

The Respecting Choices Next Steps ACP Facilitator Certification Program: A Description of Key Components

The following four sections below describe the key components of the Respecting Choices Next Steps Advance Care program that are used in the FACE-TC intervention program. All Respecting Choices® materials are created and distributed by Gunderson Health System in La Crosse, WI. The Respecting Choices® ACP Facilitator tools and other curriculum (online) can be purchased at: <http://www.gundersenhealth.org/respecting-choices/training-and-certification/online-courses/facilitator-curriculum>

I. Next Steps Advance Care Planning Interview Tool

This tool is designed to provide a structured approach to assessing the planning needs of patients with advanced illness, and/or their chosen healthcare agent/parent/guardian. Each stage of the interview has a specific purpose. The flow of the interview provides an effective “roadmap” that skillfully and respectfully guides the patient/parent through the process of understanding, reflection, and discussion of personal goals and values, to making informed and thoughtful healthcare decisions.

The NS approach *first* assists patients/parents to reflect upon, and verbalize goals and values, *then* uses this information to guide them in making decisions consistent with these goals and values.

The stages of the interview are as follows:

<i>Stage</i>	<i>Goals</i>
I. Assess illness beliefs, goals, and values	Assess patient/parent understanding of the patient’s health condition; identifying gaps, fears, and concerns. Explore goals and values related to hope and “living well”. Develop trust and open dialogue. Provide context for more specific decision making
II. Explore experiences	Identify how past experiences have helped shape patient goals and values about life sustaining treatment. Clarify the need for more discussion to assist agent in making future health care decisions
III. Explain purpose of Advance Care Planning (ACP)	Link Stage 1 and II discussion themes to assist patient/parent to understand the need for ACP and more

	specific decision making guidance
IV. Clarify goals for life-sustaining preferences	Assist patient/parent to clarify goals of care in “bad outcome” situations, using a decision aide, the <i>Statement of Treatment Preference</i> form. Provide information on treatment benefits/burdens as needed. Prepare and support healthcare agent
V. Summarize	Review what has been learned and how it will be useful to both patient/parent and agent.
VI. Develop follow-up plan	Develop plan to address identified needs, referrals, and communication of preferences

II. The *Statement of Treatment Preference* Form

Stage 4 of the NS interview is intended to assist patients/parents in making informed health care decisions using a decision aide, the Statement of Treatment Preference (SOTP) form and skills in promoting discussion. . The SOTP describes several situations of potential “bad outcomes” that could occur as a complication of the patient’s advanced illness. Respecting Choices has created the following SOTP’s. Facilitators will choose the SOTP that best aligns with the patient’s illness; the one that is most comprehensive for the patient’s needs.

- General
- Heart Disease
- Lung Disease
- Kidney Disease
- Life-limiting Cancer

III. NS Facilitator Competency Checklist

This checklist identifies all of the skills that must be demonstrated in order to achieve certification as a NS facilitator. It includes skills to deliver each stage of the NS interview, as well as general interview skills that enhance the quality of the interview (e.g., listening, exploring the meaning of words and phrases, paraphrasing, and verbalizing empathy). This competency checklist is used to communicate clear expectations for certifications, to provide consistent feedback on performance, to monitor fidelity in delivering the interview, and to evaluate video or in-person role play demonstrations

IV. The Next Steps Facilitator Certification Manual

This manual contains necessary background information in preparation for the NS Facilitator Certification classroom course. It includes the following content:

- Chapter 1 Respecting Choices Next Steps ACP Facilitator Certification Program: Overview and Program Description
- Chapter 2: Overview of Respecting Choices & History and Development of the NS ACP Intervention
- Chapter 3: The Next Steps ACP Interview: Description and Strategies for Effective Communication
- Chapter 4: Disease-specific information
- Chapter 5: Course handouts

Table 1: Description of Family CEntered (FACE) Advance Care Planning Intervention.

	Session 1	Session 2	Session 3
Session Foundation	Lyon Family Centered Advance Care Planning (ACP) Survey - Adolescent and Surrogate Versions © to set stage for EOL conversation.	<i>Next Steps: Advance Care Planning Respecting Choices Interview Interview®</i> (Briggs and Hammes, 2012-2013)	The Five Wishes © is a legal document that helps a person express how they want to be treated if they are seriously ill and unable to speak for him/herself. Unique among living will and health agent forms - it looks to all of a person's needs: medical, personal, emotional, spiritual.
Session Goals	<ol style="list-style-type: none"> 1. To assess the adolescents' values, spiritual and other beliefs, and life experiences with illness and EOL care. 2. To assess when to initiate ACP planning. 	<ol style="list-style-type: none"> 1. To facilitate conversations and shared decision-making between the adolescent and surrogate about palliative care, providing an opportunity to express fears, values, spiritual and other beliefs and goals with regard to death and dying 2. To prepare the guardian/surrogate to be able to fully represent the adolescent's wishes 	<ol style="list-style-type: none"> 1. Which person the teen wants to make health care decisions for him/her; 2. The kind of medical treatment the teen wants; 3. How comfortable the teen wants to be; 4. How the teen wants people to treat him/her. 5. What teen wants loved ones to know; 6. Any spiritual or religious concerns teen may have.
Session Process	<ol style="list-style-type: none"> 1. Orient family to study and issues. 2. Adolescent is surveyed privately; 3. Surrogate is surveyed privately with regard to what they believe their adolescent prefers. 	<p><u>Stage 1</u> assesses teen's understanding of condition;</p> <p><u>Stage 2</u> explores teen's philosophy about EOL decision-making;</p> <p><u>Stage 3</u> reviews rationale for future decisions teen would want surrogate to act on;</p> <p><u>Stage 4</u> uses Statement of Treatment Preferences to describe scenarios/choices;</p> <p><u>Stage 5</u> summarizes need for future conversations . Referrals are made.</p>	<p>For adolescents under the age of 18, the Five Wishes © must be signed by their legal guardian.</p> <p>Processes, such as labeling feelings and concerns, as well as finding solutions to any identified problem, are facilitated. Appropriate referrals .</p> <p>*These sessions may include other family members or loved ones.</p>



Draft

The Lyon Advance Care Planning Survey - Patient Version Form

☐ Site 1 ☐ Site 2 ☐ Site 3 ☐ Site 4

Study ID:

☒ Adolescent

Date:

 / /

MM

DD

YYYY

 -

Family #

Person #

Participant initials:

Visit#:

Advance Planning and Preparation

1. Have you ever written down any thoughts about your future health plans?

☐ Yes, definitely ☐ Very probably ☐ Probably ☐ Probably not ☐ Definite no ☐ Don't know

2. Advance directives allow people to make their health care choices known before becoming very ill or dying.

a. Have you ever heard about and completed a Health Care Power of Attorney (HCPA), in which you name someone to make decisions about your health care in case you could not?

☐ Have heard about and completed ☐ Have heard about but not completed

☐ Have not heard about ☐ Don't know

b. Have you ever heard about and completed an Advance Directive, such as the Five Wishes?

☐ Have heard about and completed ☐ Have heard about but not completed

☐ Have not heard about ☐ Don't know

3a. Whether you have completed any advance directives/pre-plans or not, have you talked about your wishes for care at the end of life with anyone? Select all that apply.

☐ Spouse/partner ☐ Parents ☐ Siblings (brother/sister) ☐ Friends

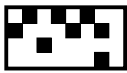
☐ Boyfriend/girlfriend ☐ Lawyer ☐ Primary physician ☐ Clergy (such as minister, rabbi, iman etc.)

☐ Other, please describe

☐ Have not talked with anyone

3b. Do you have any children? ☐ Yes (proceed to question 3c)

☐ No (proceed to question 4)



Draft

The Lyon Advance Care Planning Survey - Patient Version

Form

Family #

 0

Person #

Visit#

Date:

MM

DD

YYYY

3c. If you have children, have you talked about plans for who will take care of your child/children, if you are not able to? Select all that apply.

- ☐ Spouse/partner ☐ Parents ☐ Siblings (brother/sister) ☐ Friends
☐ Boyfriend/girlfriend ☐ Lawyer ☐ Primary physician ☐ Clergy (such as minister, rabbi, iman etc.)
☐ Other, please describe
☐ Have not talked with anyone

4. If you were very ill and knew that you would not get better, who would you want to be involved in decisions about your end-of-life care? Select all that apply.

- ☐ Myself ☐ My family ☐ My doctor
☐ Someone else, please specify:

5. When do you think it is the best time to bring up end-of-life decisions?

- ☐ Before getting sick, while healthy
☐ When first diagnosed with a life-threatening illness
☐ When first sick from a life-threatening illness
☐ When first hospitalized with a life-threatening illness
☐ If dying
☐ All of the above
☐ Don't know
☐ Other

6. Who are the best people/best person on the treatment team to bring it up with you? Select all that apply.

- ☐ Physician ☐ Nurse practitioner ☐ Nurse ☐ Social worker ☐ Psychologist
☐ Case manager ☐ Chaplain ☐ Patient advocate
☐ Other

7. Do you believe that once you make an important medical decision, for example, to be put on a respirator, a machine that breathes for you, that you would be able to change your mind?

- ☐ Yes, definitely ☐ Very probably ☐ Probably ☐ Probably not ☐ Definite no ☐ Don't know



Draft

The Lyon Advance Care Planning Survey - Patient Version

Form

			-	0
--	--	--	---	---

Family #

Person #

--	--

Visit#

Date:

--	--

 /

--	--

 /

--	--	--	--

MM DD YYYY

8. Do you think your doctor or the hospital will respect your wishes, that is, do what you want about medical care?

- ☐ Yes, definitely ☐ Very probably ☐ Probably ☐ Probably not ☐ Definitely no ☐ Don't know

9. Do you think your parent/guardian/surrogate understands your wishes?

- ☐ Yes, definitely ☐ Very probably ☐ Probably ☐ Probably not ☐ Definitely no ☐ Don't know

10. Do you think your parent/guardian/surrogate will respect your wishes, that is, do what you want about your medical care?

- ☐ Yes, definitely ☐ Very probably ☐ Probably ☐ Probably not ☐ Definitely no ☐ Don't know

Thoughts about Death and Dying

11. How often has death and dying been talked about in your family?

- ☐ Very often ☐ Often ☐ Occasionally ☐ Rarely ☐ Never ☐ Don't know

12. How comfortable are you talking about death?

- ☐ Very comfortable
☐ Somewhat comfortable
☐ Neither comfortable or uncomfortable
☐ Not very comfortable
☐ Not at all comfortable
☐ Don't know



Draft

The Lyon Advance Care Planning Survey - Patient Version

Form

 -

Family # Person #

Visit#

 Date: / /

MM

DD

YYYY

13. How likely are you to ...

Very likely	Somewhat likely	Neither likely or unlikely	Not very likely	Not at all likely
-------------	-----------------	----------------------------	-----------------	-------------------

a. Attend funerals or memorial services when a loved one, friend or classmate dies

☐☐☐☐☐☐

b. Avoid medical checkups because you are afraid the doctor will find "something serious"

☐☐☐☐☐☐

c. Speak freely to loved ones about death and dying

☐☐☐☐☐☐

d. Visit or telephone a friend or relative who has recently lost a loved one in order to see how they are doing

☐☐☐☐☐☐

e. Preplan your own funeral, for example, choose someone to speak or choose the music you would want

☐☐☐☐☐☐

14. How afraid, if at all, are you of...

Very afraid	Somewhat afraid	Neither afraid nor not afraid	Not very afraid	Not at all afraid
-------------	-----------------	-------------------------------	-----------------	-------------------

a. Dying from a long term illness

☐☐☐☐☐☐

b. Dying suddenly, such as an accident, or being killed

☐☐☐☐☐☐

c. Dying alone

☐☐☐☐☐☐

d. Dying in an institution such as a nursing home or hospital

☐☐☐☐☐☐

e. Dying painfully

☐☐☐☐☐☐
 Completed by: Initials



Draft

The Lyon Advance Care Planning Survey - Patient Version Form

☐ Site 1 ☐ Site 2 ☐ Site 3 ☐ Site 4

Study ID:

☒ Adolescent

Date:

 / /

MM

DD

YYYY

 -

Family #

Person #

Participant initials:

Visit#:

15. How strongly do you agree or disagree that...

a. Dying is an important part of life

- ☐ Strongly agree ☐ Agree ☐ Neither agree or disagree
☐ Disagree ☐ Strongly disagree ☐ Don't know

b. If someone could tell me when I would die, I would want to know.

- ☐ Strongly agree ☐ Agree ☐ Neither agree or disagree
☐ Disagree ☐ Strongly disagree ☐ Don't know

16. When you think about death and dying, how concerned are you that...

a. The family's money won't last

- ☐ Very concerned ☐ Concerned ☐ Neither concerned nor unconcerned
☐ Not concerned ☐ Not at all concerned ☐ Don't know

b. I will be a burden to, or overload, my family or friends

- ☐ Very concerned ☐ Concerned ☐ Neither concerned nor unconcerned
☐ Not concerned ☐ Not at all concerned ☐ Don't know

17. Which of the following health problems, if any, do you think are worse than death?

Select all that apply.

- ☐ Living with great pain
- ☐ Total physical dependency on others, for example, being in a wheelchair
- ☐ Not being able to communicate my wishes and/or care to family members, for example, being in a coma
- ☐ None are worse than death



Draft

The Lyon Advance Care Planning Survey - Patient Version

Form

			0
--	--	--	---

Family #

Person #

--	--

Visit#

--	--	--	--	--	--	--	--

Date:

MM

DD

YYYY

Dealing with Dying

18. How important would each of the following be to you if you were dealing with your own dying?

a. Family/friends visiting you

- | | | |
|--|--|---|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important | <input type="radio"/> Neither important nor unimportant |
| <input type="radio"/> Not very important | <input type="radio"/> Not at all important | <input type="radio"/> Don't know |

b. Being able to stay in your own home

- | | | |
|--|--|---|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important | <input type="radio"/> Neither important nor unimportant |
| <input type="radio"/> Not very important | <input type="radio"/> Not at all important | <input type="radio"/> Don't know |

c. Honest answers from your doctor

- | | | |
|--|--|---|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important | <input type="radio"/> Neither important nor unimportant |
| <input type="radio"/> Not very important | <input type="radio"/> Not at all important | <input type="radio"/> Don't know |

d. Comfort from church services or persons such as a minister, priest, imam, or rabbi

- | | | |
|--|--|---|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important | <input type="radio"/> Neither important nor unimportant |
| <input type="radio"/> Not very important | <input type="radio"/> Not at all important | <input type="radio"/> Don't know |

e. Planning your own funeral

- | | | |
|--|--|---|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important | <input type="radio"/> Neither important nor unimportant |
| <input type="radio"/> Not very important | <input type="radio"/> Not at all important | <input type="radio"/> Don't know |

f. Being able to complete an advance directive that would let loved ones know your wishes, if you were unable to speak for yourself

- | | | |
|--|--|---|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important | <input type="radio"/> Neither important nor unimportant |
| <input type="radio"/> Not very important | <input type="radio"/> Not at all important | <input type="radio"/> Don't know |

g. Fulfilling personal goals/pleasures

- | | | |
|--|--|---|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important | <input type="radio"/> Neither important nor unimportant |
| <input type="radio"/> Not very important | <input type="radio"/> Not at all important | <input type="radio"/> Don't know |

h. Reviewing your life history with your family

- | | | |
|--|--|---|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important | <input type="radio"/> Neither important nor unimportant |
| <input type="radio"/> Not very important | <input type="radio"/> Not at all important | <input type="radio"/> Don't know |

i. Having health care professionals visit you at your home

- | | | |
|--|--|---|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important | <input type="radio"/> Neither important nor unimportant |
| <input type="radio"/> Not very important | <input type="radio"/> Not at all important | <input type="radio"/> Don't know |

j. Understanding your treatment choices

- | | | |
|--|--|---|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important | <input type="radio"/> Neither important nor unimportant |
| <input type="radio"/> Not very important | <input type="radio"/> Not at all important | <input type="radio"/> Don't know |



Draft

The Lyon Advance Care Planning Survey - Patient Version

Form

 -

Family # Person #

Visit#

Date: / /

MM

DD

YYYY

19. How important are each of the following to you when you think about dying?

a. Being physically comfortable

- | | | |
|--|--|---|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important | <input type="radio"/> Neither important nor unimportant |
| <input type="radio"/> Not very important | <input type="radio"/> Not at all important | <input type="radio"/> Don't know |

b. Being free from pain

- | | | |
|--|--|---|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important | <input type="radio"/> Neither important nor unimportant |
| <input type="radio"/> Not very important | <input type="radio"/> Not at all important | <input type="radio"/> Don't know |

c. Saying everything I want to say to people in my family

- | | | |
|--|--|---|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important | <input type="radio"/> Neither important nor unimportant |
| <input type="radio"/> Not very important | <input type="radio"/> Not at all important | <input type="radio"/> Don't know |

d. Being at peace spiritually

- | | | |
|--|--|---|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important | <input type="radio"/> Neither important nor unimportant |
| <input type="radio"/> Not very important | <input type="radio"/> Not at all important | <input type="radio"/> Don't know |

e. Not being a burden to loved ones

- | | | |
|--|--|---|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important | <input type="radio"/> Neither important nor unimportant |
| <input type="radio"/> Not very important | <input type="radio"/> Not at all important | <input type="radio"/> Don't know |

f. Knowing how to say good bye

- | | | |
|--|--|---|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important | <input type="radio"/> