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**Toward early referral to palliative care  
and improved documentation of goals  
of care, levels of care and advanced  
care planning**

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November 16, 2018



# Outline

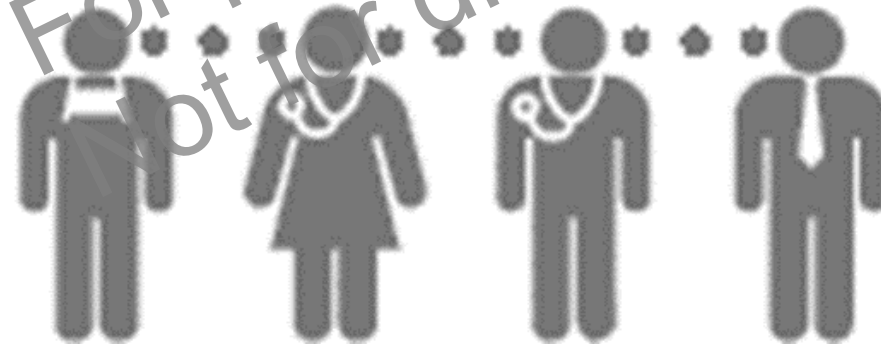
- Project goal and objectives
- Our approach
- Review of the baseline data
- Key process elements
- Tools for health care providers
- Evaluation parameters

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# Project goal

The goal of our project is to establish **early collaborative partnership** between Oncology and Palliative/Supportive Care to put in place a timely plan for patient decline.



# Project objectives

- **Improve documentation of goals of care, and advance care planning (ACP)**
  - Goals of care discussed and documented in the patient medical record
  - Level of Care (LoC) form completed
  - Advanced care planning re: a substitute decision maker discussed and documented
- **Offer early referral to supportive/palliative care for symptom management** (within 60 days of diagnosis)
  - Currently there is a **level 1 evidence** of the benefits of early integration of palliative/supportive care for patients with advanced disease. Benefits include:
    - Better quality of life (QoL)
    - Reduction in avoidable hospitalizations and treatments
    - Better alignment between patient preferences and care delivered



# Rationale

- Many patients with metastatic cancer become ill and arrive to the hospital with no prior discussion about their goals of care (GoC)
- Several guidelines (e.g. ASCO, NCCC) now recommend that oncologists have a discussion about advance care planning early in the disease trajectory
- Several studies have identified approaches that were successful in increasing rate of ACP discussion and documentation. The key elements of these approaches include:
  - Identifying patients from health records
  - Providing electronic prompts to physicians
  - Educating staff
  - Regularly reporting results

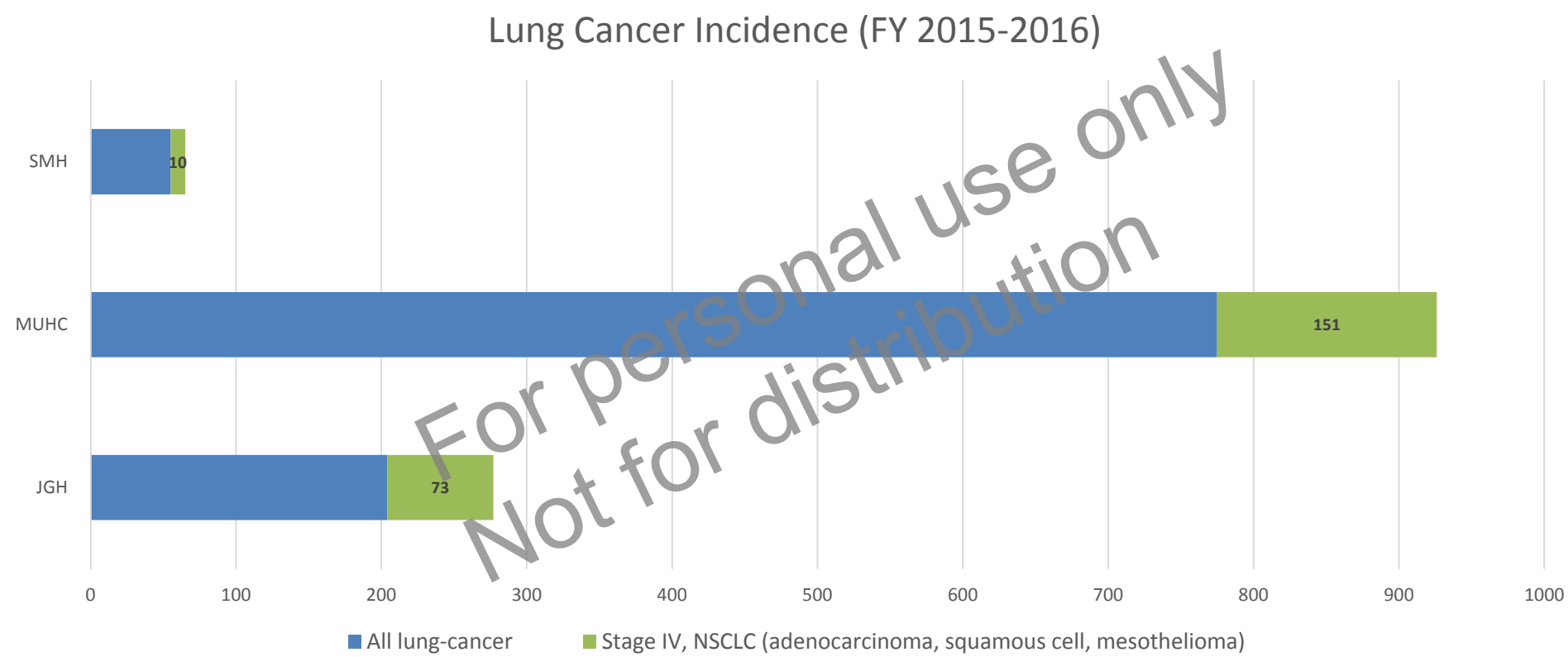


# Our approach

- Identify the eligible patient population (inclusion and exclusion criteria)
- Conduct chart reviews to obtain baseline rates
- Establish a working group at each RCN site
- Develop processes and tools to support the oncology health care providers
  - New “Goals of Care Form” approved by the Medical Records
  - Prompts and reminders to the oncology team
  - Education sessions
- Track the process adherence
- Evaluate the impact of the initiative



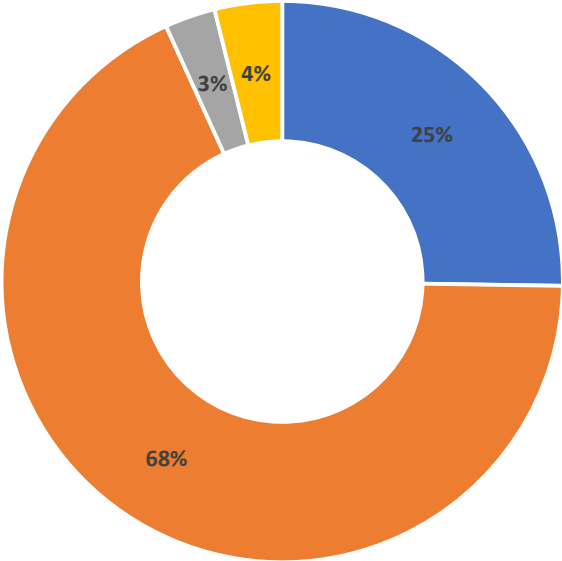
# Patient population



Source: JGH, MUHC, SMHC Cancer Registries

# Review of the baseline data: GoC documentation

GoC documentation by the medical profession (MUHC and SMHC; n=103)



- Medical Oncologist
- Radiation Oncologist
- Palliative Care Physician
- IPC nurse

RCN Site	Number of patients	Goals of care documented	Goals of care documented within 60 days	% GoC documented within 60 days
MUHC	139	96	94	67.6%
SMHC	9	7	5	55.6%





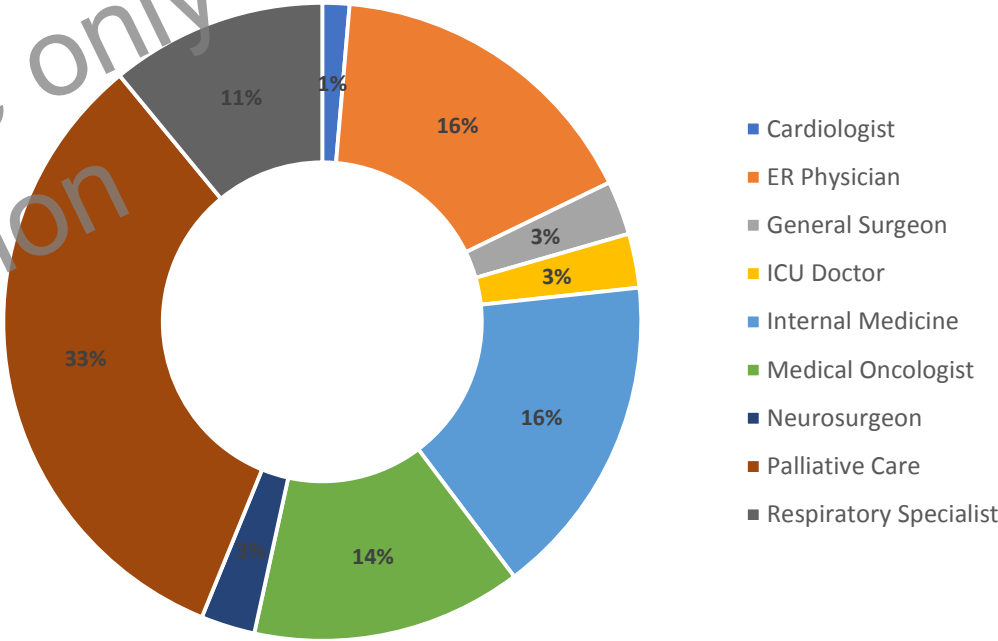
# Review of the baseline data: LoC & ACP documentation

RCN Site	Number of patients	LoC documented	LoC documented within 60 days	% LoC documented within 60 days
MUHC	139	67	36	25.9%
SMHC	9	6	1	11.1%

RCN Site	Number of patients	ACP discussion documented	ACP documented within 60 days	% ACP documented within 60 days
MUHC	139	3	1	0.7%
SMHC	9	0	0	0.0%

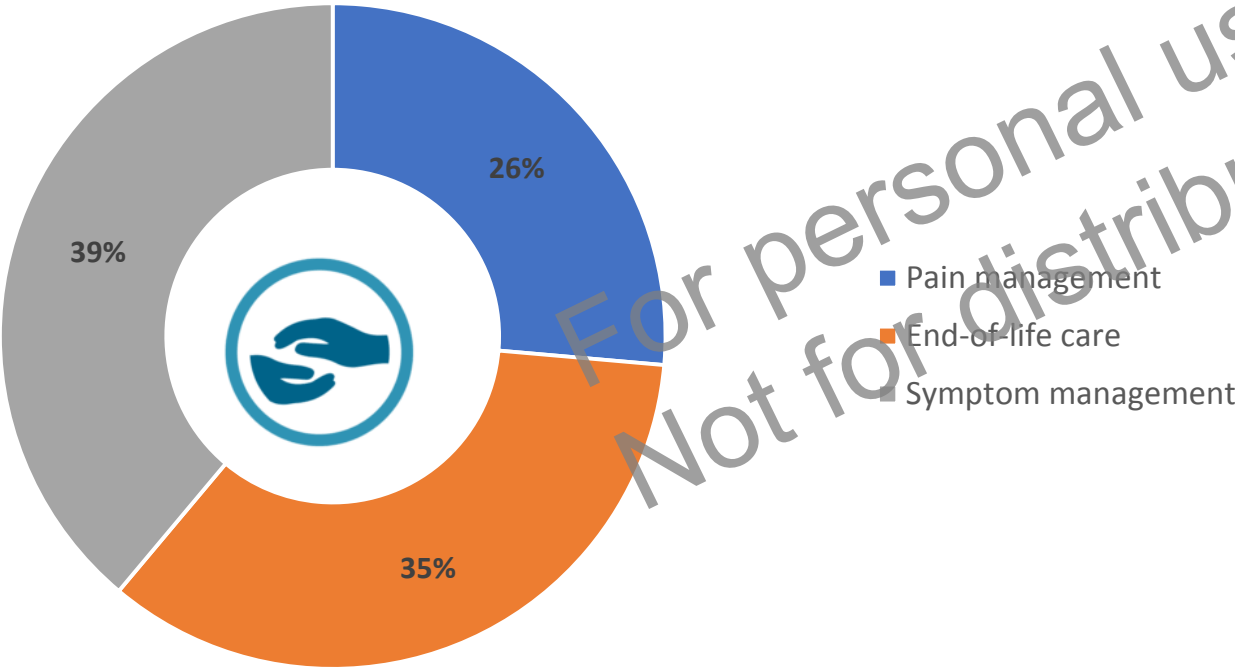


LoC documentation by medical profession (MUHC & SMHC; n=73)



