

Improving Advance Care Planning in Primary Care

NURSING AND ALLIED HEALTH CARE PROFESSIONALS VERSION

Who should complete this survey?

Nurses, social workers and other allied health care professionals who work in a family practice and meet the following criteria:

- 1) Provide care to patients with advanced or life-threatening illness (including palliative care) AND
- 2) Are involved in discussions of advance directives, living wills, advance care planning or goals of care at end of life

We would greatly appreciate your participation in this questionnaire which addresses issues around advance care planning (ACP) in a primary care practice setting. We define ACP as follows:

- ACP is a communication process wherein people prepare for making medical decisions at the end of life, particularly when they cannot make decisions for themselves.
- ACP should occur principally in home and community settings with everyone, but especially among patients diagnosed with chronic or life-limiting illnesses.
- ACP includes three steps:
 1. **Deliberation and determination of a person's values and wishes or preferences for treatments at the end of life.** By values, we mean an expression of a person's overarching philosophies or priorities in life. Wishes and preferences are used interchangeably and refer to specific preferred options for treatments or health states.

Note: ACP is generally done outside of the clinical context and not to be misconstrued as medical decisions; a medical decision requires consideration as to whether the wishes and preferences are clinically indicated and follows a prescribed process of obtaining informed consent.

2. **Communication amongst an individual, their loved ones and future substitute decision maker(s)**

Note: ACP may result in the naming of a person to make decisions for the patient should they become incapable. ACP may also result in a written expression of wishes and preferences (advance care plans), although verbal or other expressions are also useful.

3. **Communication amongst an individual and their health care provider(s)**

Note: In some provinces, the ACP process may lead to the option of a written instructional directive, advance directives (specific instructions for treatments to be used or not used) or a Goals of Care Designation. Some of these documents do not have legal standing in some provinces. The documents may also have limited clinical utility. In this survey we are NOT asking about Goals of Care Designation forms as used in Alberta (or green sleeves, for example) but rather the kind of conversation that leads to the patient being sure of their values and preferences and the naming and capacitation of a substitute decision maker.

In this questionnaire, we are interested in your perspective about:

- (1) The importance of various barriers to engaging your patients in advance care planning.
- (2) Your suggestions to improve advance care planning with patients and their families.
- (3) Your perceived role and the role that others may play in communication and decision-making about advance care planning with your patients and their families.
 - **This questionnaire will take approximately 10-15 minutes to complete.**
 - **Please circle the best response unless otherwise requested.**
 - **All responses will remain confidential.**

Section 1

Barriers to ACP Discussions

Barriers Related to the My Role in ACP

1. A barrier is something that hinders your ability to effectively engage in ACP with your patients. Below is a list of items that have been identified as health care professional-related barriers from the literature and focus groups with experts. Please read each one carefully. Reflecting on your most recent month of clinical work, please indicate if the item is a barrier to you (not your colleagues or 'in general') on a scale of 0-6 where 0 means 'not at all' (you believe that it is not a barrier to you) and number 6 means 'an extreme amount' (you believe that your ability to engage your patients in ACP is severely affected by this item).

Not At All	Very Little	A Little	A Moderate Amount	A Lot	A Great Deal	An Extreme Amount	Don't Know
a) My role in doing ACP has not been clearly defined in our practice							
0	1	2	3	4	5	6	7
b) My lack of knowledge about ACP and its relationship to advance directives and goals of care discussions							
0	1	2	3	4	5	6	7
c) My lack of knowledge about the legal status of ACP documents in the province							
0	1	2	3	4	5	6	7
d) My lack of knowledge about how to elicit values, beliefs and preferences related to end of life care							
0	1	2	3	4	5	6	7
e) My difficulties in dealing with patient's changing preferences for medical treatments at the end of life							
0	1	2	3	4	5	6	7
f) My difficulties in dealing with uncertainty of prognosis for patients with chronic illness							
0	1	2	3	4	5	6	7
g) My difficulties with defining the right moment to engage patients in ACP							
0	1	2	3	4	5	6	7
h) My having to deal with the emotional impact of ACP conversations in patients							
0	1	2	3	4	5	6	7
i) My belief that physicians are better positioned to initiate ACP							
0	1	2	3	4	5	6	7
j) My belief that patients should initiate this type of discussion							
0	1	2	3	4	5	6	7
k) My belief that advance care plans are too simplified for complicated medical scenarios							
0	1	2	3	4	5	6	7
l) My doubts about the availability or accessibility of ACP documents when they are needed in the future to make medical decisions							
0	1	2	3	4	5	6	7

