Health Care Consent & Advance Care Planning in Ontario

What You Need to Know

Health Care Consent Advance Care Planning Community of Practice

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Learning Objectives

- At the end of this session, participants will have a better understanding of:
  - What Health Care Consent and Advance Care Planning means in Ontario
  - What all HSPs need to both know and understand about Health Care Consent and Advance Care Planning
  - What Hospitals must understand about Health Care Consent and Advance Care Planning to support Patients and their Families

Key messages in the Hospital Setting

- Health Care Consent and Advance Care Planning must be implemented in ONTARIO in accordance with ONTARIO LAW
- Hospitals should NOT use forms and policies from other provinces or other jurisdictions without changing them to fit ONTARIO
- CONSENT must be obtained before treatment.
  ACP is not consent to treatment
- Obtaining advance care "plans" of patients on admission to hospital is not of much value and not much help when decisions about treatment in hospital need to be made .

Question #1

For a person who lacks the mental capacity to provide consent for treatment plans, ACP conversations can occur with substitute decision makers on behalf of the person.

True *or* False?

Question #1 - Answer

FALSE

- SDMs cannot advance care plan for another person. SDMs ONLY give or refuse consent to treatment on behalf of an incapable person.

- Only Patients when capable may do ACP for themselves.

Question #2

Wishes for treatments should be documented in either an advance directive or a living will.

True *or* False?

Question #2 - Answer

FALSE

- There are no such documents called “Advance Directives” or “Living Wills” in Ontario law and this terminology should not be used as its confusing.
- In Ontario the only part of advance care planning that must be done in writing is when a person wants to name someone as their SDM that is not their automatic SDM. That must be done in writing by preparing a POA Personal care.
- Advance Care planning about communication of wishes, values and beliefs to guide the SDM may be done ORALLY, in WRITING, or be communicated by alternative means.

Why does it matter to GET THIS RIGHT?

Outcome evidence indicates that Consent and ACP:

- Improves patient & family satisfaction with EOL care[1]
- Decreases caregiver distress & trauma[2]
- Decreases unwanted investigations, interventions & treatments[3]
- Increases the likelihood of dying in preferred setting[3]
- Decreases hospitalizations & admissions to critical care[4]
- Decreases cost to the health care system[5]

Why does it matter to GET THIS RIGHT?

Under Ontario Law, Advance Care Planning is part of the Health Care Consent Act

- Health care practitioners must always obtain informed consent or refusal before treatment from either the mentally capable patient or their substitute decision maker (SDM)

- Advance care planning wishes have been inappropriately used as consents when the health practitioners don't have a good understanding of how Informed consent and ACP are related

Why does it matter to GET THIS RIGHT?

- The Law Commission of Ontario strongly recommends using terminology in the Health Care Consent Act (HCCA):

  "**…terminology used in health care consent and advance care planning forms, tools, and policies track the language in the HCCA, and that these documents should expressly distinguish between consent and the recording of wishes, values, and beliefs**."

- i.e. Asking patients for their "Next of KIN" – BUT hospital should want to know should would be the patient's SDM
- i.e. "Advance directives/ Living wills are NOT in Ontario legislation yet that terminology appears on many forms

Who needs to worry about GETTING THIS RIGHT?

Hospitals

Patient's Care Wishes

☐ Patient has requested to discuss AD's

☐ Patient has a written directive and ☐ copy has been requested
☐ copy has been obtained and placed in record

☐ Patient has discussed care wishes with SDM(s)

Has the patient / SDM verbally expressed care wishes? ☐ Yes ☐ No
If "yes" summarize any information provided here, and notify physician:

Has the physician been informed? ☐ Yes ☐ No
(Note, if care wish information is provided physician must be notified.)

Name of Physician:_____ Date:_____ Time:_____

Name of Healthcare professional Completing this form:_____ Date:_____

Who needs to worry about GETTING THIS RIGHT?

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Name of Healthcare professional Completing this form:_____ Date:_____

These are either confusing or incorrect elements

An Electronic Medical Record (EMR) Example

Health Care Consent and Advance Care Planning

1. **My Substitute Decision Maker (SDM) is/are:** ***(May require additional space for multiple SDMs)***
   - **Name:**
   - **Contact Information:**
   - **Relationship:**

(Note 1: Confirm that the above noted SDM is the highest ranked in the SDM hierarchy list)

The Hierarchy List (Create as a drop down menu)

The following is the Hierarchy of SDMs in the Health Care Consent Act, s.21:

1. **Guardian of the Person with authority for Health Decisions**
2. **Attorney for personal care with authority for Health Decisions (See Note 2)**
3. **Representative appointed by the Consent and Capacity Board**
4. **Spouse or partner**
5. **Child or Parent or CAS (person with right of custody)**
6. **Parent with right of access**
7. **Brother or sister**
8. **Any other relative**
9. **Office of the Public Guardian and Trustee**

(Note 2: if the above noted SDM is #2 in the hierarchy list: Attorney for personal care with authority for Health Decisions - confirm this information in the person's POA for Personal Care document)

2. **I have shared my wishes, values and beliefs with my future Substitute Decision Maker as they relate to my future healthcare?**
   - **Yes**
   - **No**

(Note 3: If No, provide ACP provincially approved resources i.e., Speak-Up Ontario ACP Workbook or website information, etc.)

