Cancer Care Ontario

Advance Care Planning in Ontario – A Quality Improvement Toolkit

Introduction

What is the Advance Care Planning (ACP) Quality Improvement Toolkit?

In January 2013, the Ministry of Health and Long Term 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 partnered with various experts and leaders to develop an Advance Care Planning (ACP) Quality Improvement Toolkit[1] 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."[2] All of the above mentioned practices in Ontario are required to develop and submit a QIP to Health Quality Ontario (HQO) 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.

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

[1] Please refer to acknowledgements at the end of this document for list of collaborators involved in developing this toolkit.

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

What is ACP and How is it Connected to Health Care Consent?

ACP is the process of planning for a time when a patient no longer has the mental capacity to make health care decisions. ACP is comprised of two elements:

1. Identification of the individual(s) who will make decisions in the event a patient becomes incapable (the Substitute Decision Maker(s) or SDMs); and,
2. Expression of wishes, values, and beliefs relating to future health care decisions to be made in the event the patient becomes incapable. These wishes, values and beliefs may be expressed in writing, verbally or by alternative means of communication (e.g., Bliss Boards or sign language).

Advance care planning (ACP) does not replace informed consent. Under the Ontario Health Care Consent Act, 1996 (the HCCA), informed consent is required before a health practitioner can provide treatment (except in an emergency). If a patient is incapable of giving or refusing informed consent to treatment, the HCCA provides a hierarchy of substitute decision-makers (SDMs) who may give or refuse consent on the patient's behalf. In Ontario, informed consent must always come from communications with a person (either the patient or the SDMs if the patient is incapable).

In accordance with the HCCA, an SDM must follow the patient's last known capable wishes, provided those wishes are applicable to the treatment decision being made. If an SDM is unaware of any wishes applicable to the particular situation, he or she must act in the patient's best interests (and consider the patient's wishes as well as the patient's values and beliefs). Even if a patient has expressed wishes about future health care, health practitioners must still obtain consent before they provide treatment (except in an emergency). If a patient is mentally capable, informed consent must come from that patient. If a patient is not mentally capable, health practitioners must turn to his/her SDM(s) for consent even if the patient has written expressed wishes.

ACP is a person-centred process, requiring an appreciation for the values and expectations of the individual and his/her family. Rather than being a single event, ACP is ongoing and dynamic, with the potential for personal preferences to change over time as a person's needs and health status changes. 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.

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.[3] Including ACP in the QIP supports primary care's focus on quality patient care.
To learn more about the ACP process, please refer to Appendix A. To learn more about ACP requirements in Ontario, refer to Appendix B

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

About the ACP Quality ImprovementToolkit

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.

If you choose to use the toolkit, please let us know by emailing primarycare@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)[4] cycle of continuous improvement for QIP development.

	What happens in this part of the cycle?[4]	Tips
Plan	• Create a baseline • Define achievable goals • Define data required to track and measure your goal and how it will be collected	• Keep things simple and manageable, and set small and achievable goals (e.g., focus on one patient sub-population in the first phase)
Do	• Put the plan into practice • Collect data • Record useful observations	• Ensure that data is collected and recorded consistently
Study	• Analyze the data collected to track progress • Determine the next step needed to help meet the screening rate goal	• Set a timeline for progress checkpoints that are achievable and make sense for your practice
Act	• Make changes	• 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 conversations with patients)

[4] 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

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 introduce and facilitate ACP conversations (e.g., primary care providers, nurses, other healthcare professionals)
  - ✓ As necessary, individual(s) should pursue professional development resources to ensure a comprehensive understanding of the ACP process, and the connection to Health Care Consent, as well as the skills needed to engage in complex conversations (see Appendix E for Provider Resources and Appendix G for approach and phrasing)
- Identify who will conduct ACP group education sessions, and provide necessary education and resources
  - ✓ As necessary, individual(s) should pursue professional development resources to ensure comprehensive understanding of the ACP process, and the connection to Health Care Consent, as well as the skills needed to engage in complex conversations (see Appendix C, D and E, F and G for resources)

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.

3. Fill out the Measurement Tool

Once you have defined the criteria for your target patient population (some suggested targets are provided in *Appendix A*), 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 you have initiated ACP conversations with.