Site #	Role (ie RN)	Participant #
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	Not At All	Very Little	A Little	A Moderate Amount	A Lot	A Great Deal	An Extreme Amount	Don't Know
m) My fear that these conversations will diminish hope in patients with serious illness	0	1	2	3	4	5	6	7
n) My fear that ACP will negatively impact my relationship with patients	0	1	2	3	4	5	6	7
o) Other, please specify _____	0	1	2	3	4	5	6	7

Barriers Related to Physicians

2. A barrier is something that hinders your ability to effectively engage in ACP with your patients. Below is a list of items that have been identified as physician-related barriers from the literature and focus groups with experts. Please read each one carefully. Reflecting on your most recent month of clinical work, please indicate if the item is a barrier to you (not your colleagues or 'in general') on a scale of 0-6 where 0 means 'not at all' (you believe that it is not a barrier to you) and number 6 means 'an extreme amount' (you believe that your ability to engage your patients in ACP is severely affected by this item).

	Not At All	Very Little	A Little	A Moderate Amount	A Lot	A Great Deal	An Extreme Amount	Don't Know
a) Insufficient access to or availability of physicians to help with ACP (e.g. too busy)	0	1	2	3	4	5	6	7
b) Physician not in agreement with me about when to initiate ACP	0	1	2	3	4	5	6	7
c) Physicians' lack of time to have conversations with patients/family	0	1	2	3	4	5	6	7
d) Physicians' lack of communications skills	0	1	2	3	4	5	6	7
e) Physicians' desire to avoid conflict or strong emotions that may arise during discussions about goals of care	0	1	2	3	4	5	6	7
f) Other, please specify _____	0	1	2	3	4	5	6	7

Barriers Related to Characteristics of the Patient

3. A barrier is something that hinders your ability to effectively engage in ACP with your patients. Below is a list of items that have been identified as patient-related barriers from the literature and focus groups with experts. Please read each one carefully. Reflecting on your most recent month of clinical work, please indicate if the item is a barrier to you (not your colleagues or 'in general') on a scale of 0-6 where 0 means 'not at all' (you believe that it is not a barrier to you) and number 6 means 'an extreme amount' (you believe that your ability to engage your patients in ACP is severely affected by this item).

	Not At All	Very Little	A Little	A Moderate Amount	A Lot	A Great Deal	An Extreme Amount	Don't Know
a) Patients' difficulty accepting their poor prognosis	0	1	2	3	4	5	6	7
b) Patients' difficulty understanding the limitations and complications of life sustaining therapies (mechanical ventilation, CPR, vasopressors, etc.) at the end of life	0	1	2	3	4	5	6	7
c) Patients think ACP is not relevant to them because they are too healthy right now.	0	1	2	3	4	5	6	7
d) Patients not understanding or misinterpreting my reasons for bringing up the topic	0	1	2	3	4	5	6	7
e) Patients' lack of understanding about how treatment decisions are made at the end of life	0	1	2	3	4	5	6	7
f) Patients' fear of upsetting their families by discussing the topic	0	1	2	3	4	5	6	7
g) The patients strong religious convictions	0	1	2	3	4	5	6	7
h) Incapacity of patient because of diminished consciousness or dementia or other cognitive disability	0	1	2	3	4	5	6	7
i) Family unwillingness to support me in engaging the patient in ACP discussions	0	1	2	3	4	5	6	7
j) Other, please specify _____	0	1	2	3	4	5	6	7

Barriers Related to the Healthcare System or External factors

4. A barrier is something that hinders your ability to effectively engage in ACP with your patients. Below is a list of items that have been identified as health care system-related barriers from the literature and focus groups with experts. Please read each one carefully. Reflecting on your most recent month of clinical work, please indicate if the item is a barrier to you (not your colleagues or 'in general') on a scale of 0-6 where 0 means 'not at all' (you believe that it is not a barrier to you) and number 6 means 'an extreme amount' (you believe that your ability to engage your patients in ACP is severely affected by this item).

