

Decision-Making about Goals of Care For Hospitalized **Medical** Patients

ALLIED HEALTH PROFESSIONALS VERSION

We would greatly appreciate your participation in this questionnaire which addresses communication and decision-making about goals of care with seriously ill hospitalized patients and their families.

Goals of Care

We define communication and decision-making about *goals of care* as a conversation in which, ideally, a patient or family member and the healthcare team establish the goals of treatment (e.g., cure, prolongation of life, comfort) and agree upon the types of life sustaining technology that will (or will not) be used to achieve those goals (e.g., CPR, mechanical ventilation, dialysis, intensive care unit admission, feeding tubes, or intravenous hydration).

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

- (1) The importance of various barriers to communication and decision-making about goals of care with seriously ill hospitalized patients and their families
- (2) Your suggestions to improve communication and decision-making about goals of care with these patients and their families
- (3) Your perceived role and the role that others may play in communication and decision-making about goals of care with these patients and their families

- **This questionnaire will take approximately 15 minutes to complete.**
- **Please check the box with the best response unless otherwise requested.**
- **All responses will remain confidential.**

Section 1

Barriers to Discussions about Goals of Care

Scenario: A 70 year old patient who has severe COPD (on home oxygen), is housebound, and requires assistance for most activities of daily living, is admitted to the medical ward under your care with an exacerbation of their COPD. The patient's acute symptoms have resolved. You are uncertain about the patient's goals of care and preferences regarding the use (or non-use) of life sustaining technology.

Barriers Related to the Patient/Family

1. Reflecting on your most recent month on an acute medical ward, for patients such as the one described in the above scenario, please rate the importance of the following barriers in preventing **you** from talking to them and/or their family members about the patient's goals of care. As you rate the importance of each barrier, consider both the magnitude of the barrier and its frequency.

	Extremely Unimportant Barrier	Very Unimportant Barrier	Somewhat Unimportant Barrier	Neither Important nor Unimportant Barrier	Somewhat Important Barrier	Very Important Barrier	Extremely Important Barrier
a) Patient does not have an advance directive	1	2	3	4	5	6	7
b) Patient has an advance directive but it lacks sufficient detail	1	2	3	4	5	6	7
c) Patients' difficulty accepting their poor prognosis	1	2	3	4	5	6	7
d) Patients' difficulty understanding the limitations and complications of life sustaining therapies	1	2	3	4	5	6	7
e) Lack of patient capacity to make decisions about goals of care	1	2	3	4	5	6	7
f) Family members' difficulty accepting their loved one's poor prognosis	1	2	3	4	5	6	7
g) Family members' difficulty understanding the limitations and complications of life sustaining therapies	1	2	3	4	5	6	7
h) Lack of agreement amongst family members about goals of care	1	2	3	4	5	6	7
i) Language barriers	1	2	3	4	5	6	7
j) Differences in approach to discussing goals of care in some cultures	1	2	3	4	5	6	7
k) Family members hesitate to discuss goals of care due to your profession (non MD)	1	2	3	4	5	6	7

Barriers Related to the Role of Allied Health Professionals

2. Reflecting on your most recent month on an acute medical ward, for patients such as the one described in the above scenario, please rate the importance of the following barriers in preventing **you** from talking to them and/or their family members about the patient's goals of care. As you rate the importance of each barrier, consider both the magnitude of the barrier and its frequency.

Extremely Unimportant Barrier	Very Unimportant Barrier	Somewhat Unimportant Barrier	Neither Important nor Unimportant Barrier	Somewhat Important Barrier	Very Important Barrier	Extremely Important Barrier
a) Lack of training to have these conversations (e.g. not sure what to say, etc.)						
1	2	3	4	5	6	7
b) Desire to avoid being sued						
1	2	3	4	5	6	7
c) Desire to maintain hope						
1	2	3	4	5	6	7
d) Current regulations from your professional association (e.g. Professional College) limits your role in having these discussions						
1	2	3	4	5	6	7
e) Current hospital policy limits allied health professionals' role in having these discussions						
1	2	3	4	5	6	7
f) Discomfort with having end of life discussions						
1	2	3	4	5	6	7
g) Loss of therapeutic alliance						
1	2	3	4	5	6	7
h) Suboptimal timing for discussion						
1	2	3	4	5	6	7

Barriers Related to the System or External factors

3. Reflecting on your most recent month on an acute medical ward, for patients such as the one described in the above scenario, please rate the importance of the following barriers in preventing **you** from talking to them and/or their family members about the patient's goals of care. As you rate the importance of each barrier, consider both the magnitude of the barrier and its frequency.

Extremely Unimportant Barrier	Very Unimportant Barrier	Somewhat Unimportant Barrier	Neither Important nor Unimportant Barrier	Somewhat Important Barrier	Very Important Barrier	Extremely Important Barrier
a) Lack of time to have conversations with patients/family						
1	2	3	4	5	6	7
b) Lack of availability of substitute decision maker(s)						
1	2	3	4	5	6	7
c) Uncertainty about who is the substitute decision maker						
1	2	3	4	5	6	7
d) Lack of an appropriate location to maintain patient confidentiality and privacy						
1	2	3	4	5	6	7
e) Lack of pre-existing relationship with patient/family						
1	2	3	4	5	6	7
f) Lack of awareness of what other members of the care team have said						
1	2	3	4	5	6	7
g) Disagreement among healthcare team about goals of care						
1	2	3	4	5	6	7

Other Barriers

4. Reflecting on your most recent month on an acute medical ward, for patients such as the one described in the above scenario, please rate the importance of any **other barriers** in preventing **you** from talking to them and/or their family members about the patient's goals of care. As you rate the importance of each barrier, consider both the magnitude of the barrier and its frequency.

Extremely Unimportant Barrier	Very Unimportant Barrier	Somewhat Unimportant Barrier	Neither Important nor Unimportant Barrier	Somewhat Important Barrier	Very Important Barrier	Extremely Important Barrier
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a) Other Barrier (specify): _____

1	2	3	4	5	6	7
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b) Other Barrier(specify): _____

1	2	3	4	5	6	7
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c) Other Barrier (specify): _____

1	2	3	4	5	6	7
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d) Other Barrier (specify): _____

1	2	3	4	5	6	7
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Barriers Related to the Role of Physicians

5. Reflecting on your most recent month on an acute medical ward, for patients such as the one described in the above scenario, please rate, from your perspective, the importance of the following barriers in preventing **physicians** (staff physicians or residents) from talking to patients and/or their family members about the patient's goals of care. As you rate the importance of each barrier, consider both the magnitude of the barrier and its frequency.

Extremely Unimportant Barrier	Very Unimportant Barrier	Somewhat Unimportant Barrier	Neither Important nor Unimportant Barrier	Somewhat Important Barrier	Very Important Barrier	Extremely Important Barrier
a) In-hospital physicians do not see this as their primary responsibility (e.g., more appropriate for family physician or outpatient specialist)						
1	2	3	4	5	6	7
b) Multiple physicians looking after a single patient						
1	2	3	4	5	6	7
c) Physicians' lack of time to have conversations with patients/family						
1	2	3	4	5	6	7
d) Physicians' lack of communication skills						
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						
1	2	3	4	5	6	7
f) Physicians' attitudes or beliefs about the use of life sustaining technology						
1	2	3	4	5	6	7
g) Other physician-related barriers (please specify):						
<hr style="border: 0.5px solid black;"/>						
1	2	3	4	5	6	7
h) Other physician-related barriers (please specify):						
<hr style="border: 0.5px solid black;"/>						
1	2	3	4	5	6	7

Section 2

Suggestions to Improve Communication and Decision-Making about Goals of Care

1. Reflecting on the barriers which you rated as **Very important** or **Extremely Important** in Section 1, what specific suggestions do you have about ways to overcome these barriers and make it easier for health care providers to talk with patients and their family members about goals of care?

2. What is currently working well to promote communication and decision-making about goals of care between health care providers and patients and their family members?

Section 3

Health Care Providers' Role in Communication and Decision-Making about Goals of Care

Please consider the same scenario as in Section 1: A 70 year old patient who has severe COPD (on home oxygen), is housebound, and requires assistance for most activities of daily living, is admitted to the medical ward under your care with an exacerbation of their COPD. The patient's acute symptoms have resolved. You are uncertain about the patient's goals of care and preferences regarding the use (or non-use) of life sustaining technology.

Your Professional College may currently restrict your involvement in goals of care discussions and may consider that these conversations are out of your scope of practice. However, we would like to understand your willingness to participate in these conversations if those restrictions did not exist.

Consider that the process of communication and decision making can be broken down into the following steps: initiating the conversation, exchanging information, coaching, and deciding.

Willingness to Participate in Communication and Decision-Making about Goals of Care

Extremely Unwilling	Very Unwilling	Somewhat Unwilling	Neither Willing nor Unwilling	Somewhat Willing	Very Willing	Extremely Willing
1. Rate your willingness to <u>initiate discussions</u> about goals of care <i>with</i> patients such as these, and their families.						
1	2	3	4	5	6	7
2. Rate your willingness to <u>exchange information</u> (e.g., disclose diagnosis, prognosis and elicit values) <i>with</i> patients such as these, and their families, who are trying to reach a decision about goals of care.						
1	2	3	4	5	6	7
3. Rate your willingness to be a <u>decision coach</u> (clarifying values, assisting with weighing options for care, etc.) <i>for</i> patients such as these, and their families, who are trying to reach a decision about goals of care.						
1	2	3	4	5	6	7
4. Rate your willingness to participate in <u>making a final decision about</u> goals of care <i>with</i> patients such as these, and their families.						
1	2	3	4	5	6	7

Supportiveness of Work Environment for Participation in Communication and Decision-Making about Goals of Care

Extremely Unsupported	Very Unsupported	Somewhat Unsupported	Neither Supported nor Unsupported	Somewhat Supported	Very Supported	Extremely Supported
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5. How supported are you in your work environment (e.g., by other members of the health care team, your managers, your hospital) to participate discussions about goals of care with patients such as these, and their families?

1	2	3	4	5	6	7
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6. How supported are you in your work environment (e.g., by other members of the health care team, your managers, your hospital) to exchange information (e.g., disclose diagnosis, prognosis and elicit values) with patients such as these, and their families, who are trying to reach a decision about goals of care?

1	2	3	4	5	6	7
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7. How supported are you in your work environment (e.g., by other members of the health care team, your managers, your hospital) to be a decision coach (clarifying values, assisting with weighing options for care, etc.) for patients such as these, and their families, who are trying to reach a decision about goals of care?

1	2	3	4	5	6	7
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8. How supported are you in your work environment (e.g., by other members of the health care team, your managers, your hospital) to participate in making a final decision about goals of care with patients such as these, and their families?

1	2	3	4	5	6	7
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Participation of Health Care Professionals in Communication and Decision-Making about Goals of Care

For each category of 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:

9. Initiating discussions about goals of care:

Extremely Unacceptable	Very Unacceptable	Somewhat Unacceptable	Neither Acceptable nor Unacceptable	Somewhat Acceptable	Very Acceptable	Extremely Acceptable
a) Staff physician						
1	2	3	4	5	6	7
b) Resident/Fellow						
1	2	3	4	5	6	7
c) Bedside nurse						
1	2	3	4	5	6	7
d) Advance practice nurse (i.e., clinical nurse specialist or nurse practitioner)						
1	2	3	4	5	6	7
e) Social worker						
1	2	3	4	5	6	7
f) Physiotherapist						
1	2	3	4	5	6	7
g) Occupational therapist						
1	2	3	4	5	6	7
h) Speech language pathologist						
1	2	3	4	5	6	7
i) Registered dietician						
1	2	3	4	5	6	7
j) Pharmacist						
1	2	3	4	5	6	7
k) Other (specify): _____						
1	2	3	4	5	6	7

10. **Exchanging information** (e.g., disclose diagnosis, prognosis and elicit values):

	Extremely Unacceptable	Very Unacceptable	Somewhat Unacceptable	Neither Acceptable nor Unacceptable	Somewhat Acceptable	Very Acceptable	Extremely Acceptable
a) Staff physician	1	2	3	4	5	6	7
b) Resident/Fellow	1	2	3	4	5	6	7
c) Bedside nurse	1	2	3	4	5	6	7
d) Advance practice nurse (i.e., clinical nurse specialist or nurse practitioner)	1	2	3	4	5	6	7
e) Social worker	1	2	3	4	5	6	7
f) Physiotherapist	1	2	3	4	5	6	7
g) Occupational therapist	1	2	3	4	5	6	7
h) Speech language pathologist	1	2	3	4	5	6	7
i) Registered dietician	1	2	3	4	5	6	7
j) Pharmacist	1	2	3	4	5	6	7
k) Other (specify): _____	1	2	3	4	5	6	7

11. **Decision coach** (clarifying values, assisting with weighing options for care, etc.):

	Extremely Unacceptable	Very Unacceptable	Somewhat Unacceptable	Neither Acceptable nor Unacceptable	Somewhat Acceptable	Very Acceptable	Extremely Acceptable
a) Staff physician	1	2	3	4	5	6	7
b) Resident/Fellow	1	2	3	4	5	6	7
c) Bedside nurse	1	2	3	4	5	6	7
d) Advance practice nurse (i.e., clinical nurse specialist or nurse practitioner)	1	2	3	4	5	6	7
e) Social worker	1	2	3	4	5	6	7
f) Physiotherapist	1	2	3	4	5	6	7
g) Occupational therapist	1	2	3	4	5	6	7
h) Speech language pathologist	1	2	3	4	5	6	7
i) Registered dietician	1	2	3	4	5	6	7
j) Pharmacist	1	2	3	4	5	6	7
k) Other (specify): _____	1	2	3	4	5	6	7

12. **Making a final decision** about goals of care:

	Extremely Unacceptable	Very Unacceptable	Somewhat Unacceptable	Neither Acceptable nor Unacceptable	Somewhat Acceptable	Very Acceptable	Extremely Acceptable
a) Staff physician	1	2	3	4	5	6	7
b) Resident/Fellow	1	2	3	4	5	6	7
c) Bedside nurse	1	2	3	4	5	6	7
d) Advance practice nurse (i.e., clinical nurse specialist or nurse practitioner)	1	2	3	4	5	6	7
e) Social worker	1	2	3	4	5	6	7
f) Physiotherapist	1	2	3	4	5	6	7
g) Occupational therapist	1	2	3	4	5	6	7
h) Speech language pathologist	1	2	3	4	5	6	7
i) Registered dietician	1	2	3	4	5	6	7
j) Pharmacist	1	2	3	4	5	6	7
k) Other (specify): _____	1	2	3	4	5	6	7

Section 4 Personal Demographics

1. Describe your educational background:

(Check all that apply)

- Social Worker
- Physiotherapist
- Speech-Language Pathology Professional
- Occupational Therapist
- Pharmacist
- Registered dietician
- Other (please specify): _____

2. On average, your work on the inpatient medical ward is equivalent to what percentage of one full-time equivalent?

_____ % 1 FTE

3. How many years have you worked as an allied health professional on an acute medical ward?

_____ years

4. Where did you complete your professional education?

(Select only one)

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

5. Please rank your current level of skill in having goals of care discussions with patients and families.

Limited (skill not developed)	Fair	Average (skill comparable to colleagues at same level)	Very Good	Expert (skill comparable to a palliative care physician)
1	2	3	4	5

6. Please rank 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

7.a) Have you received any formal training regarding communication with patients and families about goals of care?

- Yes → If yes, please answer question 7b
- No → Go to question 8

7.b) Please rate the quality of the formal training you received regarding communication with patients and families about goals of care

Extremely Low	Very Low	Moderately Low	Neither High nor Low	Moderately High	Very High	Extremely High
1	2	3	4	5	6	7

8. What is your age?

_____ years

9. What is your sex?

- Male
- Female

10. Do you see yourself as:

(Select only one)

- White
- South Asian (e.g., East Indian, Pakistani, Sri Lankan, etc.)
- Chinese
- Black
- Filipino
- Latin American
- Arab
- Southeast Asian (e.g., Vietnamese, Cambodian, Malaysian, Laotian, etc.)
- West Asian (e.g., Iranian, Afghan, etc.)
- Korean
- Japanese
- Native American
- Other: _____

11. Please indicate your religious background:

(Select only one)

- Roman Catholic
- Protestant Christian
- Orthodox Christian
- Other Christian
- Muslim
- Jewish
- Buddhist
- Hindu
- Sikh
- No religious affiliation
- Other: _____

12. 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

13. Have you had personal experience with a close family member or friend being hospitalized in an intensive care unit?

- Yes
- No

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