What is required in all care settings to GET THIS RIGHT?

- Understanding of and proper implementation of the **CONSENT** process
- Consent comes from a **CAPABLE PERSON** not a document or any form of advance care planning
- Understanding that consent is required for **ALL** treatments or a Plan of Treatment based on the person's current health condition
- Understanding that patients must be informed of their health condition and that consent must be informed - risks, benefits, side effects, alternatives, what happens if patient refuses treatment

What is required in all care settings to GET THIS RIGHT?

- There must be proper determination of a person's **CAPACITY** for treatment decision-making BY A HEALTH PRACTITIONER not a CAPACITY ASSESSOR

Definition of Capacity:

- **Ability to understand** the information that is relevant to making a decision about the treatment, admission, or personal assistance service as the case may be, AND
- **Ability to appreciate** the reasonable foreseeable consequences of a decision or lack of decision

(HCCA s. 4)

What is required in all care settings to GET THIS RIGHT?

- Mental capacity:
  - Is **issue specific – for each type of decision and for each new decision**
  - Is **not a diagnosis**
  - Can fluctuate
  - Does include having INSIGHT
  - Is presumed **unless there is REASON to believe otherwise**
- If a person is mentally incapable for a particular treatment decision then the HCP must turn to the patient's SDM(s)

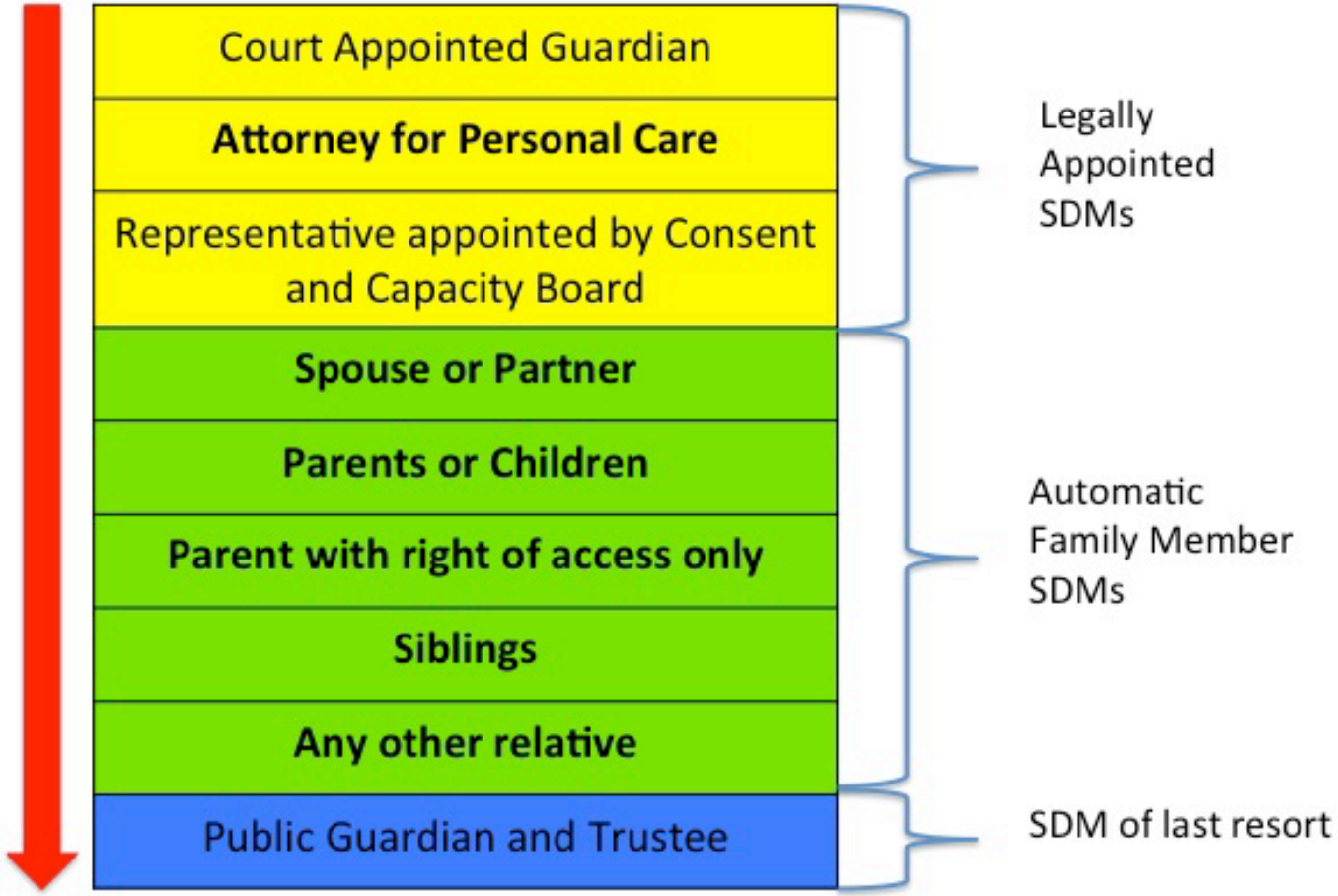
What is required in all care settings to GET THIS RIGHT?

- Understanding of who is the treatment decision maker - Patient or incapable patient's SDM
- Understanding of WHO is the RIGHT SDM according to the hierarchy and recording name and contact information properly on forms
- Understanding that the SDM must meet the requirements of being WILLING, AVAILABLE, MENTALLY CAPABLE, at least 16, and not prohibited by court order or separation agreement in order to act as SDM.

Substitute Decision Maker Hierarchy

Confirm automatic SDM(s)

Choose someone else and **Prepare** a *Power of Attorney for Personal Care* document



Ontario Health Care Consent Act, 1996

What is required in all care settings to GET THIS RIGHT?

Understanding that a resident, when **capable**, may engage in **ADVANCE CARE PLANNING** which is:

- Confirming that they want their AUTOMATIC SDM(s) OR Choosing an SDM(s) by preparing a POAPC

AND

- Communicating their Wishes, Values and Beliefs about care **to help SDM(s)** make healthcare decisions for them in the future when they are incapable

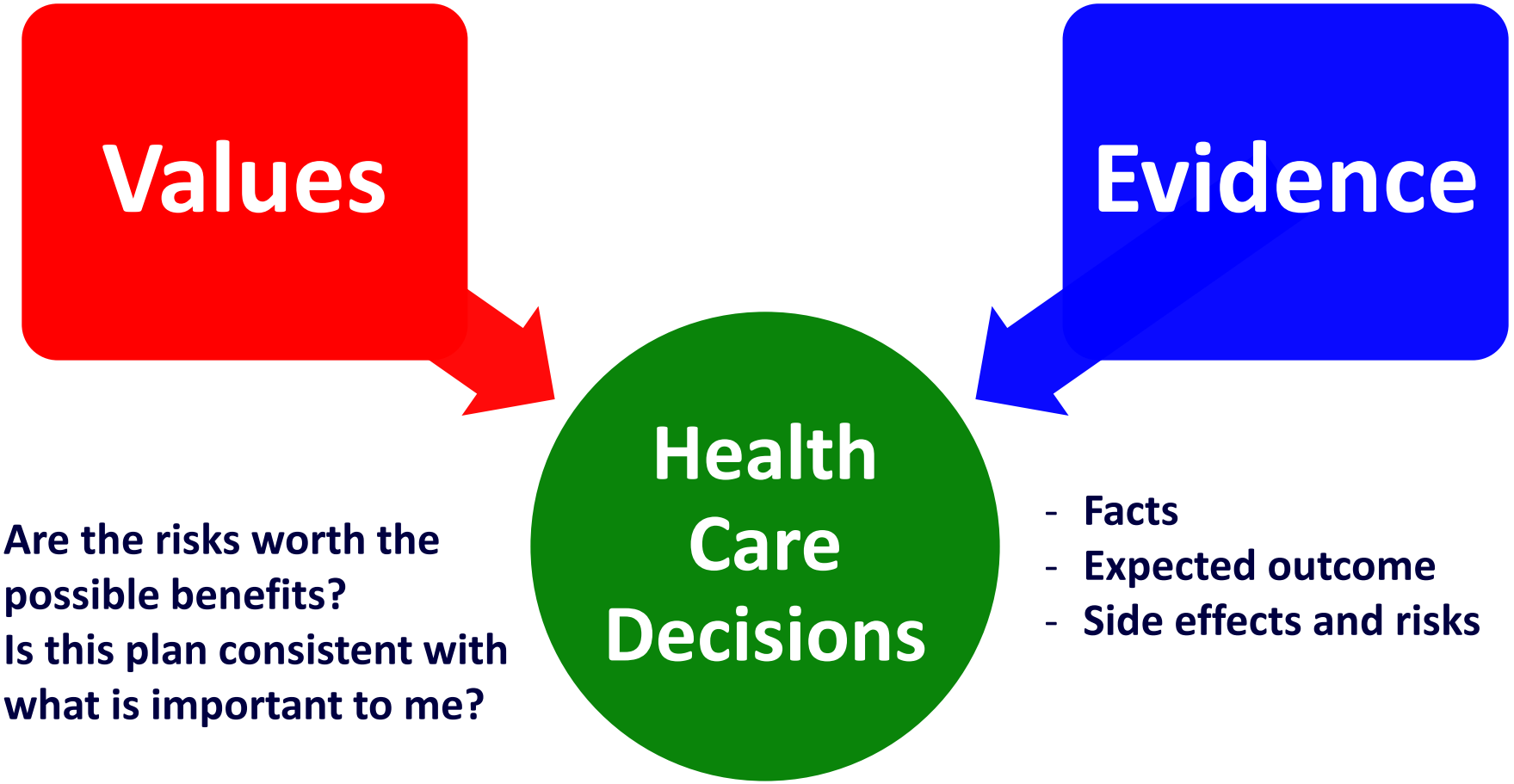
What is required in all care settings to GET THIS RIGHT?

