportive care needs early on in the cancer continuum
2. The management of lung cancer-specific symptoms
3. Improving the integration of the family practitioner into the patient’s care team

Case for Action on Palliative Care

Supportive Care Begins at Diagnosis

Supportive care, including the proactive management of physical issues that may affect treatment outcomes (e.g., nutrition) and the management of the psychosocial impacts of cancer, is an important part of the cancer journey and it begins at diagnosis. Of the lung cancer patients surveyed in the 2009 AOPSS survey, over 35% reported that they were not referred to a provider to help them manage their anxieties or fears after diagnosis (NRC Picker, 2009). Of the lung cancer patients surveyed 28%, felt they did not receive enough information about changes in their emotions, and only 53% felt they received complete information about their nutritional needs (NRC Picker, 2009). This data suggests room for improvement in the management of patients’ needs.

Lung Cancer has a Unique Symptom Profile

Lung cancer patients present with a unique symptom profile that typically reflects the advanced stage of cancer at diagnosis, as well as the cancer’s effect on the primary site: the lungs. With approximately 40% of lung cancer patients reporting a score of moderate or severe dyspnea (shortness of breath), this symptom is a priority for this patient population (Lung Cancer Disease Pathway Management, 2011). Evidence has shown that counselling patients about dyspnea can result in improved outcomes and quality of life. This counselling may include teaching patients how to manage during attacks and how to approach daily tasks to minimize onset of dyspnea.

Despite the high incidence of lung cancer and the significance of dyspnea to the population and its effects on quality of life, the management of this symptom has been inconsistent. In 2010, several pilot projects were funded and are now underway in select cancer centres. Each program uses a breathlessness management approach tailored to their needs. Data to measure impact on quality of life, functional outcomes and patient satisfaction are being collected. Results will be available from Disease Pathway Management in mid-2011.

Family Physicians Represent an Important Part of the Patient’s Care Team

The family physician represents a healthcare provider with whom the patient has an existing relationship. However, once the patient has been diagnosed with cancer and goes on to be cared for by cancer system clinicians, the family physician can be left out of the loop regarding patient status and care decisions. In addition to lack of information, some family practitioners may not be familiar with the various aspects of lung cancer including treatment, potential side effects and how to best manage and support the patient through their journey. In the 2009 AOPSS survey, approximately 51% of lung cancer patients felt their family doctor knew enough about their cancer care, suggesting that there is room for improvement (NRC Picker, 2009).
From the patient perspective, the family practitioner represents an important part of the care team: someone they may feel safe approaching with questions and someone who may be located closer to home. From a systems perspective, the family practitioner represents an important resource to support the patient throughout the cancer journey, as well as to provide continuity in follow-up and survivorship care.

Proposed Improvement Projects: Palliative Care

1. Dyspnea Management Programs
   It is proposed that a dyspnea management education program for patients and their families should be offered to every patient diagnosed with lung cancer in Ontario. This could take the form of minimal education during diagnosis about dyspnea (what it is) and the resources available, and then more formal training if dyspnea becomes an important issue for the patient.

2. Early Identification of Supportive Care Needs at Diagnosis
   To maximize the potential for positive treatment outcomes in suspected lung cancer patients, an assessment of initial supportive care needs is proposed. By conducting an assessment early in the journey, important patient needs can potentially be addressed.

   To assess individuals not yet diagnosed but with suspicious signs and symptoms, care must be taken to avoid provoking additional anxiety as the result of the assessment tool used. This project proposes to establish a working group to identify key factors to be assessed during diagnosis (e.g., nutrition, anxiety) and to recommend appropriate assessment tools for use during the diagnostic phase (e.g., Malnutrition Screening Tool for nutrition; Distress Thermometer for anxiety, etc.).

3. Educating Non-Oncology Health Care Professionals about Lung Cancer
   This project would serve to educate non-oncology health care professionals involved with lung cancer patients, including primary care practitioners, about the trajectory of the disease, what to expect and what to watch out for and how to manage palliative care. The intent is to make use of those clinicians outside of the formal cancer system who have contact and a relationship with the patient and who could be better involved in the patient’s care.