Not At All	Very Little	A Little	A Moderate Amount	A Lot	A Great Deal	An Extreme Amount	Don't Know
a) Insufficient time during scheduled appointments to deal with this topic							
0	1	2	3	4	5	6	7
b) Limited capacity to honor patients' expectations for care that arise from ACP discussions							
0	1	2	3	4	5	6	7
c) Decreased interaction with patients at end of life due to transfer of care to specialists or others							
0	1	2	3	4	5	6	7
d) Patients getting different messages from the GP and the other specialists involved in patient's care							
0	1	2	3	4	5	6	7
e) Insufficient access to or availability of other health care professionals (social works, nurses or others) to help with ACP							
0	1	2	3	4	5	6	7
f) Lack of ready access to forms and resources for patients							
0	1	2	3	4	5	6	7
g) Inability to electronically transfer patient's advance care plan to acute care							
0	1	2	3	4	5	6	7
h) Other, please specify _____							
0	1	2	3	4	5	6	7

Other Barriers

5. Reflecting on your most recent month of clinical work, please indicate if there are other barriers to engaging your patients in ACP. Please indicate whether the new item is a barrier to you (not your colleagues or 'in general') on a scale of 0-6 where 0 means 'not at all' (you believe that it is not a barrier to you) and number 6 means 'an extreme amount' (you believe that your ability to engage your patients in ACP is severely affected by this item).

Do you have additional barriers to add? **Yes** **No**

	Not At All	Very Little	A Little	A Moderate Amount	A Lot	A Great Deal	An Extreme Amount	Don't Know
a) Other Barrier: _____	0	1	2	3	4	5	6	7
b) Other Barrier: _____	0	1	2	3	4	5	6	7
c) Other Barrier: _____	0	1	2	3	4	5	6	7
d) Other Barrier: _____	0	1	2	3	4	5	6	7

Section 2

Suggestions to Improve Advance Care Planning in Primary Care

6. Reflecting on the most important barriers which you have just rated, in Section 1, what specific suggestions do you have about ways to overcome these barriers and make it easier for you and other health care providers in primary care to talk with patients about ACP?

Section 3

Health Care Providers' Role in ACP in Primary Care

7. Consider that the process of doing ACP can be broken down into the following steps: initiating the conversation, exchanging information, coaching, finalization of the plan, and communicating the plan with family and other health care providers.

Your Willingness, Current Participation, and Confidence in doing ACP with patients

	Rate your willingness to....						Are you doing this for patients 50 years of age and older....						How confident are you that you could....											
	Not at all willing	1	2	3	4	5	6	Very Willing	Not at all	1	2	3	4	5	6	All the time	Not at all confident	1	2	3	4	5	6	Very Confident
a) <u>Initiate discussions</u> about ACP <i>with</i> patients.	0	1	2	3	4	5	6		0	1	2	3	4	5	6		0	1	2	3	4	5	6	
b) Exchange information (e.g., explain ACP, reasons why it is important, related health care laws, etc.) <i>with</i> patients.	0	1	2	3	4	5	6		0	1	2	3	4	5	6		0	1	2	3	4	5	6	
c) Be a <u>decision coach</u> (clarifying values, assisting with weighing options for care, etc.) <i>for</i> patients who are trying to engage in ACP.	0	1	2	3	4	5	6		0	1	2	3	4	5	6		0	1	2	3	4	5	6	
d) Participate in finalization of the ACP plan (preferences of care, values statements, designation of substitute decision maker) <i>with</i> patients and their families.	0	1	2	3	4	5	6		0	1	2	3	4	5	6		0	1	2	3	4	5	6	
e) Help patients communicate their ACP with their families	0	1	2	3	4	5	6		0	1	2	3	4	5	6		0	1	2	3	4	5	6	
f) Help patients communicate their ACP with other health care professionals	0	1	2	3	4	5	6		0	1	2	3	4	5	6		0	1	2	3	4	5	6	