- An understanding that **SDMs** cannot engage in advance care planning for a patient

- An understanding that SDMs may ONLY give or refuse consent – They may consent to a DNR or other end of life care taking place in the near future IF this is relevant to the resident's PRESENT health condition

- An understanding of the relationship between and differences between advance care planning, goals of care and informed consent

How a person makes healthcare decisions



Fulford KWM, Peile E, Carroll H. Essential values-based practice: Clinical stories linking science with people. New York: Cambridge University Press 2012. Adapted by Dr. Nadia Incardona

What is required in all care settings to GET THIS RIGHT?

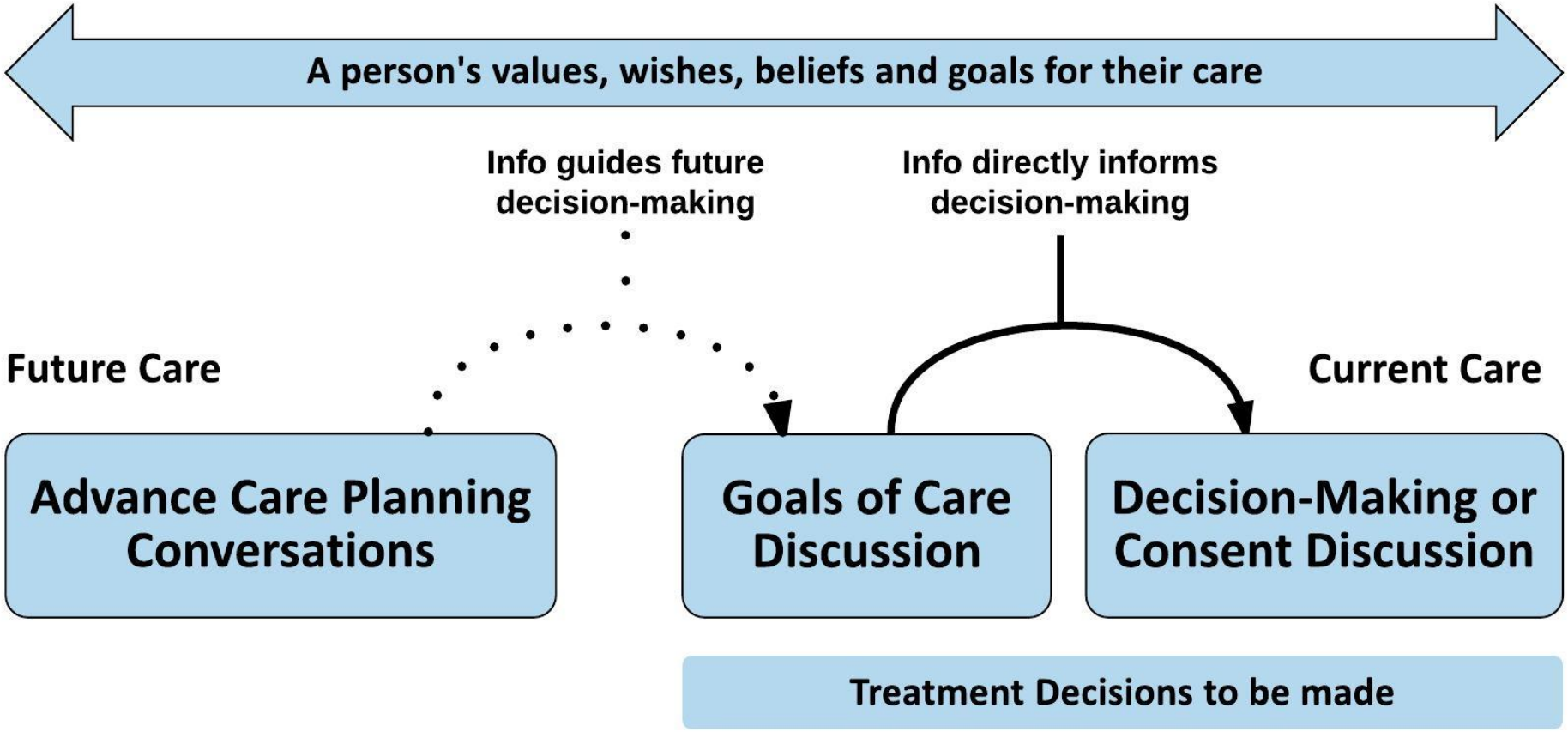


Figure: Relationship between three discussions that contribute to informed consent

What is required in all care settings to GET THIS RIGHT?

	Clinical Context	Outcome is…	Outcome is NOT…	How goals are defined
Advance Care Planning	Future	Values & wishes prepare SDM(s) for future decision-making	Code Status, POLST, etc.	Patient is to define and describe
Goals of Care Discussion	Current	Patient understands illness Clinician understands patient's values & goals	Code Status, POLST, etc.	Patient is to define and describe
Decision-making Discussions	Current	Care or treatment decision(s) e.g. code status, POLST, etc.		Treatment oriented e.g. cure, resuscitation, comfort

What's the clinical approach to GET THIS RIGHT?