   Ideas for the implementation of such a project include a formal accredited education program targeted at primary care providers or a travelling academic detailing ‘roadshow’. Topics to cover could include: the disease trajectory, typical treatment pathways, side effects, signs of progression, and how to manage the patient, etc.
The Patient Experience

Identified Priorities for Action

1. Improving psychosocial support offered to individuals in the diagnostic phase
2. Defining provincial standards for patient information: what should be offered and when
3. Explicitly addressing transitions between phases of the cancer journey and care providers
4. Improving alternative access to care where appropriate

Case for Action on the Patient Experience

Diagnosis Represents a Period of Uncertainty and Anxiety

It has been identified that the time period surrounding diagnosis can be very distressing for patients. Lung cancer patients may face additional anxieties due to the nature of the diagnostic process, which involves multiple procedures, potentially over a period of time. Despite the knowledge that diagnosis can be distressing, the level of psychosocial support offered during the diagnostic phase of the journey varies. The launch of DAPs across the province presents an opportunity to incorporate psychosocial support into the diagnostic pathway for suspected lung cancer patients.

The Information Provided to Patients about Lung Cancer Varies Provincially

Information may help patients and their families make sense of their diagnosis and what to anticipate as they follow their cancer journey. In a provincial system with 13 Regional Cancer Programs, and many more institutions in which patients receive cancer care, there may exist a disparity in the information that is provided to patients across the province including content, and how and when the information is provided. In the 2009 AOPSS, just under 70% of lung cancer patients reported receiving enough information about their therapies, leaving approximately 30% whose needs may not have been met (NRC Picker, 2009). Of the patients surveyed, 53% reported that they always knew who to go to with questions, suggesting that there is room for improvement (NRC Picker, 2009).

Transitions throughout the Cancer Journey can be Better Managed

Transitions are an important milestone to examine along the patient journey. Patients may switch between managing physicians as they progress through their treatments; patients also experience transitions upon entry into and exit from the cancer system. At each point of transition there is the potential for communication gaps, or for the patient to experience uncertainty regarding next steps.

According to the 2009 AOPSS, over 77% of responding lung cancer patients reported that they “completely” knew who was in charge of their care (NRC Picker, 2009). Addressing transitions with patients and helping them prepare for what to expect may help alleviate anxieties experienced when entering a new clinical relationship or phase of the journey.

Elements of Comprehensive Cancer Care can be Delivered Remotely

Supportive care, including psychosocial and nutrition counselling, among others, is an important part of the cancer journey. In a large province such as Ontario, access to supportive care resources can be difficult and inequitable due to geographic disparities. Additionally, accessing this type of care in person may add time and stress to the patient’s experience. Therefore, delivering appropriate types of supportive care remotely presents an opportunity to improve the overall patient experience of cancer.
Proposed Improvement Projects: Patient Experience

1. Defining Standards of Care for Psychosocial Support through Diagnosis

This project proposes to identify a minimum standard of psychosocial care and support that should be offered to patients during the pre- and peri-diagnostic phases. This project would take advantage of the development and launch of lung-specific DAPs across the province. Such a project would include providing recommendations regarding the type of supportive care that needs to be planned for and offered to individuals going through the diagnostic phase of the cancer journey.

2. Transition Meetings (between managing physicians) and Discharge Care Plans

This project proposes to specifically address the timepoints of transitions along the cancer journey to ensure that patients are well-prepared for the transition and that all relevant information about the patient and their history is transferred appropriately to the subsequent managing physician.

For patients undergoing active treatment, it is recommended that at each point of transition, a review of action to date and what to expect in the next phase should be conducted with the patient by a nurse or a similar role. The transition review would provide a defined point at which the patient can ask questions about their retrospective and prospective care, and also would provide the opportunity for the patient to act as a supplementary vehicle for information to the next provider. To support the knowledge translation to the next care team, synoptic transition summaries could be created and delivered with the patient.

For patients treated successfully (i.e., ‘survivors’), a discharge meeting could take place between the patient and nurse or managing physician. In this meeting, the provider would review the treatment received to date, provide the patient with information about what to keep watch for, along with information about treatment to share with their primary care provider. A synoptic transition report could be created to support the transition back to regular care by the family practitioner.

3. Making Standard Patient Information Available Provincially

Given the current variation in patient education programs and materials across institutions and LHINs, some standardization of the type of information provided to patients at each phase of the journey is recommended. The current patient guide provided by CCO, *Understanding Lung Cancer: a guide for patients and their families*, published in 2004 is under review and will be updated. In addition to this, more collaboration regarding the development and publication of information across and between cancer programs is recommended.

4. Facilitating Supportive Care by Distance Wherever Possible

The goal of this project is to provide the individuals involved in delivering supportive care (e.g. social workers, nutritionists, psychologists), the tools with which to conduct their patient visits remotely, where possible. In effect, this would mean that visits could be conducted via an online videoconferencing service. Where technology is not yet available, or where patients are uncomfortable with videoconferencing, teleconferencing could be used as a secondary option.