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.

Leverage existing ACP promotional material that is Ontario specific to display in the waiting room, including brochures, and other ACP patient education materials. Send letters to patients who you plan to have ACP discussions with, to introduce them to the process, and to normalize the conversation. 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 C, D, E and F 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 conversations and/or 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

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 DIMEN-SION	OBJECTIVES 1	MEASURE / INDICATOR	UNIT / POPULATION	SOURCE / PERIOD	ORG ID	CURRENT OR BASELINE PERFORMANCE 2	TARGET PERFORMANCE 3	TARGET JUSTIFI-CATION	PLANNED IMPROVEMENT INITIATIVES (CHANGE IDEAS) 4	METHODS 5	PROCESS MEASURES	GOAL FOR CHANGE IDEAS 6	COMMENTS
Patient-centred care	All patients in the target population have been invited to engage in ACP (either a group education session, or an ACP conversation) or it is documented that they did not wish to participate.	% of patients within target population who have participated in an ACP education session or conversation, 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 group education session or ACP conversation 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 group education session or ACP conversation 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 ACP group education session or introduce and engage in ACP conversations	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	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 ACP group education sessions	Number of eligible staff who have learned about ACP Number of group ACP education sessions offered. Number of ACP conversations introduced. Documentation of patient response in patient record (EMR) (refused, not sure, session or conversation booked)	All eligible staff learn about ACP All eligible patients in target population are identified. Targets for offering ACP conversations and documenting response are met.	

Step			
AIM	1 **Identify the objective and measure /indicator**	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.	*State the objective of this initiative* • *e.g., All patients over 50 years have been invited to engage in ACP conversations or it is documented that they did not wish to participate.* *List measure(s)/indicator(s)* • *e.g., percent of patients within the target group who have* - *Participated in an ACP group education session, or documentation that they did not wish to participate* - *Engaged in an ACP conversation or documentation that they did not wish to participate* - *Identified his/her Substitute Decision Maker (guided by the hierarchy)* *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)*
MEASURE	2 **Establish a baseline for performance**	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 *Measurement Tool*. **NOTE:** 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.	*Identify baseline (for each indicator identified)* *Describe the method for baseline calculation (for each indicator identified) and data sources used*

MEASURE	3 **Identify what your target(s) for year will be**	Your targets should be achievable with a bit of a stretch component, but not unattainably high.	*Identify the target for each of the indicators selected:* • *E.g. initiate ACP conversations with 50% (target to be set by practice) of the patients within the target group* *Describe target justification, including assumptions and adjustments:* • *E.g. Education process takes time; some patients may not feel comfortable engaging in ACP conversations and should not be pressured.*
CHANGE	4 **Decide on what changes the practice will make to current workflows in order to achieve the goal**	Depending on your practice structure and supports available, some activities that could be implemented include: • Run an EMR query to generate a list of your patient population that you will target for this initiative *(Note: this may be done in phases)* • Use existing Ontario specific patient education handouts and packages to support your initiative (see Appendix C, D and F) • Use Ontario specific communication tools that provide conversation starters and key messages to support the staff who will be having ACP conversations with patients and provide appropriate education (see Appendix G) • Assign a health care professional(s) on your team to conduct ACP group education sessions with patients and provide them with the patient packages (suggested materials are provided in Appendix C) • Determine where in the chart to document that patients have received education re: ACP ** NOTE: Refer to Appendix A and B for an overview of the ACP process*	*List the activities that your practice will be implementing:*

	5 **Identify how changes will be implemented and identify process measures**	This section identifies the activities and process measures that the practice will be implementing and the targets for each measure.	*List process measure(s) for the activities identified in Part 4:* • *E.g. Schedule 4 (target to be set by practice) appointments per month for patients within the target population to attend an optional ACP group education session* • *Schedule optional ACP group educational sessions*
	6 **Goal for change ideas**	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.	*Identify goal(s):* • *Conduct 4 (target to be set by practice) optional ACP group education sessions with patients per month*

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.

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

2. Process Measure Selection	
Process Measure(s)	**Methodology**
E.g., Patient identified as within target group	*E.g., Develop list and flag chart (patient record) for patients that should be invited to attend a group ACP education session, or invited to engage in an ACP conversation*

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

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

Period: *(e.g., May 1st–June 1st)*

1. Indicator Evaluation			
Indicator(s)	**Period-End Result**	**Change from Baseline**	**Change from Last Period**
E.g., Percentage of patients in the target population who have been offered a consult or education session	*Numerator: Patients who have been offered an ACP group education session (add: patients who are part of the baseline+ patients who have been offered an ACP group education session 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 group education session since the baseline measurement/400 total patients in target population = 17.5%*	*E.g., 17.5% – 12.5% = +5.0%*	*E.g., N/A*

2. Process Measure Evaluation			
Process Measure(s)	**Current Value**	**Change from Last Period**	**Interpretation (this section will inform the Period Analysis)**
E.g., Percentage of patients within the target group who have scheduled an appointment for an ACP group education session	*E.g., Only 10% of patients in the target group have been offered an ACP group education session*	*E.g. N/A*	*E.g., Staff not offering, do not feel committed to the initiative, too busy*

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

Part C: Final Evaluation

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

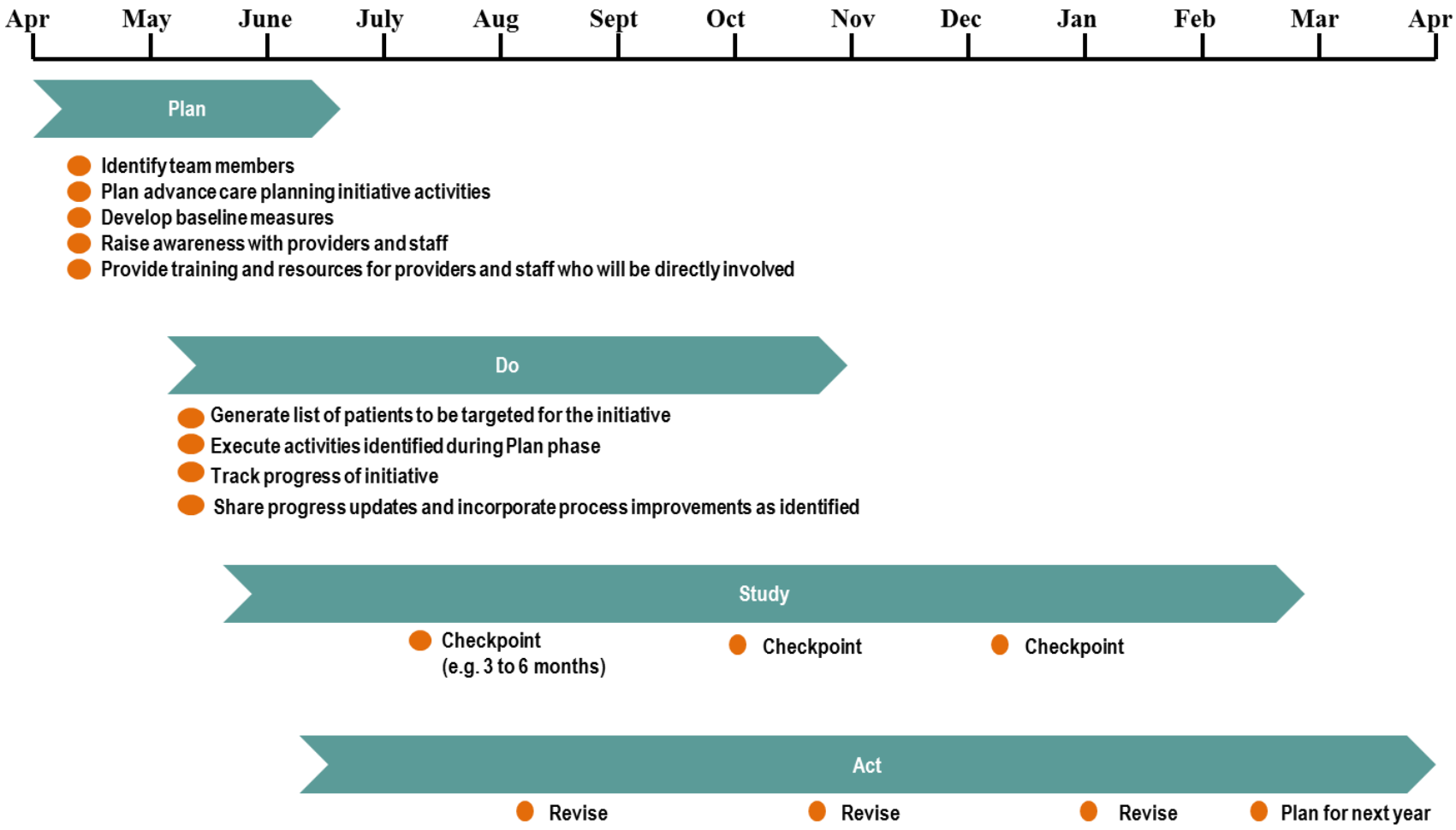
1. Indicator Evaluation			
Indicator(s)	**Period-End Result**	**Change from Baseline**	**Change from Last Period**
E.g., Percentage of patients who were offered an ACP group education session or invited to engage in an ACP conversation, as documented on chart.	*(Use methodology outlined above to calculate this)*	*(Calculate current period percentage and subtract baseline value)*	*(Calculate current period percentage and subtract from previous period percentage)*

2. Process Measure Evaluation			
Process Measure(s)	**Current Value**	**Change from Last Period**	**Interpretation (this section will inform the Period Analysis)**
E.g., Staff offered ACP group education/ initiated ACP conversation to patients in target group if no documentation on chart to indicate it had already been done.	*Use same methodology as previous periods*	*Subtract current period performance from previous period performance*	*(Interpret results)*

3. Final Period Analysis ***- How did the practice perform over the final period?***

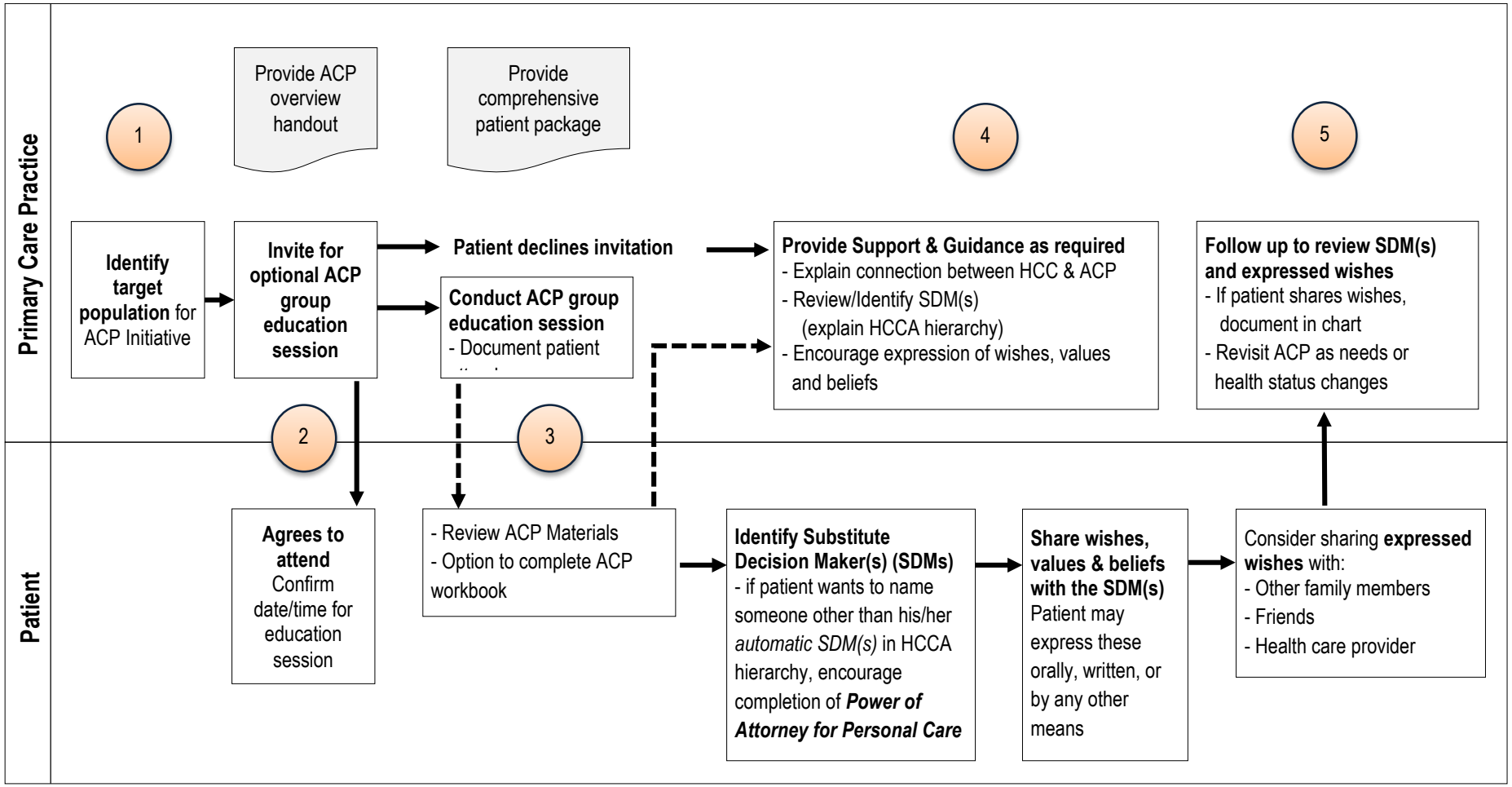
4. Final Review of Initiative ***- How did the practice perform over the entire initiative?*** ***- Were targets achieved?*** ***- What successes were achieved?*** ***- What issues arose? How were they mitigated/addressed? How successful were the plans to address the issues?***