# Baseline referral patterns to Palliative Care (PC)

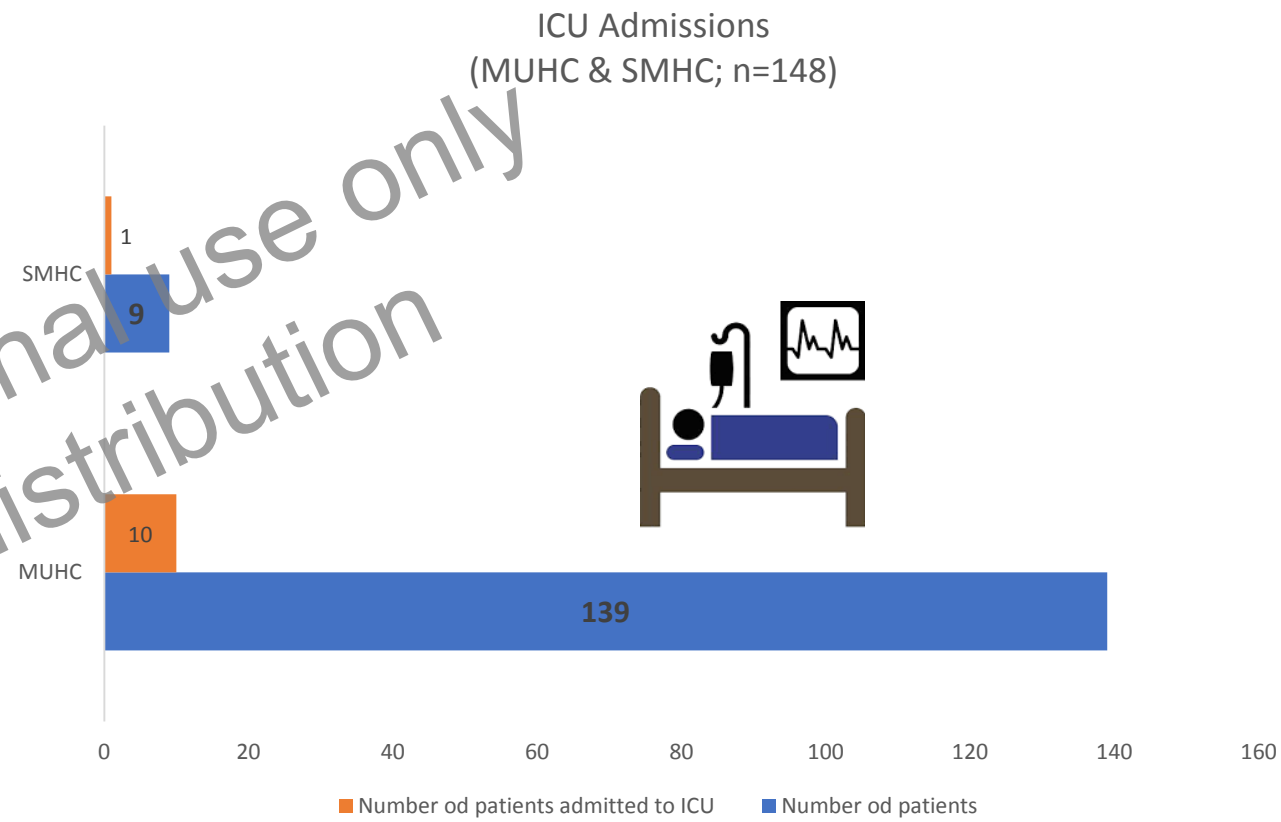
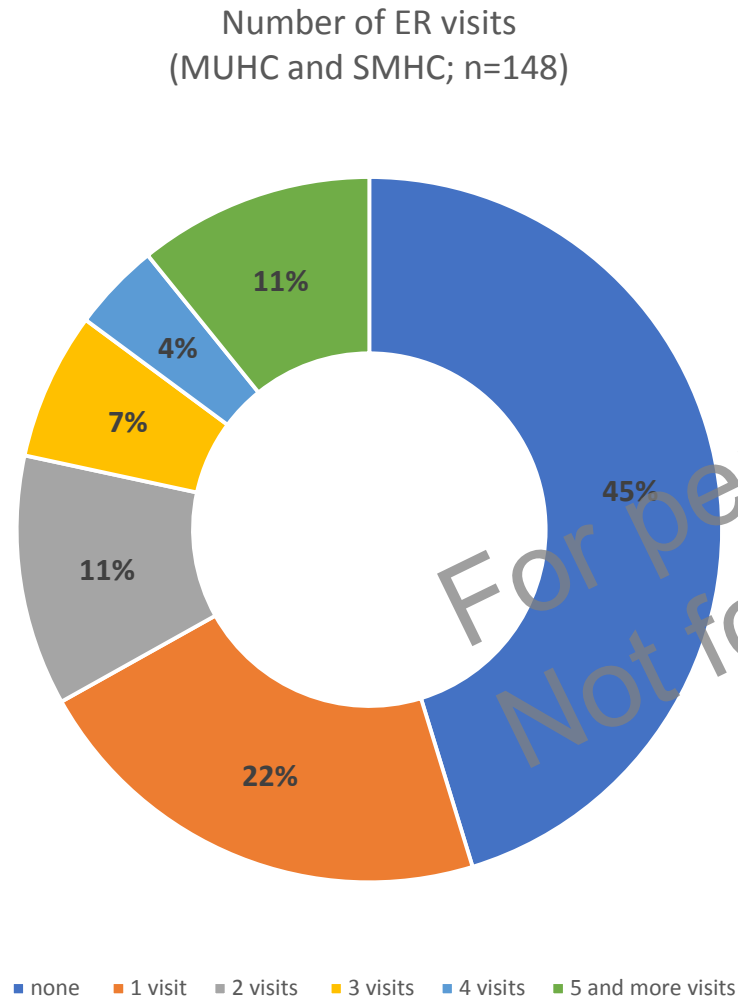
Primary reason for referral to palliative care  
(MUHC & SMHC; n=72)



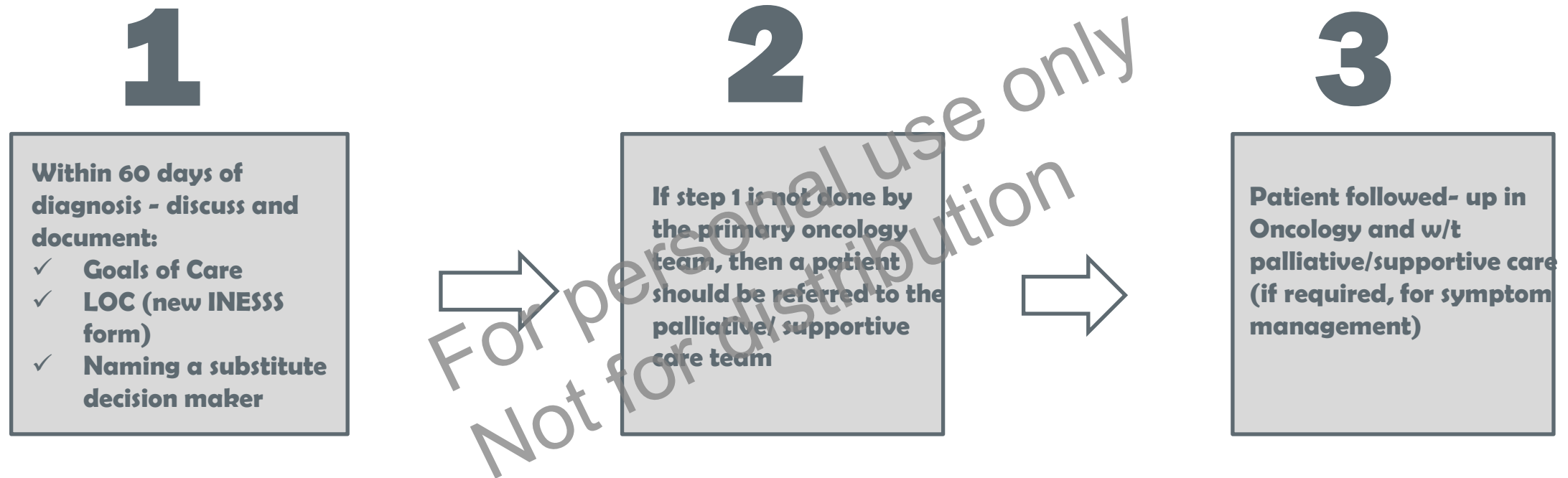
RCN Site	Number of Referral to palliative patients	care	Referral to PC within 60 % referral to PC within days	60 days
MUHC	139	67	38	27.3%
SMHC	9	5	3	33.3%



# ER visits & ICU Admissions

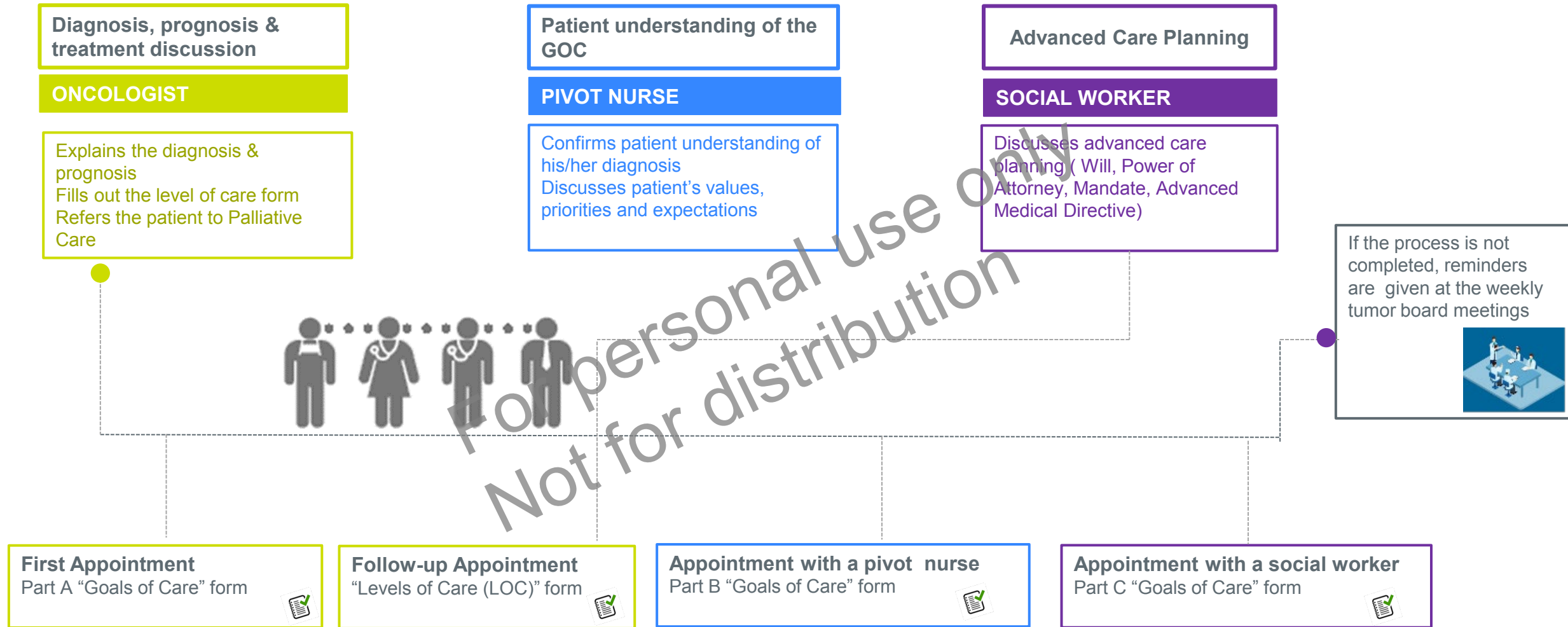


# Key process elements



Key elements remain the same across RCN, but **the process is tailored to the existing organizational structure and resources available** at each RCN site