Not helpful Consent and ACP Conversations…

Commonly used	Think about it for a moment…
"No heroics and no machines"	Ever? Or when there is no chance of recovery? What about a 90% chance?
"No tubes"	What if the circumstances were short term and reversible… would a "tube" be acceptable?
"Do everything"	What does this mean? What "state of being" is to be achieved? How will the SDM know when everything has been done?

What's the clinical approach to GET THIS RIGHT?

Helpful Consent and ACP Conversations…

	Explore further
"No heroics and no machines"	What experiences have you had to bring you to this? What is it about "heroics and machines"?
"No tubes"	What is it about a tube that makes you not want one?
"Do everything"	What does it mean to not "do everything"? What worries or fears come to mind? How should we approach reconciling this?

What's the clinical approach to GET THIS RIGHT?

Outcomes of an ideal Consent and ACP conversation

- SDM is aware of the person's values and what he or she views as meaningful in life
- SDM begins to understand how the person makes decisions (i.e. how they view benefit and burdens)
- SDM has information that would guide decision making
- Avoids statements such as "no machines" or "no heroics" or "no feeding tubes" without modifiers that would make these situations bearable or unbearable for the person

What's the clinical approach to GET THIS RIGHT?

Outcome evidence of Consent and ACP conversations:

- Improves patient & family satisfaction with EOL care[1]
- Decreases caregiver distress & trauma[2]
- Decreases unwanted investigations, interventions & treatments[3]
- Increases the likelihood of dying in preferred setting[3]
- Decreases hospitalizations & admissions to critical care[4]
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This was not always the case…what changed?

Important points to remember about ACP

- Ensure staff and SDMs understand the role of the SDM in **INTERPRETING** and applying any form of the patient's advance care planning (if any)
- Promote understanding that staff **DO NOT** take direction from any form of advance care planning (whether written, oral or communicated by alternative means) except in an emergency
- **DNRC forms are NOT** the same as consent to a DNR status in hospital
  - must confirm through discussion with a capable patient (or their SDM(s) if the patient is no longer capable)

System Strategies to GET THIS RIGHT

To improve the quality and effectiveness of HCC ACP in Ontario, culture must be changed. Culture change requires:

1. **Education:**
   - **People & SDMs**:
     - Aware
     - Informed
     - Self management strategies
   - **Clinician competence**:
     - Attitudes/Aware
     - Knowledge/Information
       - Legal framework
       - Actual conversation
     - Skills

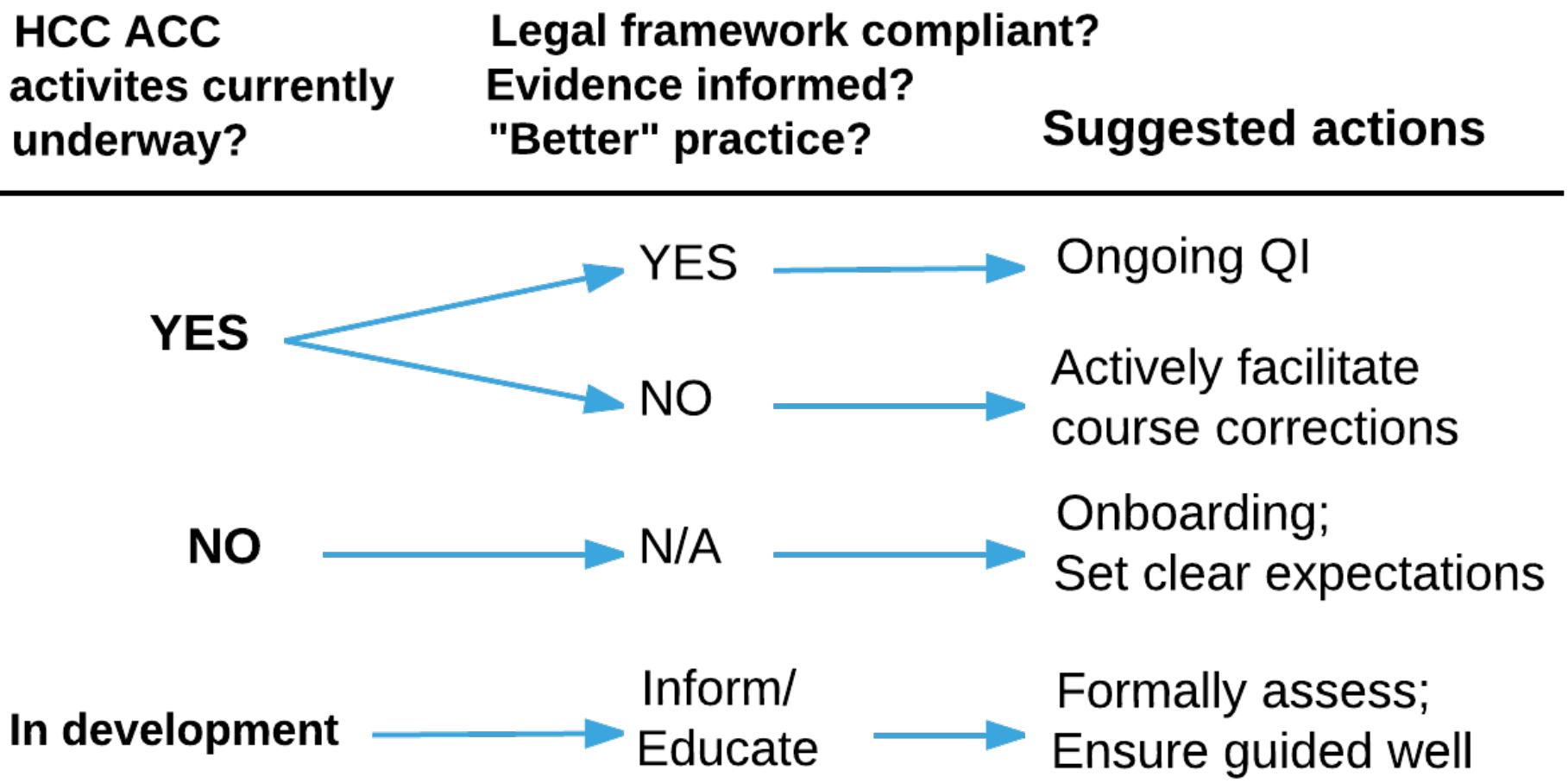
2. **Documentation/EMR**
   - Standardized
   - Accessible

