

# Advance Care Planning in Ontario – a Quality Improvement Plan Toolkit

## Introduction

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### What is the ACP QIP Toolkit?

In January 2013, the Ministry of Health and LongTerm Care (MOHLTC) introduced Quality Improvement Plans (QIP) to the primary care sector, including Aboriginal Health Access Centres (AHACs), Community Health Centres (CHCs), Family Health Teams (FHTs) and Nurse Practitioner Led Clinics (NPLCs). Beginning in 2014, QIPs were introduced to Community Care Access Centres (CCACs). Cancer Care Ontario (CCO) has developed an Advance Care Planning (ACP) toolkit<sup>1</sup> for those practices that decide to include ACP as part of their QIP.

“The QIP is about improving patient/client and provider experience, care effectiveness and value, through system improvement, continuously over time.”<sup>2</sup> All of the above mentioned practices in Ontario are required to develop and submit a QIP to Health Quality Ontario (HQQ) by April 1 of each year, outlining their planned quality improvement efforts for the upcoming fiscal year. This toolkit is for primary care practices that choose to include ACP as part of their annual QIPs.

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<sup>1</sup> The primary care team at Cancer Care Ontario would like to acknowledge the collaboration of Louise Hanvey, Director of Advance Care Planning in Canada, Speak Up: Start the conversation about end-of-life care, Canadian Hospice Palliative Care Association and Dr. Daren Heyland, Professor of Medicine, Queen’s University, Director, Canadian Researchers at the End of Life Network (CARENET).

<sup>2</sup> Cancer Care Ontario, Prevention & Care, Screening, Breast Cancer Screening. Available from: <http://www.cancercare.on.ca/pcs/screening/breastscreening>.

Guidance and materials about QIPs are available on the Ontario Ministry of Health and Long-Term Care website at:

[http://www.health.gov.on.ca/en/pro/programs/ecfa/legislation/qi\\_primary.aspx](http://www.health.gov.on.ca/en/pro/programs/ecfa/legislation/qi_primary.aspx)

## What is ACP?

ACP is a process that involves a capable individual communicating their personal preferences for future health or care in the event of being incapacitated and unable to give informed consent. The process involves reflection, discussion with others (such as family members, friends, or health care providers), and communication of decisions. Rather than being a single event, ACP is ongoing and dynamic, with the potential for personal preferences to change over time as health status changes. An ACP is a verbal or written instruction describing what kind of care an individual would want (or not want) if they are no longer able to speak for themselves. It is therefore important to identify a substitute decision maker as part of this process who will be able to speak on behalf of the patient if they cannot.

ACP is a patient-centred process, requiring an appreciation for the values and expectations of individual patients and their families. It may be initiated at any point in the health care process, and may involve individuals who are currently healthy. The requirements of ACP will vary depending on whether patients are currently healthy or where they are in the illness trajectory, particularly with respect to the specificity of treatment preferences.

Research shows us that ACP : improves quality of life and quality of end-of-life care; reduces stress and anxiety for patients, families and caregivers; improves communication between patients, families and the health care team and reduces strain on the health care system.<sup>3</sup> Including ACP in the QIP supports primary care's focus on quality patient care.

It is important to note that ACP is separate from health care consent. In Ontario, health care consent must be obtained before a health care provider can provide any type of treatment, except in an emergency.

**Advance Care Plans do not negate the responsibility of health care providers to obtain consent before providing treatment.**

## About the ACP QIP Toolkit

This toolkit is for primary care practices that choose to include ACP in their annual QIP. It contains Instructions (Section 1), a Planning Tool (Section 2), a Measurement Tool (Section 3), a Sample Timeline (Section 4) plus two appendices.

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<sup>3</sup> Wright, AA, et al. Associations between end-of-life discussion, health care expenditures, JAMA, 2008, 300 (14) 1665-1673.

If you choose to use the toolkit, please let us know by emailing [Katherin.Creighton-Taylor@cancercare.on.ca](mailto:Katherin.Creighton-Taylor@cancercare.on.ca) with “QIP” in the subject line. Informing us of your decision to participate will allow us to provide you with any support you may require.



CCO recommends applying the Plan, Do, Study, Act (PDSA)<sup>4</sup> cycle of continuous improvement for QIP development.

	What happens in this part of the cycle? <sup>4</sup>	Tips
<b>Plan</b>	<ul style="list-style-type: none"> <li>• Create a baseline</li> <li>• Define achievable goals</li> <li>• Define data required to track and measure your goal and how it will be collected</li> </ul>	<ul style="list-style-type: none"> <li>• Keep things simple and manageable, and set small and achievable goals (e.g., focus on one patient sub-population in the first phase)</li> </ul>
<b>Do</b>	<ul style="list-style-type: none"> <li>• Put the plan into practice</li> <li>• Collect data</li> <li>• Record useful observations</li> </ul>	<ul style="list-style-type: none"> <li>• Ensure that data is collected and recorded consistently</li> </ul>
<b>Study</b>	<ul style="list-style-type: none"> <li>• Analyze the data collected to track progress</li> <li>• Determine the next step needed to help meet the screening rate goal</li> </ul>	<ul style="list-style-type: none"> <li>• Set a timeline for progress checkpoints that are achievable and make sense for your practice</li> </ul>
<b>Act</b>	<ul style="list-style-type: none"> <li>• Make changes</li> </ul>	<ul style="list-style-type: none"> <li>• Make simple changes to help achieve goals (e.g., develop a list of frequently asked questions and develop responses that are shared with all practitioners who conduct ACP consultations with patients)</li> </ul>

<sup>4</sup> Langley et al. 1996. *The Improvement Guide: A Practical Approach to Enhancing Organisational Performance*, National Academy for State Health Policy. PDSA Cycles. Available from: <http://www.nashp.org/sites/default/files/abcd/abcd.ut.pdsa.cycles.definedsimple.pdf>.

# Section 1: Instructions

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## 1.1 Plan

Your practice should begin by creating an ACP QIP. There are five steps involved in this process.

### *Five-Step Plan Checklist:*

- 1. *Identify team members*
- 2. *Fill out the Planning Tool (Section 2)*
- 3. *Fill out Part A of the Measurement Tool (Section 3)*
- 4. *Orient primary care providers, healthcare professionals and other staff who will be involved in the initiative*
- 5. *Make staff and patients aware of initiative*

### **1. Identify team members**

Identifying who will be involved and ensuring that they are properly oriented is key to successful implementation. The practice will need to:

- Select a lead coordinator to act as the main point of contact
- Ensure that there is enough staff support to carry out the initiative
- Identify who will conduct ACP consultations (e.g., primary care providers, nurses, other healthcare professionals)
  - ✓ **Assess competencies related to facilitating ACP discussions** (core competencies for engaging in ACP are outlined in the document *Advanced Care Planning in Canada: National Framework*, pg 23, and 24<sup>5</sup>)
- Provide training and resources required to conduct the ACP consultation
  - ✓ **As necessary, pursue professional development resources to ensure effectiveness of both ACP discussions and documentation** (see Appendix G, or refer to education offered here <http://www.fraserhealth.ca/professionals/advance-care-planning>, and refer to *Provider Handout, Patient Handout, Patient Package link in Appendix E*)

### **2. Fill out the Planning Tool**

The Planning Tool (Section 2) provided by Cancer Care Ontario is a step-by-step planning guide. It will help your practice identify its goals, measurement plan, and approach for change implementation for the initiative. In Appendix A, you will find a workflow diagram outlining the proposed ACP process and instructions to guide you through each part of the process. Appendix B contains a list of useful resources.

### **3. Fill out the Measurement Tool**

Once you have defined the criteria for your target patient population, you will be able to run a report using your Electronic Medical Record (EMR) of patients who meet the criteria. Develop a system of tracking patients who have had an ACP consultation.

- **As a strategy to prioritize patients based on the urgency to have ACP related discussions, consider using the *Surprise Question*. This question asks “Would you be surprised if this patient were to die within the next year?” and can be used as a trigger to help identify the need to take action. If you would not be surprised, this should prompt you to initiate an ACP discussion in a more urgent manner.**
  - For more information about the *Surprise Question*, and how it can be used as an effective indicator of urgency, please refer to the Gold Standards Framework which can be accessed here: <http://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf>

NOTE: It is important to be consistent when developing measures and tracking progress. All primary care providers, healthcare professionals and staff involved should be trained to follow a consistent methodology. Your practice can decide what data source is used, whether it be the EMR, a registration database or another source from which a patient list can be created and activity documented.

### **4. Orient staff directly involved**

Once you have filled out the Planning Tool (Section 2), it is important to hold an orientation session for primary care providers, healthcare professionals and other staff members directly involved in the initiative. Provide participants with this toolkit and build/formalize changes to current practice workflows to accommodate the new initiative.

### **5. Educate staff and patients indirectly involved**

Hold staff meetings, send emails and post notices on staff bulletin boards to educate primary care providers, healthcare professionals and other staff who are indirectly involved in the initiative so that the QIP process runs smoothly.

Develop posters and stock the waiting room with ACP patient education materials. Communicating this type of initiative to patients will show them that your practice is proactive in delivering quality care and may even encourage them to raise the topic with their primary care provider. Please refer to Appendix B for helpful resources.

## 1.2 Do

In the **Do** phase, you execute your plan.

**Execute your planned activities.** Throughout the process, your lead coordinator should supervise the initiative and provide timely responses to staff questions. Holding regular team meetings to track progress, troubleshoot challenges and celebrate successes are key to ensuring that the team stays engaged and motivated and that issues are addressed.

## 1.3 Study

There are three steps in the **Study** phase of the ACP QIP.

### ***Three-Step Study Checklist:***

- 1. Fill out **Part B of the Measurement Tool** (Section 3)
- 2. Review results with team
- 3. Share results with all primary care providers, healthcare professionals and other staff members

### **1. Fill out Part B of the Measurement Tool**

Fill out Part B of the Measurement Tool (Section 3) periodically (e.g., every three months) to track your team's progress.

### **2. Review results**

Hold regular checkpoint meetings (e.g., every three months), where the Measurement Tool (Section\_3) can be used to review outcome and process measures, and review progress made since the start of the initiative.

### **3. Share results**

Results can be shared within the practice and with patients to keep them informed of the initiative's progress.

## 1.4 Act

**Modify the plan, as appropriate, based on feedback from the Study phase.** Make any necessary adjustments to the process and ensure that all involved primary care providers, healthcare professionals and other staff members are kept abreast of these changes.

**At the end of the fiscal year, evaluate the quality improvement initiative.**

1. **Take your final measures and** complete **Part C** of the Measurement Tool (Section 3) to determine whether your practice achieved its target rates of ACP consultations and education sessions.
2. **Get feedback** from primary care providers, healthcare professionals, other staff and patients who were involved in the initiative regarding:
  - What went well
  - What challenges/difficulties were encountered
  - What could be done differently

Staff can evaluate the initiative through online or paper surveys. Selected patients can complete the evaluation through a patient satisfaction survey (which could be included in a patient package) or through documented verbal discussions.

## Section 2: Planning Tool

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This Planning Tool is intended to support the development of your practice’s ACP QIP and is to be used in conjunction with the accompanying Instructions document. As you fill out this step-by-step tool, please refer to the sample completed ACP QIP below.