# St. Mary's Multidisciplinary Team Approach to Early Referral to PC and Documentation of GoC, LoC, ACP



# Tools for Health Care Providers to facilitate better and earlier conversation about GoC, LoC and ACP

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# Serious Illness Conversation Guide

- Serious Illness Conversation Guide developed by the team of palliative care specialists at Dana Faber
- The guide offers a structured way of discussing values, goals and priorities of patients with advanced disease
- Topics include:
  - Setting up the conversation
  - Assessing patient understanding and preferences
  - Sharing prognosis
  - Exploring key topics
  - Closing the conversation
  - Documenting the conversation
  - Communicating with key clinicians

Serious Illness Conversation Guide	
CONVERSATION FLOW	
1. Set up the conversation	Introduce purpose Prepare for future decisions Ask permission
2. Assess understanding and preferences	
3. Share prognosis	Share prognosis Frame as a "wish...worry", "hope...worry" statement Allow silence, explore emotion
4. Explore key topics	Goals Fears and worries Sources of strength Critical abilities Tradeoffs Family
5. Close the conversation	Summarize Make a recommendation Check in with patient Affirm commitment
6. Document your conversation	
7. Communicate with key clinicians	

(<https://www.talkaboutwhatmatters.org/documents/Providers/PSJ-H-Serious-Illness-Conversation-Guide.pdf> )





## Care at the End of Life for Advanced Cancer Patients: When to stop cancer treatment



When you have cancer and you have tried many treatments without success, it can be very hard to know when to stop treatment. Sometimes, even with the best care, cancer continues to spread. It is hard to accept, but the best thing for you at that point may be to stop the cancer treatment. Instead, you could focus on getting care to keep you comfortable and out of pain.

This fact sheet explains how to know when it is time to stop treatment and focus on end-of-life care. You can use this information to talk with your health care provider about your options and choose the best care for you.



### Cancer responds best to treatment the first time.

When you treat a tumour for the first time, there is hope that the treatment will destroy the cancer cells and keep them from returning. If your tumour keeps growing, even with treatment, there is a lower chance that more treatment will help.

This is especially true for solid tumour cancers, like breast, colon, and lung cancer, and sarcoma. Health care providers know a lot about how these cancers grow or shrink over time and how they respond to treatment. They have found that treatment after treatment often offers little or no benefit.

### How do you know when to stop treatment?

It can be hard for the patient, caregivers and the health care provider to talk about stopping treatment for the cancer and focus on end-of-life care. Your health care provider may bring it up, but sometimes you may need to start the discussion. Your health care provider should give you clear answers to any questions you ask.

You need to understand how advanced your cancer is. Ask your health care provider about the stage of your cancer and how much it has spread. Ask about

*Canadian reviews of this pamphlet included the Canadian Association of Medical Oncologists, Canadian Association of Radiation Oncology, Canadian Society for Surgical Oncology, and Canadian Partnership Against Cancer.*

## Patient Education Material



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## Advanced Cancer



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DT9262

LEVELS OF CARE AND  
CARDIOPULMONARY RESUSCITATION

The goals of care below are indicative and are intended  
to orient medically appropriate care.

Institution name

Last name of user			
First name			
File number		Date of birth Year    Month    Day	
Sex <input type="checkbox"/> M <input type="checkbox"/> F	Health insurance number		

Revise using a new form following any change in health status or at the request of the user or his/her representative.

<b>Capacity to discuss levels of care</b>	
<input type="checkbox"/> Competent <input type="checkbox"/> Incompetent: <input type="checkbox"/> Homologated mandate <input type="checkbox"/> Public/private curator; Name: _____	
<input type="checkbox"/> Minor under 14 years old    Name of tutor, relationship with user: _____	
Previous advance wishes: <input type="checkbox"/> None available <input type="checkbox"/> Prior level of care form <input type="checkbox"/> Advance medical directive <input type="checkbox"/> Living will or other	
<b>Levels of care: check and provide details in the box below (Explanatory notes on the reverse side)</b>	
<input type="checkbox"/> Goal A: Prolong life with all necessary care <input type="checkbox"/> Goal B: Prolong life with some limitations to care <input type="checkbox"/> Goal C: Ensure comfort as a priority over prolonging life <input type="checkbox"/> Goal D: Ensure comfort without prolonging life	Give details on specific interventions in the box below, as needed. e.g., hemodialysis, blood transfusion, nutritional support (enteral or parenteral), preventive care, etc.
<b>Cardiopulmonary resuscitation (CPR): check and provide details in the box below (Explanatory notes on the reverse side)</b>	
<b>Cardiac (circulatory) arrest</b>	Check if NOT desired, to guide prehospital care for goals B and C (see reverse side)
<input type="checkbox"/> Attempt CPR <input type="checkbox"/> Do NOT attempt CPR	<input type="checkbox"/> NO emergency intubation (goals B and C only)
<b>Explanatory notes on the discussion and instructions</b>	
Discussed with: <input type="checkbox"/> User <input type="checkbox"/> Representative	
Contact information	
Record the names of the participants as well as the words used during the discussion and all information that helps clarify the user's wishes.	
Name of physician	
Signature	
Date (year, month, day)	
Contact information	
If a copy of this form is given to the user or his/her representative, it is signed by him/her so that paramedic ambulance technicians can follow the instructions on the form.	
Name of user or representative	Signature
Date (year, month, day)	

AH-744A DT9262 (2016-01)

LEVELS OF CARE AND  
CARDIOPULMONARY RESUSCITATION☐ User's file  
☐ Physician's copy

## Explanatory notes

- This form is not a substitute for consent to treatment, which must always be obtained (except in certain emergency situations).
- This form must be signed by a physician.

## Description of levels of care

The discussion about levels of care is carried out with the user or, in the case of incapacity, with his/her representative, in the spirit of shared decision-making about medically appropriate care. The explanations and examples provided in the following descriptions do not assume capacity on the part of the user, nor do they necessarily reflect his/her usual care setting.

<b>Goal A</b> Prolong life with all necessary care	<ul style="list-style-type: none"><li>• Care includes all interventions that are medically appropriate and transfer<sup>1</sup> if the intervention is not available in the current setting.</li><li>• All invasive interventions can be considered, including, for example, intubation and intensive care.</li></ul> <p><b>In the prehospital setting</b>, unless otherwise advised by the user or his/her representative, all protocols apply; intubation, assisted ventilation<sup>2</sup> and assisted respiration<sup>2</sup> are included when appropriate.</p>
<b>Goal B</b> Prolong life with some limitations to care	<ul style="list-style-type: none"><li>• Care incorporates interventions with the aim of prolonging life, which offer the possibility of correcting deterioration in health status while preserving quality of life.</li><li>• Interventions may lead to discomfort that is judged to be acceptable by the user or his/her representative acting in the sole interests of the user, given the circumstances and the expected outcomes.</li><li>• Certain interventions are excluded since they are judged to be disproportionate<sup>3</sup> or unacceptable<sup>3</sup> by the user or his/her representative acting in the sole interests of the user, given the potential for recovery and undesired consequences (e.g., short-term or long-term intubation, major surgery, transfer).</li></ul> <p><b>In the prehospital setting</b>, unless otherwise advised by the user or his/her representative, all protocols apply; assisted ventilation<sup>2</sup> and assisted respiration<sup>2</sup> are included; intubation is included unless indicated as not desired on the form (checked in the prehospital care box).</p>
<b>Goal C</b> Ensure comfort with some limitations to care	<p>as needed in order to correct certain reversible health problems, his/her representative acting in the sole interests of the user (e.g., oral or intravenous analgesics, antiemetics, etc.).</p> <p>considered only if care available locally is insufficient to ensure comfort (e.g., for pain, trouble breathing, constipation, anxiety).</p> <p><b>In the prehospital setting</b>, unless otherwise advised by the user or his/her representative, all protocols apply; assisted respiration<sup>2</sup> is included; intubation and assisted ventilation<sup>2</sup> are included unless indicated as not desired on the form (checked in the prehospital care box).</p>
<b>Goal D</b> Ensure comfort without prolonging life	<ul style="list-style-type: none"><li>• Care is exclusively aimed at maintaining comfort through the management of symptoms (e.g., pain, trouble breathing, constipation, anxiety).</li><li>• Interventions do not aim to prolong life; illness is left to its natural course.</li><li>• A treatment that is usually given with curative intent may be used, but only because it represents the best option to relieve discomfort (e.g., oral analgesics for a lower urinary tract or C. difficile infection).</li><li>• Transfer to an appropriate care setting is considered only if care available locally is insufficient to ensure comfort (e.g., for a hip fracture with significant discomfort or for respiratory distress at home).</li></ul> <p><b>In the prehospital setting</b>, unless otherwise advised by the user or his/her representative, the following protocols apply: oxygenation, salbutamol, nitroglycerin (chest pain) and glucagon. For respiratory distress in a conscious user, assisted respiration<sup>2</sup> (CPAP) can be used unless refused. Intubation and assisted ventilation<sup>2</sup> are excluded. Manoeuvres to clear an obstructed airway in a living user can be carried out.</p>

## Cardiopulmonary resuscitation (CPR)

CPR is part of the same discussion as levels of care. The decision is specified in a distinct manner to allow rapid decisions in the case of cardiorespiratory arrest. A CPR decision is only applicable in the case of a cardiac arrest with arrest in circulation. In the case that a CPR attempt is desired, measures available on site will be deployed while awaiting the arrival of emergency medical services, according to the situation.

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Part A: Goals of Care Discussion		
<b>Discussion participants:</b> <input type="checkbox"/> Patient <input type="checkbox"/> Family member(s) <input type="checkbox"/> Substitute decision maker (SDM) <input type="checkbox"/> Treating physician <input type="checkbox"/> Others		
<b>Discussion content:</b> Was the medical condition thoroughly explained to the patient? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> To some degree   		
What is the patient's understanding of their medical condition? <input type="checkbox"/> Poor <input type="checkbox"/> Fair <input type="checkbox"/> Good <input type="checkbox"/> Very good <input type="checkbox"/> Excellent		
Were the patient's values, priorities and expectations discussed? <input type="checkbox"/> Yes <input type="checkbox"/> No If yes, please provide specifics   		
Were the goals of care (cure vs palliation) discussed with the patient? <input type="checkbox"/> Yes <input type="checkbox"/> No If no, please state the reason  		
Part B: Level of Intervention Form/ Level of Care Form		
Was the level of care (LOC) form completed? <input type="checkbox"/> Yes <input type="checkbox"/> No If no, please state the reason  		
Part C: Advanced Care Planning Discussion		
Does the patient have a legally binding document that designates a substitute decision maker? <input type="checkbox"/> Yes <input type="checkbox"/> No If yes, please indicate the appropriate document type: <input type="checkbox"/> Will <input type="checkbox"/> Power of Attorney (POA) <input type="checkbox"/> Mandate <input type="checkbox"/> Living Will/RAMQ Advanced Medical Directives Please indicate the name of the SDM:  		
Part D: Palliative Care Consult or Referral		
Does the patient need to be seen by a palliative care specialist for symptom assessment and/or symptom management? <input type="checkbox"/> Yes <input type="checkbox"/> No		
Name of health care professional	Signature	Date (yyyy/mm/dd)

## Goals of Care Form\* (short version)

Section A: Discussion sur les objectifs des soins		
<b>Participants à la discussion :</b> <input type="checkbox"/> Patient <input type="checkbox"/> Membre(s) de la famille <input type="checkbox"/> Mandataire spécial (MS) <input type="checkbox"/> Médecin traitant <input type="checkbox"/> Autres		
<b>Contenu de la discussion :</b> Est-ce que la condition médicale a été expliquée au patient ? <input type="checkbox"/> Oui <input type="checkbox"/> Non <input type="checkbox"/> à un certain degré   		
Quelle est la compréhension du patient de son état de santé ? <input type="checkbox"/> Mauvais <input type="checkbox"/> Raisonnable <input type="checkbox"/> Bonne <input type="checkbox"/> Très bonne <input type="checkbox"/> Excellente		
Est-ce que les valeurs, les priorités et les attentes du patient ont été discutées ? <input type="checkbox"/> Oui <input type="checkbox"/> Non Si oui, s.v.p. spécifiez   		
Est-ce que les objectifs des soins (traitement vs palliatif) ont été discutés avec le patient ? <input type="checkbox"/> Oui <input type="checkbox"/> Non Si non, s.v.p. spécifiez la raison  		
Section B: Formulaire de niveau d'intervention / Formulaire de niveau de soins		
Est-ce que le formulaire sur le niveau de soins a été rempli ? <input type="checkbox"/> Oui <input type="checkbox"/> Non Si non, s.v.p. spécifiez la raison  		
Section C: Discussion sur la planification des soins avancés		
Est-ce que le patient a un contrat ayant force obligatoire qui désigne un mandataire spécial ? <input type="checkbox"/> Oui <input type="checkbox"/> Non  Si oui, veuillez indiquer le type de document approprié : <input type="checkbox"/> Testament <input type="checkbox"/> Procuration <input type="checkbox"/> Mandat <input type="checkbox"/> Testament de vie/Directives médicales avancées (RAMQ)		
Veuillez indiquer le nom du mandataire spécial :  		
Section D: Consultation ou orientation vers les soins palliatif		
Est-ce que le patient doit être examiné par un spécialiste en soins palliatifs pour l'évaluation et / ou la gestion des symptômes ? <input type="checkbox"/> Oui <input type="checkbox"/> Non		
Nom du professionnel de la santé	Signature	Date (aaaa/mm/jj)

\*This version of the GoC form is in use at MUHC and JGH. SMHC uses a longer version of the form to facilitate the multidisciplinary approach to early referral to PC and early documentation.



# Project evaluation (summer/fall 2019)

- **Process indicators:**

- % patients with chart documentation re: goals of care; advance directive; LOC; (within 60 days)
- % pts. having a least one visit w/t a supportive/ palliative care team (within 60 days)
- % HCPs taking part in education sessions

- **Outcome indicators:**

- % ICU admissions and % ER visits
- % pts. on multiple of lines of systemic therapy (2nd, 3rd line)
- % pts. on systemic therapy (last 30 days);

# Acknowledgements

## Project Team:

Dr. Manuel Borod, Dr. Hitesh Bhanabhai, Gligorka Raskovic, Rebecca Fox, Genevieve Redstone, Nathalie M. Aubin, Doneal Thomas, Myriam Fernandez

## JGH, MUHC, SMHC Working Groups:

Dr. Jason Agulnik, Dr. Marcia Gillman, Dr. Scott Owen, Dr. Nicole Ezer, Dr. Joan Zidulka, Jeff Margenpan, Laura Delany, Rajesh Sharma

**RCN Supportive Care Program Lead:** Dr. Adrian Langleben



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**Thank you!**