3. **Quality improvement**

4. **System wide planning & coordination**

System Strategies to GET THIS RIGHT

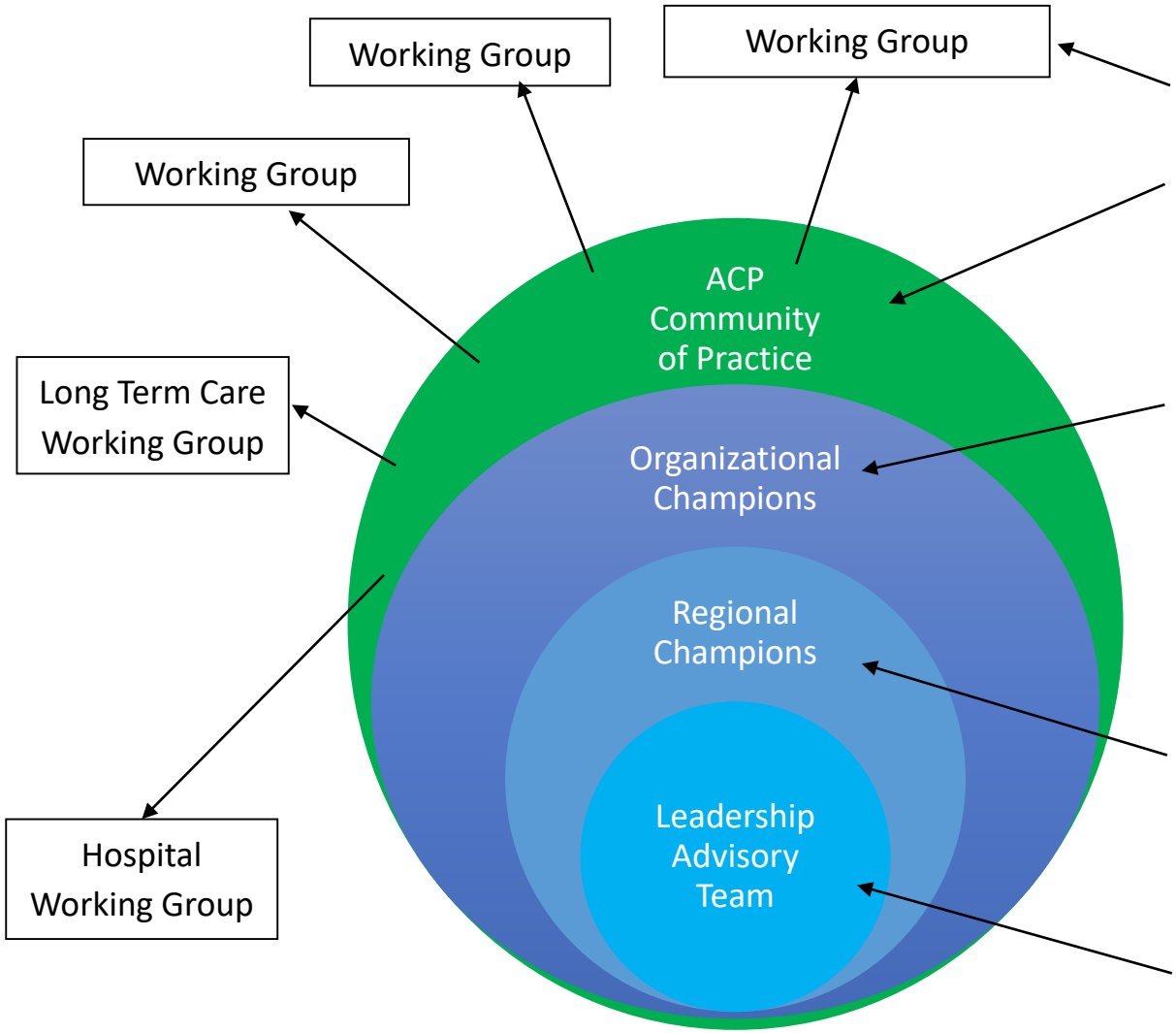
Process for assessing organizations and institutions



HPCO HCC ACP CoP

- Creation of CoP's to respond to the need for a resource for HCC and ACP utilizing an Ontario legal framework.
- The CoP supports Ontario clinicians, administrators, caregivers, policymakers, researchers, educators and leaders who are committed to the promotion of HCC ACP in Ontario.
- Goal of the CoP are to reinforce the link between HCC and ACP to health care providers.
- Hospice Palliative Care Ontario (HPCO) hosts and supports the work of the CoP

How we can help you to GET THIS RIGHT?



Ad Hoc **Working Groups** determined by the membership and advised by the Leadership Team

The **Broad Membership** is comprised of anyone interested in coming together to better understand and promote HCC ACP in Ontario; and to encourage the recommended Ontario tools and resources, and build capacity and awareness.

The **Organizational Champions Group** is comprised of individuals, who want to expand into a lead role for promoting and/or implementing HCC ACP within their organization/facility/sector etc. Broad representation from all disciplines and sectors are sought (clinical, legal, social, financial etc.).

The **Regional Champions Group** is comprised of 1-2 leads from each LHIN area that have a lead role for promoting and/or implementing HCC ACP ideally across their regional geography.

The **Leadership Advisory Team** is comprised of a diverse group of experts in the legal, policy, clinical, operational, knowledge translation and implementation domains of HCC ACP in Ontario

HPCO Hospice Palliative Care Ontario

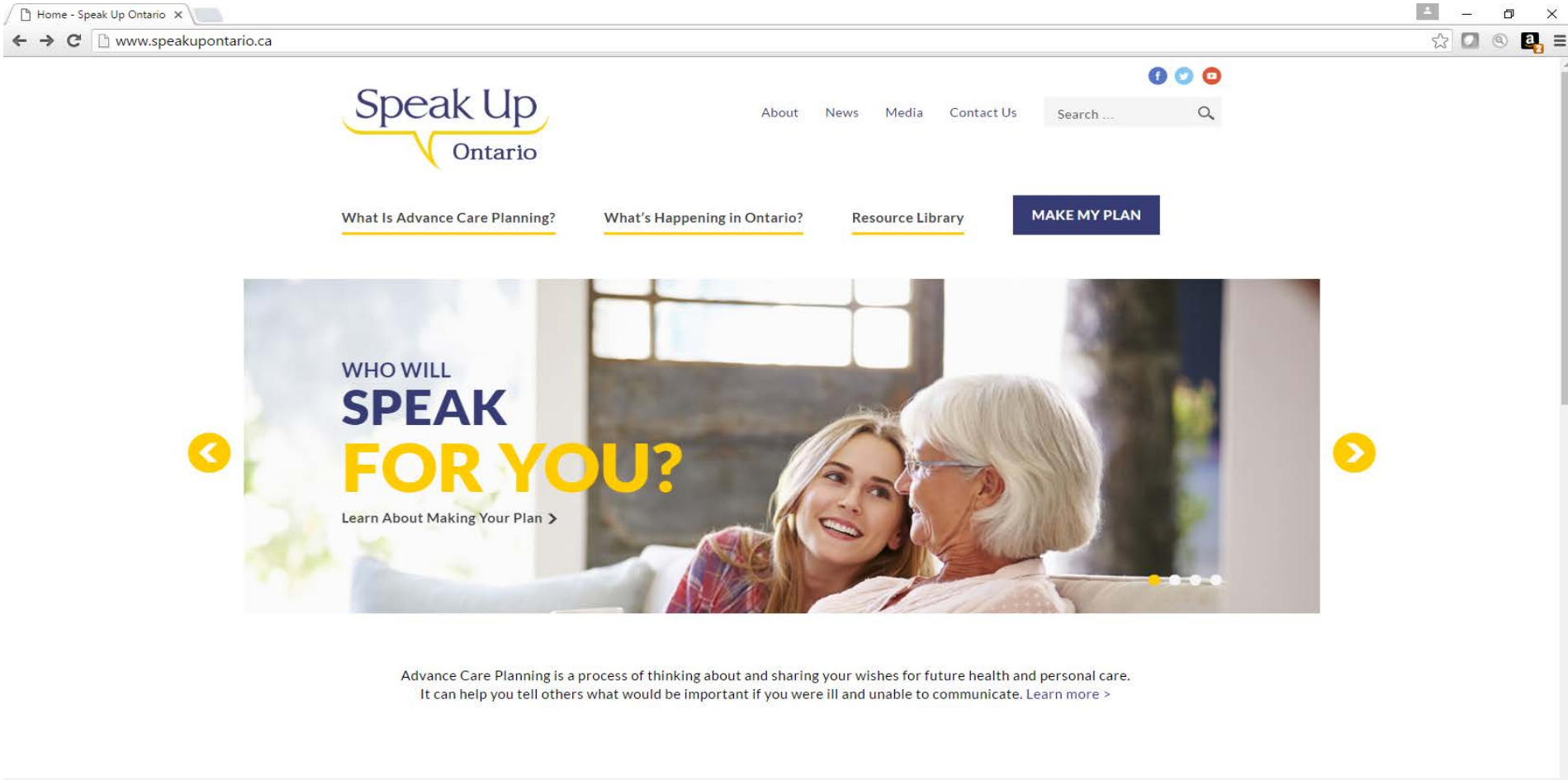
Hospital Working Group

- Scope:
  - To develop Ontario based best practice HCC ACP LTC resources
  - To support positive change with HCC ACP practices across LTC Homes in Ontario
  - To incorporate a knowledge translation approach in all of the project activities to ensure that best practice theory is translated to practice and is sustainable.
- Work Plan:
  - Environmental Scan of Current State, Issues and Challenges
  - Repository of innovative/compliant HCC ACP Hospital initiatives
  - Alignment with Law Commission of Ontario Paper Recommendations
  - Develop principles, guidelines and templates
  - Support Education/Knowledge Translation
  - Capacity Building
- Working with Senior Friendly Hospitals Initiative, Northern Ontario School of Medicine
- Partnership with OHA & OMA

Speak Up Ontario Resources

www.speakupontario.ca

Ontario Advance Care Planning Workbook



HCC ACP CoP Ontario Tool Kit

1. Health Care Consent Advance Care Planning Common Themes and Errors Tool
2. Leadership in Advance Care Planning in Ontario Tool
3. Leadership Screening Tool
4. Health Care Consent and Advance Care Planning Glossary of Terms for Ontario
5. Medical Assistance in Dying (MAiD) (Previously Physician Assisted Dying (PAD)) and Advance Care Planning (ACP)
6. National Consent Legislation Summary Chart
7. ACE Tip Sheet #1: Health Care Consent and Advance Care Planning the Basics
8. ACE Tip Sheet #2: HIERARCHY of Substitute Decision Makers (SDMs) in the Health Care Consent Act
9. ACE: Advance Care Planning – ONTARIO – SUMMARY – Health Care Consent Act List of "approved" HCC and ACP resources

Key Ontario Reference Sites

- Ontario Health Care Consent Act, 1996 - https://www.ontario.ca/laws/statute/96h02
- Ontario Substitute Decisions Act, 1992 - https://www.ontario.ca/laws/statute/92s30