Participation of Other Health Care Professionals in ACP in Primary Care

For each category of primary care-based health care professionals listed below, please rate how acceptable you would find it for that group of individuals to be involved with each of the following activities:

8. Initiating discussions about ACP:

	Extremely Unacceptable	Very Unacceptable	Somewhat Unacceptable	Neither Acceptable nor Unacceptable	Somewhat Acceptable	Very Acceptable	Extremely Acceptable
a) Family Physician	0	1	2	3	4	5	6
b) Family Medicine Resident	0	1	2	3	4	5	6
c) Medical Student	0	1	2	3	4	5	6
d) Nurse	0	1	2	3	4	5	6
e) Advance practice nurse (i.e., clinical nurse specialist or nurse practitioner)	0	1	2	3	4	5	6
f) Social worker	0	1	2	3	4	5	6
g) Home care personnel (i.e., RN, case manager, social worker)	0	1	2	3	4	5	6
h) Other (specify): _____	0	1	2	3	4	5	6

9. **Exchanging information** about ACP (e.g., explain ACP, reasons why it is important, related health care laws, etc.):

	Extremely Unacceptable	Very Unacceptable	Somewhat Unacceptable	Neither Acceptable nor Unacceptable	Somewhat Acceptable	Very Acceptable	Extremely Acceptable
a) Family Physician	0	1	2	3	4	5	6
b) Family Medicine Resident	0	1	2	3	4	5	6
c) Medical Student	0	1	2	3	4	5	6
d) Nurse	0	1	2	3	4	5	6
e) Advance practice nurse (i.e., clinical nurse specialist or nurse practitioner)	0	1	2	3	4	5	6
f) Social worker	0	1	2	3	4	5	6
g) Home care personnel (i.e., RN, case manager, social worker)	0	1	2	3	4	5	6
h) Other (specify): _____	0	1	2	3	4	5	6

10. **Acting as a decision coach** (clarifying values, assisting with weighing options for care, etc.):

a) Family Physician	0	1	2	3	4	5	6
b) Family Medicine Resident	0	1	2	3	4	5	6
c) Medical Student	0	1	2	3	4	5	6
d) Nurse	0	1	2	3	4	5	6
e) Advance practice nurse (i.e., clinical nurse specialist or nurse practitioner)	0	1	2	3	4	5	6
f) Social worker	0	1	2	3	4	5	6
g) Home care personnel (i.e., RN, case manager, social worker)	0	1	2	3	4	5	6
h) Other (specify): _____	0	1	2	3	4	5	6

11. Participating in the finalization of the ACP plans (preferences of care, values statements, designation of substitute decision maker)

	Extremely Unacceptable	Very Unacceptable	Somewhat Unacceptable	Neither Acceptable nor Unacceptable	Somewhat Acceptable	Very Acceptable	Extremely Acceptable
a) Family Physician	0	1	2	3	4	5	6
b) Family Medicine Resident	0	1	2	3	4	5	6
c) Medical Student	0	1	2	3	4	5	6
d) Nurse	0	1	2	3	4	5	6
e) Advance practice nurse (i.e., clinical nurse specialist or nurse practitioner)	0	1	2	3	4	5	6
f) Social worker	0	1	2	3	4	5	6
g) Home care personnel (i.e., RN, case manager, social worker)	0	1	2	3	4	5	6
h) Other (specify): _____	0	1	2	3	4	5	6

12. Assisting the patient in communicating the ACP plan to their family members

a) Family Physician	0	1	2	3	4	5	6
b) Family Medicine Resident	0	1	2	3	4	5	6
c) Medical Student	0	1	2	3	4	5	6
d) Nurse	0	1	2	3	4	5	6
e) Advance practice nurse (i.e., clinical nurse specialist or nurse practitioner)	0	1	2	3	4	5	6
f) Social worker	0	1	2	3	4	5	6
g) Home care personnel (i.e., RN, case manager, social worker)	0	1	2	3	4	5	6
h) Other (specify): _____	0	1	2	3	4	5	6

13. **Assisting the patient in communicating** the ACP plan to other health care professionals.

	Extremely Unacceptable	Very Unacceptable	Somewhat Unacceptable	Neither Acceptable nor Unacceptable	Somewhat Acceptable	Very Acceptable	Extremely Acceptable
a) Family Physician	0	1	2	3	4	5	6
b) Family Medicine Resident	0	1	2	3	4	5	6
c) Medical Student	0	1	2	3	4	5	6
d) Nurse	0	1	2	3	4	5	6
e) Advance practice nurse (i.e., clinical nurse specialist or nurse practitioner)	0	1	2	3	4	5	6
f) Social worker	0	1	2	3	4	5	6
g) Home care personnel (i.e., RN, case manager, social worker)	0	1	2	3	4	5	6
h) Other (specify): _____	0	1	2	3	4	5	6

Section 4

Personal Demographics

1. **What is your age?** _____ years

2. **What is your sex?**

- Male
- Female

3. **Which of the following best describes your ethnic or cultural identity?** (*check only one*)

- Aboriginal (e.g. First Nations, Métis, Inuk/Inuit)
- Arab (e.g. Middle Eastern, North African, etc.)
- Black (e.g. African, Afro-Canadian, Afro-Caribbean, etc.)
- Chinese
- Filipino
- Japanese
- Korean
- Latin American
- South Asian (e.g. East Indian, Pakistani, Sri Lankan, etc.)
- Southeast Asian (e.g. Vietnamese, Cambodian, Malaysian, Laotian, etc.)
- West Asian (e.g. Iranian, Afghan, etc.)
- White (e.g. Caucasian, European Descent, etc.)
- Other: _____

4. **Please indicate your religious background:** (*check only one*)

- | | |
|---|---|
| <input type="checkbox"/> Roman Catholic | <input type="checkbox"/> Buddhist |
| <input type="checkbox"/> Protestant Christian | <input type="checkbox"/> Hindu |
| <input type="checkbox"/> Orthodox Christian | <input type="checkbox"/> Sikh |
| <input type="checkbox"/> Other Christian | <input type="checkbox"/> No religious affiliation |
| <input type="checkbox"/> Muslim | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Jewish | |

5. **How important is spirituality or religion in your life?**

Extremely Unimportant	Very Unimportant	Somewhat Unimportant	Neither Important nor Unimportant	Somewhat Important	Very Important	Extremely Important
1	2	3	4	5	6	7

6. **Role as Allied Health Care Provider?**

- Licensed Practical Nurse/Registered Practical Nurse
- Registered Nurse
- Advance practice nurse (i.e., clinical nurse specialist or nurse practitioner)
- Social Worker
- Other: _____

7. Where did you graduate?

- Canada
- United States
- United Kingdom / Ireland / Australia / New Zealand
- Europe
- Asia
- Middle East
- Central or South America
- Africa
- Other: _____

8. In what year did you become licensed in Canada? _____

9. Do you work in your clinic

- 3 or more days per week
- Fewer than 3 days per week

10. How many years have you worked at your clinic? _____

11. Do you work:

- Only in this clinic
- Across a multi-site network, team or family practice group, or part-time for another organization

12. Are you employed by:

- The physician(s) in your practice
- A primary care group model (e.g. Primary Care Network, Family Health Team)
- A community organization
- Other: _____

13. Have you undertaken extra training (e.g. workshop, course) or certification in palliative care since you became licensed?

- Yes
- No

14. Please rate your current level of skill in having ACP discussions and supporting patients in the finalization of their advance care plans:

Limited (skill not developed)	Fair	Average (skill comparable to colleagues at same level)	Very Good	Expert (skill comparable to an expert)
1	2	3	4	5

15. Please rate your priority (1 to 5) for learning this skill:

Low Priority (not of interest or already mastered)				High Priority (#1 on personal learning agenda)
1	2	3	4	5

— — —	-	— — —	-	— — —
Site #		Role (ie RN)		Participant #

Thank you for your participation in this survey!
Please return this survey in the provided envelope.