AIM		MEASURE							CHANGE				
QUALITY DIMENSION	OBJECTIVES	MEASURE / INDICATOR	UNIT / POPULATION	SOURCE / PERIOD	ORG ID	CURRENT OR BASELINE PERFORMANCE	TARGET PERFORMANCE	TARGET JUSTIFICATION	PLANNED IMPROVEMENT INITIATIVES (CHANGE IDEAS)	METHODS	PROCESS MEASURES	GOAL FOR CHANGE IDEAS	COMMENTS
	<b>1</b>					<b>2</b>	<b>3</b>		<b>4</b>	<b>5</b>		<b>6</b>	
Patient-centred care	All patients over 50 years old have an ACP or it is documented that they did not wish to have an ACP .	% of patients within target population who have participated in an ACP education session or consultation, or documentation that they did not wish to participate	Target population identified by the care practice  (i.e. all patients over 50 years old)	Patient list generated from existing data set over duration of project (i.e. billing data/ EMR)		If documented and data obtainable, identify how many patients have been offered an ACP discussion or consultation and how many have participated.	If current state is known (documented and data available) calculate the % of the target population that has been offered an ACP discussion or consultation and how many have participated.  Set a target for improvement.	Based on how many people are in the target group and the capacity of staff to provide the consultation	1. Staff will receive opportunities to learn about ACP and health care consent.  2. ACP will be introduced to all people within the target population or those identified through the surprise question.	Provide staff with materials and access to educational resources  Introduce ACP to patients within the target group when they are in the practice for an appointment  Plan and deliver group education sessions about ACP	Number of eligible staff who have learned about ACP  Number of ACP consultations offered.  Documentation of patient response in patient record (EMR) (refused, not sure, consultation booked)	All eligible staff learn about ACP  All eligible patients in target population are identified.  Targets for offering ACP discussions or consultations and documenting response are met.	

AIM	<b>1</b>	<b>Identify the objective and measure /indicator</b>	This will form the basis of all of your activities. The indicator selected should be detailed and the methodology of measurement should be clearly identified.	<p><i>State the objective of this initiative (e.g., All patients over 50 years have an ACP or it is documented that they did not wish to have an ACP.)</i></p> <p><i>List measure(s)/indicator(s) (e.g., percent of patients within the target group who have):</i></p> <p><i>Percent of patients within target population who have participated in an ACP educational session or consultation, or documentation that they did not wish to participate</i></p> <p><i>Identify methodology (e.g., numerator: number of patients within the target population who have (see each measure above) / denominator: total number of patients in the target group)</i></p>
	<b>2</b>	<b>Establish a baseline for performance</b>	Using the measure or indicator outlined in Part 1, identify the practice's baseline by running a report/query in your EMR. Record the baseline in both the QIP and the <i>Measurement Tool</i> . <b>NOTE:</b> It is important to be consistent when developing measures and tracking progress. All impacted primary care providers, healthcare professionals and staff should be trained on following a consistent methodology. Your methodology has to be consistent but not perfect.	<p><i>Identify baseline (for each indicator identified):</i></p> <p><i>Describe the method for baseline calculation (for each indicator identified) and data sources used:</i></p>
	<b>3</b>	<b>Identify what your target(s) for year will be</b>	Your targets should be achievable with a bit of a stretch component, but not unattainably high.	<p><i>Identify the target for each of the indicators selected:</i></p> <ul style="list-style-type: none"> <li>• <i>E.g. Offer 50% (target to be set by practice) of the patients within the target group education / consult about ACP through group ACP education sessions</i></li> </ul> <p><i>Describe target justification, including assumptions and adjustments:</i></p> <ul style="list-style-type: none"> <li>• <i>E.g. Education process takes time; some patients may initially be resistant to developing an ACP and should not be</i></li> </ul>
MEASURE				
MEASURE				

			<i>pressured.</i>
<b>CHANGE</b>	<p><b>4</b> <b>Decide on what changes the practice will make to current workflows in order to achieve the goal</b></p>	<p>Depending on your practice structure and supports available, some activities that could be implemented include:</p> <ul style="list-style-type: none"> <li>• Run an EMR query to generate a list of your patient population that you will target for this initiative (<i>Note: this may be done in phases</i>)</li> <li>• Create patient education handouts and packages to support your initiative (you may choose to use the patient handout tool developed by <a href="#">Advance Care Planning in Canada - Appendix F or the</a>)</li> <li>• Develop a script with key messages for primary care providers and other health care professionals within your practice who will be having conversations about ACP with patients and provide appropriate training (you may choose to use the practitioner tool found at <a href="#">Advance Care Planning in Canada – Appendix G</a>)</li> <li>• Assign a health care professional(s) on your team to conduct ACP education consultations with patients and provide them with the patient packages (you may choose to use the patient materials created by the CHPCA provided in Appendix E)</li> <li>• Determine where in the chart to document that patients have received education re: ACP</li> <li>• <i>NOTE: Refer to Appendix A for an overview of the ACP process and Appendix B for support resources</i></li> </ul>	<p><i>List the activities that your practice will be implementing:</i></p>
	<p><b>5</b> <b>Identify how changes will be implemented and identify process measures</b></p>	<p>This section identifies the activities and process measures that the practice will be implementing and the targets for each measure.</p>	<p><i>List process measure(s) for the activities identified in Part 4:</i></p> <ul style="list-style-type: none"> <li>• <i>E.g. Schedule 4 (target to be set by practice) appointments per month for patients within the target population to attend an optional ACP education consultation</i></li> <li>• <i>Schedule optional group educational sessions</i></li> </ul>

  <b>Goal for change ideas</b>	Identify the goals that the practice is aiming to achieve based on the process measures. These should tie back to the overall objectives of the initiative.	<i>Identify goal(s):</i> <ul style="list-style-type: none"><li>• <i>Conduct 4 (target to be set by practice) optional ACP consultations with patients per month</i></li></ul>
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# Section 3: Measurement Tool

## Part A: Performance Measurement Planning

Identify the indicators and process measures for your initiative and fill out the tool below. For each indicator, identify the baseline/current value. Below find some examples of possible indicators, methodologies and baselines.

<b>1. Indicator Selection</b>			
<i>-What is/are the indicator(s)/outcome measure(s) of this initiative?</i>			
<i>-How is/are the indicator(s)/outcome measure(s) going to be calculated?</i>			
<i>-What is the baseline?</i>			
<b>Indicator(s)</b>	<b>Methodology</b>	<b>Baseline Value</b>	<b>Target Values</b>
<i>e.g., Percentage of the target population who have been invited to attend ACP education session as documented in their chart</i>	<i>Numerator: (E.g., number of patients who have been invited to attend group education session or ACP consultation) Denominator: (E.g., total number of patients identified within the target population and invited to consult) Note: Practice to determine the measure methodology</i>	<i>E.g., 50 patients/400 total patients who fall within the target population= 12.5%</i>	<i>(as stated in QIP) E.g., 25%</i>
			<i>(as stated in QIP)</i>
			<i>(as stated in QIP)</i>

<b>2. Process Measure Selection</b>	
<b>Process Measure(s)</b>	<b>Methodology</b>
<i>e.g., Patient identified as within target group</i>	<i>E.g., Develop list and flag chart (patient record) that patient should be offered a consult</i>

<b>3. Period Duration</b> <i>-How often will the checkpoints occur?</i>
<i>E.g., every quarter/month/week</i>

## Part B: Periodic Checkpoint Review (to be filled out routinely)

Period: (e.g., May 1<sup>st</sup>–June 1<sup>st</sup>)

<b>1. Indicator Evaluation</b>			
<b>Indicator(s)</b>	<b>Period-End Result</b>	<b>Change from Baseline</b>	<b>Change from Last Period</b>
<i>E.g., Percentage of patients in the target population who have been offered a consult or education session</i>	<i>Numerator: Patients who have been offered an ACP consultation (add: patients who are part of the baseline+ patients who have been offered an ACP consultation since the day of baseline measurement and checkpoint review) Denominator: Total pool of patients within the target group E.g., 50 patients at baseline + 20 additional patients who have been offered an ACP consultation since the baseline measurement/400 total patients in target population = 17.5%</i>	<i>E.g., 17.5% – 12.5% = +5.0%</i>	<i>E.g., N/A</i>
<b>2. Process Measure Evaluation</b>			
<b>Process Measure(s)</b>	<b>Current Value</b>	<b>Change from Last Period</b>	<b>Interpretation (this section will inform the Period Analysis)</b>
<i>E.g., Percentage of patients within the target group who have scheduled an appointment for an ACP education consultation</i>	<i>E.g., Only 10% of patients in the target group have been offered an ACP education consultation</i>	<i>E.g., N/A</i>	<i>E.g., Staff not offering, do not feel committed to the initiative, too busy</i>

<b>3. Period Analysis</b> <i>-Overall, how is the practice performing?</i> <i>-What issues have arisen? What is the issue mitigation plan?</i>
<i>-E.g. Issue: Staff not seeing ACP as a priority</i> <i>Mitigation Plan: Schedule optional staff education workshops once per month and discuss initiative, concerns and barriers</i>

## Part C: Final Evaluation

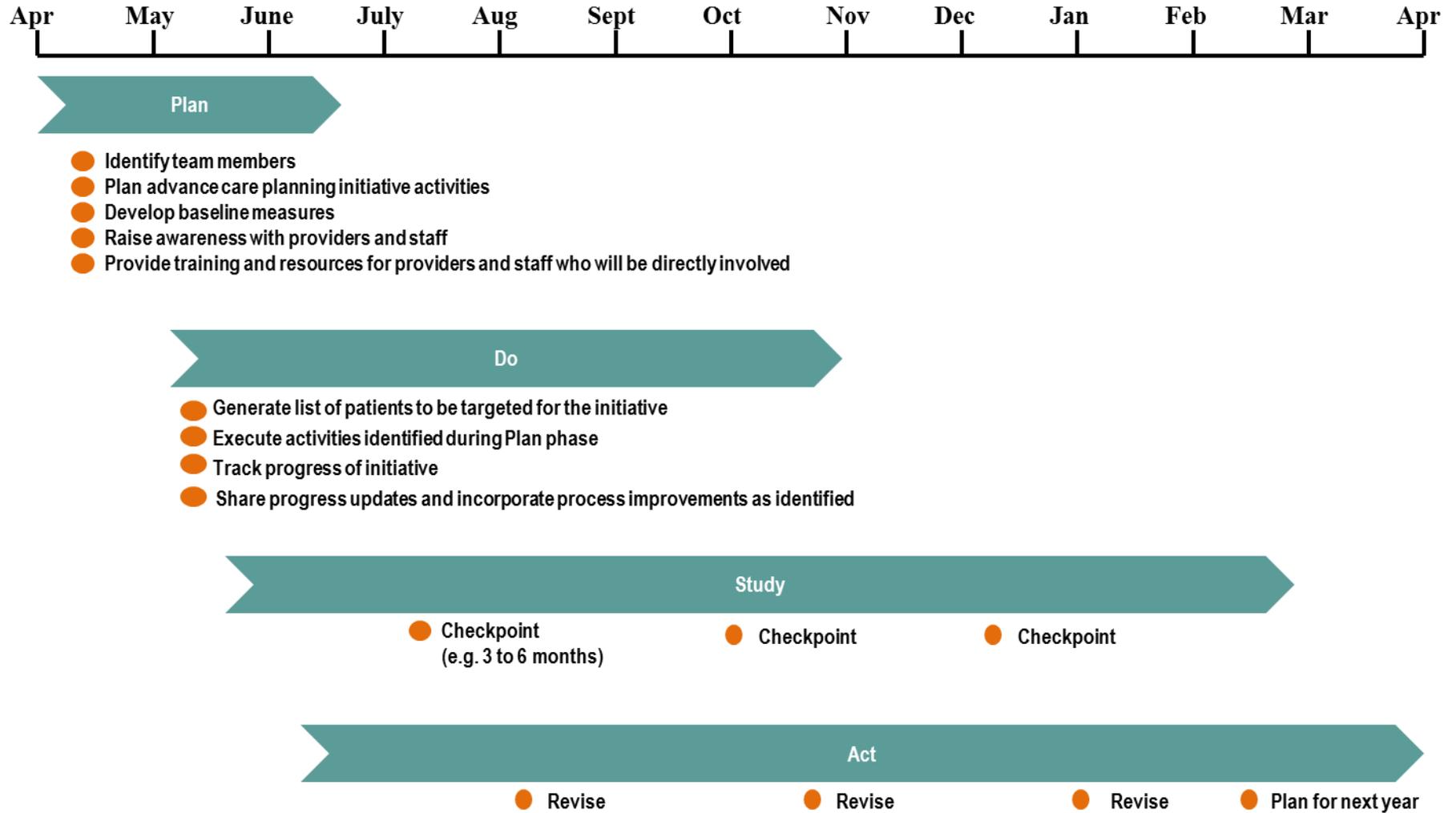
To be conducted in preparation for submission of final QIP report and to plan for next period.

<b>1. Indicator Evaluation</b>			
<b>Indicator(s)</b>	<b>Period-End Result</b>	<b>Change from Baseline</b>	<b>Change from Last Period</b>
<i>E.g., Percentage of patients who were offered an ACP consultation or to attend an education session, as documented on chart.</i>	<i>(Use methodology outlined above to calculate this)</i>	<i>(Calculate current period percentage and subtract baseline value)</i>	<i>(Calculate current period percentage and subtract from previous period percentage)</i>
<b>2. Process Measure Evaluation</b>			
<b>Process Measure(s)</b>	<b>Current Value</b>	<b>Change from Last Period</b>	<b>Interpretation (this section will inform the Period Analysis)</b>
<i>E.g., Staff offered consult to patients in target group if no documentation on chart to indicate it had already been done.</i>	<i>Use same methodology as previous periods</i>	<i>Subtract current period performance from previous period performance</i>	<i>(Interpret results)</i>

<b>3. Final Period Analysis</b> <i>-How did the practice perform over the final period?</i>
<b>4. Final Review of Initiative</b> <i>-How did the practice perform over the entire initiative?</i> <i>-Were targets achieved?</i>

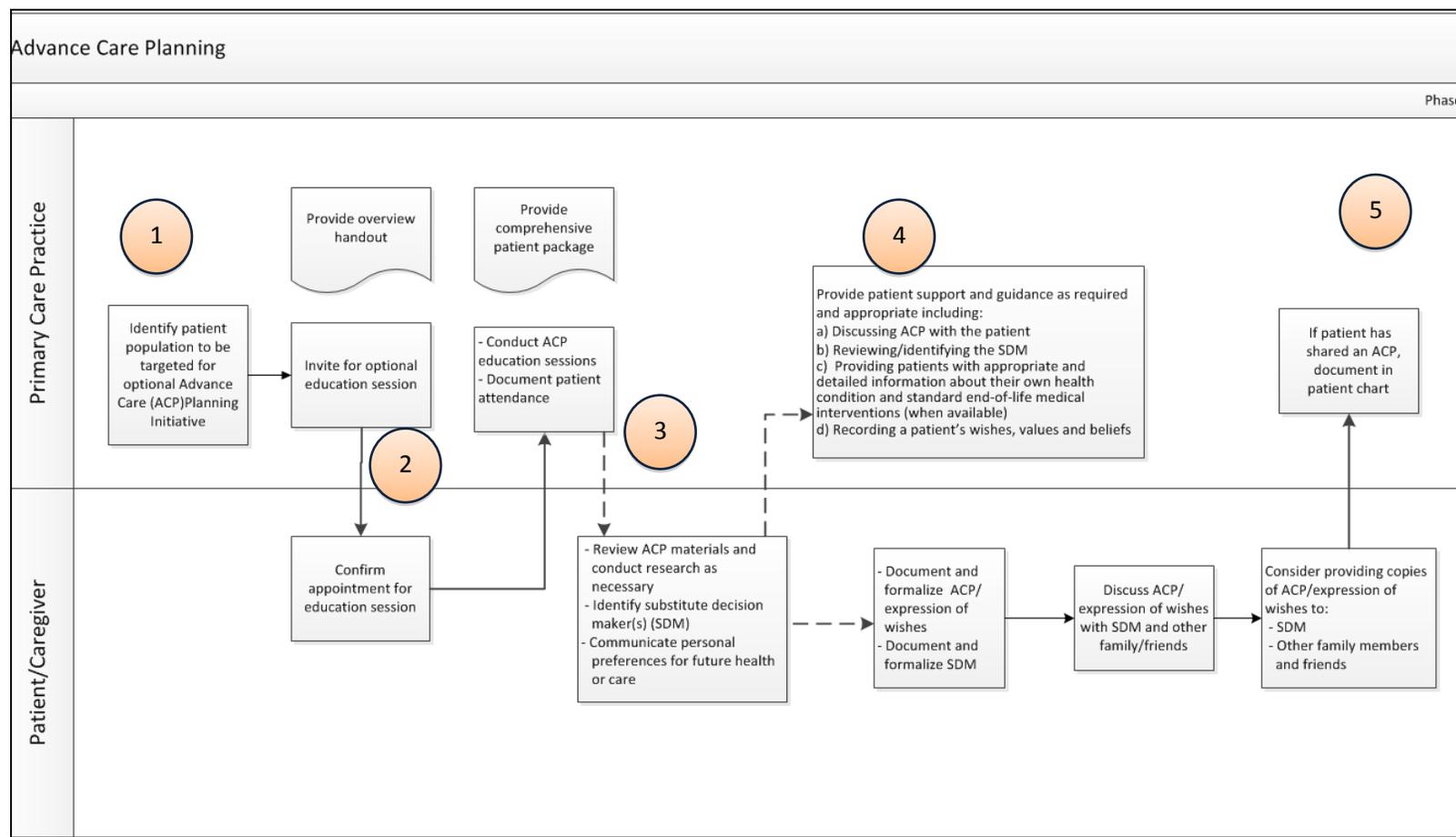


# Section 4: ACP Sample QIP Timeline



# Appendix A: Supporting patients through Advance Care Planning in Ontario

Part 1 (NOTE: This sample workflow is to be used in conjunction with Steps in Part 2):



# Appendix A: Supporting patients through Advance Care Planning in Ontario

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Part 2 (NOTE: This section outlines suggested steps in implementing an ACP quality improvement initiative within your practice and is to be used in conjunction with the ACP Workflow diagram in Part 1):

## Steps:

- 1. Identify patients within your practice to target for the ACP initiative
- 2. Invite them to attend an optional ACP education consultation
- 3. Conduct ACP consultation with patient
- 4. Provide support and guidance as required, including:
  - Discussing ACP with the patient
  - Reviewing/identifying the Substitute Decision Maker
  - Providing patients with appropriate and detailed information about their own health condition and standard end-of-life medical interventions (when available)
  - Recording a patient's wishes, values and beliefs
- 5. Conduct meeting to review final ACP plan with patient and substitute decision maker

## 1 Identify patients within your practice to target for the ACP initiative

- i. Your practice may identify several patient sub-populations that might be appropriate for the ACP initiative and choose to start with one sub-population using the Plan, Do, Study, Act (PDSA) cycle before expanding the initiative to other sub-populations. For example, you might target:
  - All patients with end stage organ disease, cancer and other serious illnesses OR
  - All patients over a certain age (E.g., you may choose to focus on all patients over 65 years of age) OR
  - All patients with an urgent need for an ACP identified through use of **the Surprise Question**, which asks **“Would you be surprised if this patient were to die within the next year?”**
- ii. You can create searches within your EMR to identify the patient population targeted for the ACP initiative

### **Invite patients to attend an optional ACP education session**

- i. The primary care provider can introduce the topic of ACP when a patient within the target population attends an appointment (*Refer to Appendix G: Provider Resource, Approach and Phrasing*)
- ii. Provide the patient with a one page overview document in preparation for the education consultation (*Refer to the patient handout created by CHPCA link provided in Appendix E*) and the handout on Substitute Decision Makers and Power of Attorney for Personal Care created by the CHPCA (*Refer to link in Appendix E*)
- iii. Invite the patient to an optional group patient education session facilitated by a provider within your practice for patients within your target population.

### **3 Conduct optional ACP education session**

- i. Designate healthcare practitioner(s) to conduct optional ACP education consultations with patients (I.e., the team may choose to have this done by another member of your team such as a Nurse Practitioner or Social Worker)
  - Assess competencies related to facilitating ACP discussions (core competencies for engaging in ACP are outlined in the document *Advanced Care Planning in Canada: National Framework*, pg 23, and 24 )
- ii. Provide training and resources required to ensure effectiveness of both ACP discussions and documentation (see Appendix G, or refer to education offered here <http://www.fraserhealth.ca/professionals/advance-care-planning>, and refer to *Provider Handout, Patient Handout, Patient Package link in Appendix E*)
- iii. Create patient packages containing:
  - Patient information on the ACP process in Ontario (*Refer to patient handout created by the CHPCA, link in Appendix E*)
  - Template for “*Thinking About My Wishes for Future Health Care*” (*link in Appendix E*) if your practice uses the form
  - Information on other resources
- iv. Provide information on how the patient can request support from your practice
- v. Schedule date for follow up meetings, if required
- vi. Document patient attendance at optional education sessions

### **4 Provide follow up support and guidance as required**

### **5 If patient has shared an ACP or attended an education session, document in patient chart**

# Appendix B: Sample Advance Care Planning Template

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In this appendix you will find a link to a sample template that can be used in the process of ACP. You may choose to adopt this for use in your practice or to create your own. **As you decide what would work best for your practice, please keep in mind the requirements for ACP in Ontario (refer to Appendix C).**

1. [“Thinking About My Wishes for Future Health Care” template \(link\)](#)

You may find it helpful to use this with the Advance Care Planning Workbook: Ontario Edition

This workbook provides Ontario patients and families with a guide to doing ACP. It was developed by Advance Care Planning in Canada (Canadian Hospice Palliative Care Association) and the Ontario Hospice Palliative Care Association.

This workbook can be downloaded for free from <http://www.advancereplanning.ca/making-your-plan/how-to-make-your-plan/provincial-territorial-resources/advance-care-planning-workbook-ontario-version.aspx>

Hardcopies are available from Hospice Palliative Care Ontario for \$5.00 by contacting [alecoche@hpco.ca](mailto:alecoche@hpco.ca) or 1-800-349-3111 ext 22.

# Appendix C: Advance Care Planning Requirements in Ontario\*

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In Ontario, you can CHOOSE someone (or more than one person) to be your Substitute Decision Maker(s) by preparing a Power of Attorney for Personal Care.

If you have not signed a Power of Attorney for Personal Care, **the law in Ontario provides that you will always automatically have a Substitute Decision Maker for health care.** There is a ranking list of Substitute Decision Maker(s) – and the person or persons in your life that are the highest ranked in this list and meet the requirements to act as a Substitute Decision Maker will be your Substitute Decision Maker(s) for health care. For example, this might be your spouse or your child/children. Ask your doctor or nurse practitioner for a copy of this list or you can find it at [www.advancecareplanning.ca](http://www.advancecareplanning.ca) in the *Advance Care Planning Workbook: Ontario Edition* (Refer to link in Appendix E).

**If you want someone other than the first person at the top of the list to make decisions on your behalf – you must complete a Power of Attorney for Personal Care to appoint that person.**

## Power of Attorney for Personal Care

A Power of Attorney for Personal Care is a document, in writing, in which you name someone to act on your behalf and have the legal authority to do so.

To be legal, the document must be signed by:

- You, in the presence of two witnesses;
- The two witnesses in front of you. (Witnesses cannot be your spouse, partner or child.)
- You must sign it of your own free will.

You must be mentally able to understand what you are signing and what you are doing by signing such a document.

Your Substitute Decision Maker must be mentally capable and at least 16 years old. He or she must be available and willing to take on this task. There must not be any legal reasons stopping him or her from doing this.

You do not have to see a lawyer to prepare a Power of Attorney for Personal Care – of course you can if you prefer. You can get the form to fill out from the Government of Ontario at 1-800-366-0335 or <http://www.attorneygeneral.jus.gov.on.ca>.

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\*Source: *Advance Care Planning Workbook: Ontario Edition. Speak Up: Start the Conversation about end-of-life care.*

<http://www.advancecareplanning.ca/making-your-plan/how-to-make-your-plan/provincial-territorial-resources/advance-care-planning-workbook-ontario-version.aspx>

## Appendix D: Word List/Glossary\*\*

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By learning more about common end-of-life terms and treatments, you can develop an ACP that truly reflects your wishes. You may also wish to include some of these terms in your ACP. For more detailed descriptions of specific treatments and their role at the end of life, you may also consider consulting the Ian Anderson Continuing Education Program in End-of-Life Care, University of Toronto, “Module 4 – End-of-Life Decision-Making” starting on page 25 (<http://www.cme.utoronto.ca/endoflife/End-of-Life%20Decision-Making.pdf>).

**Allow natural death** refers to decisions NOT to have any treatment or procedure that will delay the moment of death. It applies only when death is about to happen from natural causes.

**Cardiopulmonary resuscitation (CPR)** refers to medical procedures used to restart your heart and breathing when the heart and/or lungs stop working unexpectedly. CPR can range from mouth-to-mouth breathing and pumping of the chest to electric shocks that may restart the heart and machines that breathe for the individual.

**Comfort measures** are treatments to keep you comfortable (E.g., pain relievers, psychological support, physical care and oxygen).

**Dialysis** is a medical procedure that cleans your blood when your kidneys can no longer do so.

**End-of-life** care refers to health care provided at the end of a person’s life. This type of care focuses on you living the way you choose during your last days or weeks and providing comfort measures until the time of death.

A **feeding tube** is a way to feed someone who can no longer swallow food.

**Healthcare professional** is a person licensed, certified or registered in their province/territory to provide healthcare (E.g., a doctor, nurse or social worker).

**Informed consent** refers to the permission you give to healthcare providers that allows medical investigations and/or treatments. Healthcare providers are required to offer you, and you are entitled to receive, detailed explanations of the investigations/treatments and their risks, benefits and side effects; alternatives to these options; and what would likely happen if you refused the options. They must also answer any questions you have about the treatments and the information must be provided before you give verbal consent or sign a consent form.

**Intravenous (IV)** is a way to give you fluids or medicine through a vein in your hand or another part of your body.

**Life support with medical interventions** refers to medical or surgical procedures such as tube feeding, breathing machines, kidney dialysis, some medications and CPR. All of these use artificial means to restore and/or continue life. Without them, you would die.

**Life limiting illness** refers to an incurable medical condition caused by injury or disease.

**Palliative care** focuses on providing good quality of life, in other words, keeping you as comfortable and free of pain or other symptoms as possible. Palliative care may involve medicines, treatments, physical care, psychological/social services and spiritual support, both for you and for those who are helping to care for you. Palliative care can be provided anywhere, at any stage of any illness along with care and treatment aimed at cure or prolonging life.

**Power of Attorney for Personal Care** is a document in Ontario that you prepare when you are mentally capable to name a person or persons to be your Substitute Decision Maker(s) for health and other personal care decisions. That person or persons would make decisions about treatment and healthcare on your behalf if you become mentally incapable.

**Substitute Decision Maker (SDM)** is a person(s) who provides consent or refusal of consent for treatment or withdrawal of treatment on behalf of another person when that person is mentally incapable to make decisions about treatment. The Substitute Decision Maker(s) is required to make decisions for you following any wishes you expressed about your care when you were mentally capable. If your Substitute Decision Maker does not know your wishes applicable to the treatment decision to be made, he or she is required to act in your best interests.

**Symptoms** are signs that you are unwell (E.g., pain, vomiting, loss of appetite or high fever).

**Terminal illness** means an incurable medical condition caused by injury or disease. These are conditions that, even with life support, would end in death within weeks or months. If life support is used, the dying process takes longer.

**A ventilator** is a machine that helps people breathe when they cannot breathe on their own.

*\*\*Source: Advance Care Planning Workbook: Ontario Edition. Speak Up: Start the Conversation about end-of-life care.*  
<http://www.advancedcareplanning.ca/making-your-plan/how-to-make-your-plan/provincial-territorial-resources/advance-care-planning-workbook-ontario-version.aspx>

# Appendix E: Listing of Resources

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While there are common elements in the ACP process across Canada, many of the resources that are found in Appendix B highlight specific aspects of ACP in Ontario to assist you in supporting your patients through this journey:

1. CCO website for toolkit – [Toolkit link](#)
2. [ACP resources created by CHPCA](#): written intro to give patients, information for providers, generic Substitute Decision Maker and Advance Care Plan Note (Ontario specific)
  - a. [Patient handout created by CHPCA](#)
  - b. [Provider tool created by CHPCA](#)
  - c. [Your Substitute Decision Maker and Power of Attorney for Personal Care](#)
  - d. [ACP template form create by CHPCA](#)
  - e. [Glossary of terms for patients](#)
  - f. [Poster](#)
3. [Advance Care Planning in Canada/Speak Up: Start the conversation about end-of-life care](#)

Advance Care Planning in Canada is a national initiative that provides resources for individuals, communities and health care providers about Advance Care Planning. It is facilitated by the Canadian Hospice Palliative Care Association (CHPCA). There are many resources on the website [www.advancecareplanning.ca](http://www.advancecareplanning.ca)

Resources are organized specific to the province or territory.

<http://www.advancecareplanning.ca/making-your-plan/how-to-make-your-plan/provincial-territorial-resources.aspx>

Of particular value is the [Advance Care Planning Workbook – Ontario Edition](#). It enables patients and families to explore their values and express their wishes for care.

<http://www.advancecareplanning.ca/making-your-plan/how-to-make-your-plan/provincial-territorial-resources/advance-care-planning-workbook-ontario-version.aspx> This Workbook can be downloaded for free at the above link. Hardcopies are available from Hospice Palliative Care Ontario for \$5.00 by contacting [alecoche@hpco.ca](mailto:alecoche@hpco.ca) or 1-800-349-3111 ext 22.

ACP in Canada has implemented a campaign entitled Speak Up: Start the conversation about end of life care. This campaign is intended to raise awareness among the public and professionals regarding ACP. Speak Up has a Campaign Toolkit with many resources that can be used to

increase awareness and educate your community about ACP. Access *the Campaign Toolkit* at <http://www.advancecareplanning.ca/community-organizations/download-the-speak-up-campaign-kit.aspx>

ACP in Canada has developed two ACP tools – one for patients and families and one for professionals – specifically for patients with a cancer diagnosis. They were developed as a partnership between the Advance Care Planning in Canada initiative, the BC Cancer Agency and members of the BC Patient Voices Network. *Cancer and Advance Care Planning* – This tool for patients and families describes the process of ACP and why it is important; issues to consider around diagnosis and treatment plans; and other resources. *Cancer and Advance Care Planning: Tips for Oncology Professionals* – This tool for oncology professionals provides practical suggestions for when to have the discussion, with specific conversation starters that can help professionals get started. It also includes the rationale for ACP with references to the relevant literature. Download them at <http://www.advancecareplanning.ca/community-organizations/download-the-speak-up-campaign-kit/bc-cancer-toolkit.aspx>

#### 4. **Ontario Seniors Secretariat**

The Ontario Seniors' Secretariat has developed a comprehensive Guide to Advance Care Planning (also available in Chinese) and a wallet card to document that you have conducted ACP and the contact information of your Substitute Decision Maker.

<http://www.seniors.gov.on.ca/en/advancecare/>

#### 5. **Canadian Virtual Hospice**

The Canadian Virtual Hospice provides support and personalized information about palliative and end-of-life care to patients, family members, healthcare providers, researchers and educators.

[http://www.virtualhospice.ca/en\\_US/Main+Site+Navigation/Home.aspx](http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx)

#### 6. **Ontario Attorney General**

The Office of the Public Guardian and Trustee has a Power of Attorney Kit that will help you appoint a Substitute Decision Maker.

<http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poa.pdf>

7. **Hospice Palliative Care Ontario**

Hospice Palliative Care Ontario (HPCO) provides leadership on behalf of their members by informing policy and promoting awareness, education, knowledge transfer and best practices in the pursuit of quality hospice palliative care in Ontario. Their membership includes 170 organizations and 500 individual members providing high quality hospice palliative care in Ontario, representing a range of stakeholders from all aspects of hospice palliative care. HPCO coordinates Speak Up Ontario! which is a network of ACP champions who provide ACP education within their LHIN regions. For more information regarding Speak Up Ontario! and the champions in your region, contact Anna LeCoche at [alecoche@hpcoco.ca](mailto:alecoche@hpcoco.ca).

8. **Canadian Hospice Palliative Care Association**

Canadian Hospice Palliative Care Association provides an ACP resource commons searchable to the provincial level for patients and families, professionals (health, legal, planning) and communities.

<http://www.chpca.net/resource-commons/advance-care-planning-resource-commons.aspx>

# Appendix F: Initial Patient Information Handout



**Talk to your doctor or nurse practitioner about**

## **Advance Care Planning**

What would happen if you were sick or injured and could not tell doctors what kind of care you wanted?  
Who would speak for you and make decisions for you?

### **What is Advance Care Planning?**

It's thinking about what is important to you if you were sick or injured and could not speak for yourself. You need to decide who would make decisions for you – and tell them what kind of care you would want.

### **Why should you do it?**

It can be very hard for others to have to make decisions for you if they do not know your wishes. You need to tell others what you want and do not want if you could not speak for yourself.

### **How do you do it?**

You need to decide who will be your Substitute Decision Maker – the person who would talk for you if you cannot talk for yourself – and talk to them about your wishes. You can also write down your wishes, or make a recording or video. There are workbooks at: [advancecareplanning.ca](http://advancecareplanning.ca)

### **Who should do it?**

Everyone should do advance care planning.

### **When should you do it?**

As soon as possible. Do it when you are healthy. Always take time to think about it again when things change in your life.

### **Find out more:**

Ask your Doctor or Nurse Practitioner about Advance Care Planning

Visit: [www.advancecareplanning.ca](http://www.advancecareplanning.ca)

# Appendix G: Provider Resource, Approach and Phrasing

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## Why should you talk to your patients about

### Advance Care Planning?

- You have a longstanding relationship with your patients and they trust you. This allows you to initiate the discussion and help educate them about the importance of advance care planning.
- You have knowledge and expertise about their illness.
- Research shows us that advance care planning
  - Improves quality of life and quality of end-of-life care.
  - Reduces stress and anxiety for patients, families and caregivers.
  - Improves communication between patients, families and the health care team.
  - Reduces strain on the health care system.

**Advance Care Planning** is a process of reflection and communication. It is a time for patients to reflect on their values and wishes, and to let others know what kind of health and personal care they would want in the future if they became incapable of consenting to or refusing treatment or other care. It involves having discussions with family and friends – especially their Substitute Decision Maker(s) – who is the person or people who will provide consent or refusal of consent for care and treatment if the patient is incapable.

### Practical Suggestions

- Introduce the topic of advance care planning to all patients over 50 years of age. Also to all patients with end stage organ disease and cancer.
- Use the scripts below to start the conversation.
- You will probably need to make a second appointment to discuss this in more detail. Ask your patient to bring their Substitute Decision Maker to that appointment. Allow time for reflection and decision-making.
- Refer patients to the [Speak Up: Advance Care Planning Workbook – Ontario Edition](#) – to help them explore their values and wishes.
- Utilize the template, “*Thinking about my wishes for future health care*”. Make sure the patient and their Substitute Decision Maker have copies. And that there is one in their chart.
- Make this a practice wide initiative by involving other healthcare professionals and practice staff.

**Here are some suggested phrases for introducing the topic to your patients.**

- You are well now, but it is good to plan for the future. What if you suddenly became very ill or had an accident – and couldn't speak for yourself?
- The best time to think about advance care planning is when you are well and are able to make decisions in a calm state of mind.
- If you were to get very sick and could not speak for yourself, who would you trust to make medical decisions for you?
- I'd like to talk to you about your wishes for care in case you get very sick. That might not happen, but if it does and you can't communicate, it would be important to know who would speak for you and about your wishes for care.
- Advance care planning is similar to writing your will. It is good to be prepared and let your wishes be known.
- I want to give you the best care possible. Talking about your wishes will help me do that.

# Acknowledgements

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## *Disclaimer*

Care has been taken in the preparation of the information contained in this toolkit. Nonetheless, any person seeking to apply or consult the report is expected to use independent medical judgment in the context of individual clinical circumstances or seek out the supervision of a qualified clinician. Cancer Care Ontario makes no representation or guarantees of any kind whatsoever regarding the report content or use or application and disclaims any responsibility for its application or use in any way.