Section 4: ACP Sample QIP Timeline



Appendix A: Supporting the Advance Care Planning Process in Ontario

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



Appendix A: Supporting the Advance Care Planning Process in Ontario

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):

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)

ii. You can create searches within your EMR to identify the patient population targeted for the ACP initiative

2 **Invite patients to attend an optional ACP group education session**

i. The primary care provider can introduce the topic of ACP when a patient within the target population attends an appointment

ii. Provide the patient with a one page overview document in preparation for an ACP conversation. *(Refer to Appendix D for the Patient Information on Advance Care Planning in Ontario Handout, or Appendix F, Speak Up Initial Patient Handout)*

iii. Invite the patient to an optional group patient education session facilitated by a provider within your practice for patients within your target population.

*** If a person declines the invitation** to attend an ACP group education session, skip step 3, and move to step 4: provide support and guidance as required.

3 **Conduct optional ACP group education session**

i. Designate healthcare practitioner(s) to conduct optional ACP group education sessions 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)
   - ensure healthcare practitioner(s) have a comprehensive understanding of the ACP process, and the connection to Health Care Consent, as well as the skills needed to engage in complex conversations (see Appendix C, D and E for resources)

ii. Provide Ontario specific education and resources to facilitate ACP discussions *(see Appendix C, E and F for resources)*
iii. Create patient packages that may include:
    - Patient Information on Advance Care Planning in Ontario *(see Appendix D)*
    - Speak Up Patient Handout *(see Appendix F)*
    - Information on other resources *(refer to Appendix C for a list of patient 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

***If a person is not ready to have an ACP conversation**, you can still provide the educational materials, and let them know that you can revisit the conversation in the future once the person feels comfortable.

4

Provide support and guidance as required *(see Appendix B for ACP Requirements in Ontario, and G for approach & phrasing)*

- Explain the connection between ACP and Health Care Consent with the patient
- Review the hierarchy of SDM's and assist the person to identify his/her automatic Substitute Decision Maker or encourage the person to consider completing a POAPC if they wish to name a specific person(s) who is not their automatic SDM
- Guide and encourage the patient to share his/her wishes, values and beliefs with his/her SDM(s), and more generally his/her preferences for how he/she would like to be cared for in the event of incapacity to give or refuse consent for treatment or care
- Identify where in the conversation one is talking about wishes (ACP) versus creating a plan of treatment related to a current condition(s).
- Initiate an informed consent discussion if the patient expresses wishes related to his or her their current condition(s).