- Consent and Capacity Board - http://www.ccboard.on.ca/scripts/english/aboutus/index.asp
- Public Guardian and Trustee Office - https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/
- ACE Advocacy Centre for the Elderly - http://www.acelaw.ca/advance_care_planning_-_publications.php
- Hospice Palliative Care Ontario - http://www.hpco.ca
- Speak Up Ontario – http://www.speakupontario.ca
- Community Legal Education Ontario (CLEO) - http://www.cleo.on.ca/en/publications/power http://www.cleo.on.ca/en/publications/continuing

Repository of Examples of Resources that meet the Ontario Legal Framework

- **ACP CONVERSATION GUIDE,** *Produced by Dr. Nadia Incardona and Dr. Jeff Myers, 2016, includes:*
  - ACP Conversation Guide template, Clinical Primer
- The Waterloo Wellington ACP Education Program **"CONVERSATIONS WORTH HAVING"**
  - General Public Fact Sheet, Health Care Fact Sheet, Wallet Card
- East Toronto Health Link's **ONTARIO ACP TOOLKIT FOR PATIENTS WITH CHRONIC DISEASES AND THE HEALTHCARE PROVIDERS WHO CARE FOR THEM**
  - ACP Brochure, ACP Workbook, cpr Brochure, sdm Brochure, Wallet Card

Provincial Webinars on "HCC ACP in Ontario"

2016 Education Series:

- LHIN Staff - June 1, 2016,
- Provincial Associations - July 19, 2016
- Health Links and Community Partners - September 28, 2016
- Long Term Care Homes - October 7, 2016
- Hospitals - November 18, 2016
- Community Care Access Centres - December 9, 2016

2017 Education Series:

- General Session – January 13th, 2017
- Regional HPC Networks – February 10th, 2017
- LTC Corporations and Compliance Officers – March 10th, 2017 (AM)
- Primary Care – March 10th, 2017 (PM)
- Lawyers and Legal Clinics – May 12th, 2017
- Clinical Ethicists and Social Workers – June 9th, 2017

How we can help you to GET THIS RIGHT?

To become a member of the Community of Practice simply register at:

http://fluidsurveys.com/s/hpco-hcc-acp-cop/

To schedule a resources review or to request additional support or assistance from the CoP simply go to:
http://www.speakupontario.ca/resource/ontario-guides/

System Strategies to GET THIS RIGHT

- Clarify confusions, dispel misconceptions and correct incorrect information
- Provide accurate knowledge about the **Ontario** legal framework
- Encourage consistent practices
- Expect accurate language which promotes clear communication
- Discover and utilize Ontario specific tools, supports and resources (paper & people)

Ontario needs to GET THIS RIGHT

- 100% of people in Ontario will die
- **CONSENT and ACP is relevant to 100% of Ontarians**
- It is **NOT** a matter of **IF** we get this right, it is now about **HOW** and **WHEN** we get this right
- Effectiveness requires a system wide approach
- Ideally a coordinated effort at provincial, regional and community levels is required for success

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Questions and Discussion