Providing the infrastructure to deliver supportive care remotely would improve the patient experience by reducing the time, energy and cost required to physically come in to see a supportive care specialist. For those living in remote areas, distances can be significant and travel may impact the patient’s well-being. For those in urban areas, time and cost of a visit (e.g. parking) can be reduced.
Conclusion and Next Steps

Should your team or cancer program implement any of the proposed improvement projects listed here, or any of your own, we would like to hear from you.

By sharing information about your improvement approaches, we can help other institutions and cancer programs learn from your experience.

Contact:

You can reach the Disease Pathway Management team at CCO the following ways:

- **DPM General Mailbox**
  Disease.pathway.management@cancercare.on.ca

- **DPM Program Manager**
  Nathalie Assouad: nathalie.assouad@cancercare.on.ca

- **DPM Project Coordinator**
  Vivian Yu: vivian.yu@cancercare.on.ca

Or visit us online at: www.cancercare.on.ca/DPM
## Appendix 1 – Listing of Lung Cancer DPM Team Members

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<thead>
<tr>
<th>Name</th>
<th>Role</th>
<th>Institution</th>
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<tbody>
<tr>
<td>Dr. Chris Allen</td>
<td>Respirologist</td>
<td>St. Joseph’s Healthcare</td>
</tr>
<tr>
<td>Ms. Laurie Bass</td>
<td>Nurse, Orthopaedic Surgery</td>
<td>Lung Cancer Canada</td>
</tr>
<tr>
<td>Dr. Andrea Bezjak</td>
<td>Radiation Oncologist - Lung Cancer DSG</td>
<td>Princess Margaret Hospital</td>
</tr>
<tr>
<td>Mrs. Catherine Black</td>
<td>Caregiver</td>
<td>Lung Cancer Canada (Board)</td>
</tr>
<tr>
<td>Mrs. Brigitta Bokkers</td>
<td>Surviving patient</td>
<td>Windsor Regional Hospital</td>
</tr>
<tr>
<td>Dr. Michael Coughlin</td>
<td>Thoracic Surgeon</td>
<td>Windsor Regional Hospital</td>
</tr>
<tr>
<td>Dr. Gail Darling</td>
<td>Thoracic Surgeon</td>
<td>Princess Margaret Hospital</td>
</tr>
<tr>
<td>Dr. Anil Dhar</td>
<td>Respirologist</td>
<td>Windsor Regional Hospital</td>
</tr>
<tr>
<td>Dr. Julian Dobranowski</td>
<td>Radiologist, Provincial Imaging Head</td>
<td>Cancer Care Ontario</td>
</tr>
<tr>
<td>Dr. Lee Donohue</td>
<td>Family Practice Physician lead</td>
<td>Champlain LHIN</td>
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<tr>
<td>Mr. John Drury</td>
<td>Surviving patient</td>
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<tr>
<td>Dr. Peter Ellis</td>
<td>Medical Oncologist</td>
<td>Juravinski Cancer Centre</td>
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<tr>
<td>Ms. Margaret Fitch</td>
<td>Psychologist</td>
<td>Odette Cancer Centre</td>
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<tr>
<td>Dr. Andrea Frolic</td>
<td>Ethicist</td>
<td>Hamilton Health Sciences</td>
</tr>
<tr>
<td>Dr. Marcio Gomes</td>
<td>Anatomical Pathologist</td>
<td>The Ottawa Hospital</td>
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<tr>
<td>Ms. Sandra Hardy</td>
<td>Bereavement counselor</td>
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<tr>
<td>Dr. D. Linn Holness</td>
<td>Occupational and Environmental Health</td>
<td>St. Michael’s Hospital</td>
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<tr>
<td>Dr. Doris Howell</td>
<td>Oncology Nursing Education &amp; Research</td>
<td>UHN &amp; U of T</td>
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<tr>
<td>Ms. Julia Johnston</td>
<td>APN, Palliative Care Program</td>
<td>Trillium Health Centre</td>
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<tr>
<td>Dr. Alan Kaplan</td>
<td>Family Physician</td>
<td>Family Med Resp Centre</td>
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<tr>
<td>Ms. Cathy Kiteley</td>
<td>Clinical Director, Systemic Therapy (APN)</td>
<td>Credit Valley Regional Cancer Centre</td>
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<td>Dr. Sara Kuruvilla</td>
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<tr>
<td>Dr. Keith Kwan</td>
<td>Pathologist</td>
<td>London Health Sciences Centre</td>
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<tr>
<td>Dr. Natasha Leighl</td>
<td>Treatment researcher</td>
<td>Princess Margaret Hospital</td>
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<tr>
<td>Mr. Peter MacKenzie</td>
<td>Board member</td>
<td>Lung Cancer Canada (Board)</td>
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<tr>
<td>Dr. Chris Mackie</td>
<td>Associate Medical Officer of Health</td>
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<tr>
<td>Ms. Lorraine Martelli-Reid</td>
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<td>Juravinski Cancer Centre</td>
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<td>Dr. Donna Maziak</td>
<td>Thoracic Surgeon</td>
<td>The Ottawa Hospital</td>
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<tr>
<td>Ms. Karen Melenchuk</td>
<td>RN - outpatient oncology unit</td>
<td>Thunder Bay Regional HSC</td>
</tr>
<tr>
<td>Dr. Jim Morris</td>
<td>Program Director Nicotine Dependence Centre</td>
<td>Thunder Bay Regional HSC</td>
</tr>
<tr>
<td>Dr. Dan Mozeg</td>
<td>Radiologist</td>
<td>Odette Cancer Centre</td>
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<tr>
<td>Ms. Liane Murphy</td>
<td>Oncology Social Work</td>
<td>The Ottawa Hospital, Cancer Assessment Clinic for Lung</td>
</tr>
<tr>
<td>Name</td>
<td>Role and Responsibilities</td>
<td>Organization</td>
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<tr>
<td>Ms. Jennifer Parkins</td>
<td>RN - Thoracic Diagnostic Assessment Unit</td>
<td>Grand River RCC</td>
</tr>
<tr>
<td>Dr. Serge Puksa</td>
<td>Respirologist</td>
<td>Henderson General Hospital</td>
</tr>
<tr>
<td>Dr. Bob Reid</td>
<td>Associate Director, Minto Prevention &amp; Rehab Centre</td>
<td>Physicians for a Smoke Free Canada</td>
</tr>
<tr>
<td>Dr. Heidi Roberts</td>
<td>Radiology - led screening initiatives</td>
<td>Toronto General Hospital</td>
</tr>
<tr>
<td>Dr. Bob Reid</td>
<td>Associate Director, Minto Prevention &amp; Rehab Centre</td>
<td>Physicians for a Smoke Free Canada</td>
</tr>
<tr>
<td>Dr. Sharon Russell</td>
<td>Palliative care physician lead</td>
<td>Juravinski Cancer Centre</td>
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<tr>
<td>Dr. Harman Sekhon</td>
<td>Pathologist</td>
<td>The Ottawa Hospital</td>
</tr>
<tr>
<td>Dr. Carmine Simone</td>
<td>Thoracic Surgeon</td>
<td>Toronto East General Hospital</td>
</tr>
<tr>
<td>Ms. Jennifer Smylie</td>
<td>Clinical Manager</td>
<td>Cancer Assessment clinic</td>
</tr>
<tr>
<td>Dr. Ivan Stewart</td>
<td>Palliative care</td>
<td>Queen's University</td>
</tr>
<tr>
<td>Dr. Sudhir Sundaresan</td>
<td>Thoracic Surgeon</td>
<td>The Ottawa Hospital</td>
</tr>
<tr>
<td>Ms. Karen Taillefer</td>
<td>Senior Director Client Services</td>
<td>North Simcoe Muskoka CCAC</td>
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### Appendix 2 – List of Lung DPM Project Concepts

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<td>Smoking Cessation Programs in Regional Cancer Programs</td>
<td>Prevention &amp; Screening</td>
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<td>2</td>
<td>Raising Awareness of Occupational and Environmental Risks at the Primary Care Level</td>
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<td>Promoting Awareness and Reducing Stigma: a Public Education Campaign</td>
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<td>Research Briefs: Early Detection of Lung Cancer</td>
<td>Prevention &amp; Screening</td>
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<td>5a</td>
<td>Improving Diagnostic Imaging via Synoptic Reporting</td>
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<td>5b</td>
<td>Supporting High Quality Diagnostic Imaging via Radiologist Education</td>
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<td>Standardized Requisition Form for all Modalities</td>
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<td>Educating and Raising Awareness of the Referral Process</td>
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<td>8</td>
<td>Developing Standards for Access to Care (including diagnosis and treatment)</td>
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<td>Dyspnea Management Programs</td>
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<td>Defining Standards of Care for Psychosocial Support through Diagnosis</td>
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<td>17</td>
<td>Facilitating Supportive Care by Distance Wherever Possible</td>
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References


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