5

Follow up with the patient, and periodically review his/her expressed wishes, values and beliefs

- Suggest a follow up meeting with the patient and substitute decision maker to review his/her expressed wishes.
- If patient has shared his/her expressed wishes or attended an education session, document in patient chart
- Revisit ACP if the patients' needs or health status changes
- Create care plans or plans of treatment based on informed consent and as informed by the 'wishes' discussions where applicable
- Ensure the patient communicates with his/her SDM(s) if their wishes, values or beliefs change.

Appendix B: Advance Care Planning Requirements in Ontario

Identifying the SDM (please refer to Appendix D for a handout that can be provided to patients about SDMs)

Health practitioners should discuss with the mentally capable patient the hierarchy of decision-makers under the *HCCA* to determine whether the patient is satisfied with their automatic SDM(s) in the event he/she becomes incapable of giving or refusing consent. If the patient is dissatisfied with their automatic SDM(s), he/she should be encouraged to complete a Power of Attorney for Personal Care (POAPC) to designate an attorney (s) who will rank ahead of the automatic family member SDMs. Health practitioners should not provide legal advice to patients on drafting POAPCs, but should refer patients to available resources explaining how to designate an attorney for personal care.

Encouraging discussions with the SDM(s) to express wishes, values and beliefs

Health practitioners should encourage the mentally capable patient to express his/her wishes, values and beliefs to his/her SDM(s), and more generally how he/she would like to be cared for in the future. Health practitioners should explain that ACP conversations are meant to prepare the SDM(s) to make future health care decisions on behalf of the patient only if he/she were to become incapable of giving or refusing consent for treatment or care.

These conversations should avoid highly specific, yet clinically uninformed, wishes with respect to future treatments that may categorically bind future SDMs. Rather, conversations should focus on more general wishes, as well as the values of the patient that would be used to inform future health care decision making.

Obtaining Health Care Consent

Health practitioners must recognize that informed consent to treatment is required from the mentally capable patient (or the incapable patient's SDM) even if he or she has engaged in ACP or expressed prior wishes (except in an emergency). Health practitioners have a duty to communicate to the patient (or the incapable patient's SDM) about the patient's present condition, the available treatment options, risks and benefits and sides effects of the treatments, alternatives to the treatment, and what may happen if he or she does not agree to the treatment. The health practitioner should not pre-screen treatment options based on their own interpretation of the patient's wishes, values, and beliefs. Health practitioners must propose a full list of options to be narrowed through discussions with the patient or SDM(s).

Health practitioners have an obligation to explain to the SDM(s) the criteria for making decisions on behalf of the incapable patient.

Health practitioners should recognize that SDMs cannot express new wishes, values and beliefs on behalf of the patient.

Appendix C: Advance Care Planning Patient Resources

In this appendix you will find a list of patient resources that can be used in the process of ACP. In Ontario, ACP is governed by unique laws, and as a result, it is essential for your practice to only use resources that have been developed specifically for Ontario,

As you decide what would work best for your practice, please keep in mind the requirements for ACP in Ontario (refer to Appendix B).

1. **Patient Information on Advance Care Planning in Ontario (see Appendix D)**
2. **Advance Care Planning Workbook: Ontario Edition**
   http://www.advancecareplanning.ca/wp-content/uploads/2015/09/acp_ontario_workbook_-_03.2015_colour_final-web-form.pdf

   This workbook provides Ontario patients and families with a guide to doing ACP. It was developed by the Ontario Health Care Consent and Advance Care Planning Community of Practice in collaboration with Hospice Palliative Care Ontario and the Canadian Hospice Palliative Care Association

   Hardcopies are available from Hospice Palliative Care Ontario for $5.00 by contacting alecoche@hpco.ca or 1-800-349-3111 ext. 22.

3. **Speak Up Patient Handout (see Appendix F)**
4. **Advance Care Planning Quick Guide: Ontario Edition**
   This is a summary version of the Advance Care Planning Workbook
   http://www.advancecareplanning.ca/wp-content/uploads/2015/09/ACP-Ontario-Quick-Guide-03.2015_colour_FINAL-web.pdf

5. **Power of Attorney Kit**
   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

Appendix D: Patient Information on Advance Care Planning in Ontario

What is Advance Care Planning?

In Ontario, Advance Care Planning (ACP) is a process that involves:

- Identifying your Substitute Decision Maker(s) (SDM) (i.e. automatic with hierarchy or naming a specific person in a POAPC document)
- Sharing with that person(s) what your wishes, values, and beliefs are or future care.

The SDM is the person or people who will provide consent or refusal of consent for treatment or other care for you, if you are not mentally capable to do so for yourself. You can express your wishes, values, and beliefs in writing, verbally or by alternative means of communication (e.g., Bliss Boards or sign language). The goal of these conversations is to give your SDM(s) the confidence to make future healthcare decisions that reflect what's important to you based on your known wishes.

Under Ontario Law, ACP is part of the Health Care Consent Act. In Ontario, Health care professionals are required to get an "Informed consent" before they provide treatments or care. Informed consent must come from you, if you are mentally capable, or from your SDM if you are not mentally capable. Your health care professionals must always get consent or refusal of consent from the person and not from a written document or any other form of expressed wishes for treatment or care.

Who is Your Substitute Decision Maker(s) According to Ontario Laws?

In Ontario, the law provides you with an automatic Substitute Decision Maker for health care. The Ontario Health Care Consent Act includes a hierarchy (a ranked list) of SDMs. The person or persons in your life that are the highest ranked in this hierarchy and that meet the requirements to act as a Substitute Decision Maker(s) will be your Substitute Decision Maker(s) for health care. For example, this might be your spouse or your child/children. Ask your health provider for a copy of this list or you can find it in the Speak Up Advance Care Planning Ontario workbook.

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

What are the requirements to be a Substitute Decision Maker?

The person must be:

- Willing to act as your Substitute Decision Maker
- Be mentally capable to make the needed health decisions for you
- AVAILABLE (in person or by phone or by some other means) when a decision needs to be made
- Not prohibited by a court order from acting as your substitute decision maker and
- Be at least 16 years of age.

If the person in your life that is the highest ranked in the hierarchy does not meet these requirements, then the health care professional will move down the hierarchy to the next person in the list in your life.

Appendix E: Important Resources

While there are common elements in the ACP process across Canada, because of the unique laws that govern ACP in Ontario, you should always leverage tools and resources that are Ontario specific to assist you in supporting your patients through this journey:

1. **CCO website for toolkit** – Toolkit link

2. **Speak Up Advance Care Planning Resources (Ontario Specific)**
   Speak Up is a national initiative that provides ACP resources for individuals, communities and health care providers. It is facilitated by the Canadian Hospice Palliative Care Association (CHPCA). There are many Ontario specific resources on the website http://www.advancecareplanning.ca/resource/ontario/
   - Advance Care Planning Workbook – Ontario Edition helps patients and families to explore their values and express their wishes for care.
   - Advance Care Planning Quick Guide a summary version of the workbook.
   - Primary Care Toolkit- Ontario which provides Ontario specific tools and resources for health care professionals who want to engage in advance care planning discussions with their patients

3. **Hospice Palliative Care Ontario**
   HPCO manages the Ontario Speak Up campaign, and supports the Health Care Consent Advance Care Planning Community of Practice (HCC ACP CoP). The HCC ACP CoP has developed provider and public educational materials and includes a network of ACP champions who provide ACP education within their LHIN regions. For more information about ACP champions in your region, contact Julie Darnay at jdarnay@hpco.ca.
   - ACP and HCC Educational Resources: PowerPoint presentations and facilitator guides for health care providers, and the public

4. **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

5. **Advocacy Centre for the Elderly (ACE) tip sheets:**
   - Health Care Consent and Advance Care Planning: the Basics
   - Hierarchy of SDMs in the Health Care Consent Act (HCCA)
   - 25 Common Misconceptions About The Substitute Decision Act and Health Care Consent Act

6. **Consent and Capacity Board:**
   - Information sheets
   - Frequently asked questions

Appendix F: Initial Patient Information Handout

Please see the following page for a patient handout developed by Speak Up

Talk to your Health Care Provider 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 make healthcare decisions for you?

What is Advance Care Planning?

Advance Care Planning is a process of reflection and communication. It is a time for you to reflect on your values and wishes, and to let people know what kind of health and personal care you think you may want in the future if you became mentally incapable of consenting to or refusing treatment or other care.

Why should you do it?

It can be very hard for others to have to make health and personal care decisions for you if they do not know your wishes. Research shows us that advance care planning has many benefits, including

- Improving quality of life and quality of end-of-life care
- Reducing stress and anxiety for patients, families and caregivers
- Improving communication between patients, families and the health care team.

How do you do it?

Talk to your family and friends about your wishes, values and beliefs so they feel confident to make healthcare decisions that reflect what's important to you when you are no longer mentally capable to make those decisions.

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. Conversations should be ongoing. Always take time to think about it again when things change in your life. Revisit the conversation as your wishes and values change.

Find out more:

Ask your health care provider about Advance Care Planning. Visit: **www.advancecareplanning.ca/wp-content/uploads/2015/09/acp_ontario_workbook_-_03.2015_colour_final-web-form.pdf**

Speak Up

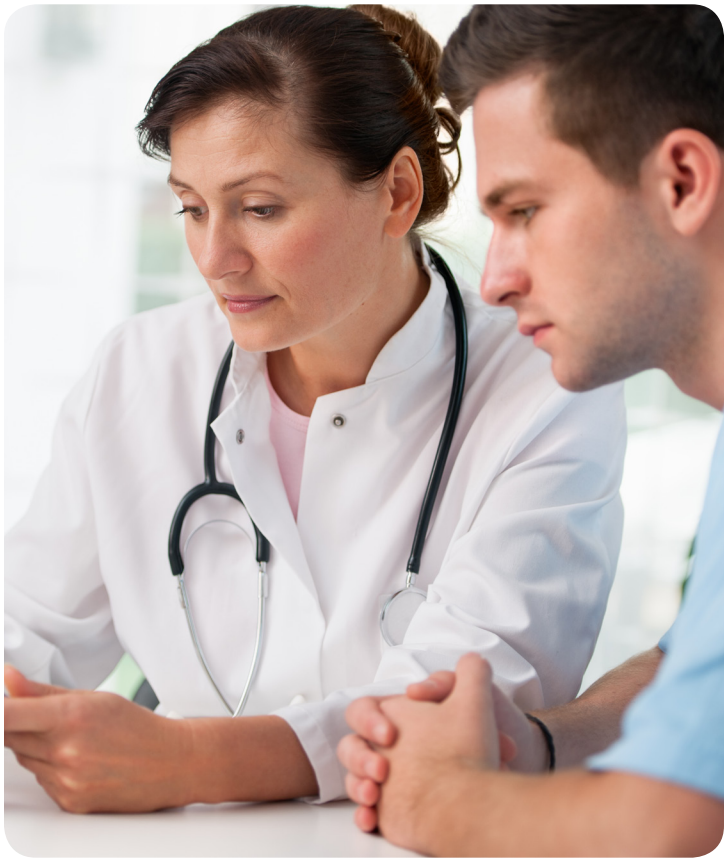
Start the conversation about end-of-life care

Appendix G: Provider Handout, Approach and Phrasing

Please see the following 2 pages for the provider handout developed by Speak Up

Why should you encourage Advance Care Planning conversations?

- You have a relationship with your patients and they trust you. This allows you to initiate the discussion and provide education 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; and
  - 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 mentally incapable.

Speak Up

Start the conversation about end-of-life care

(continued...)

Practical Suggestions

- Learn about the Ontario Legal Framework, and how Advance Care Planning connects to Health Care Consent
- Introduce the topic of advance care planning to all patients.
- Use the scripts below to start the conversation.
- Refer patients to the *Speak Up: Advance Care Planning Workbook – Ontario Edition* – to help them explore their wishes and values with their Substitute Decision Maker
- Offer support and guidance as required to facilitate the conversation with the patient and his or her substitute decision maker(s)
- Allow time for reflection (ACP) and decision-making (HCC, plan of treatments).
- Recognize that this is a process and additional discussions may be required
- 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 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.
- What do we need to know about you as a person, in order to provide you with the best possible care?

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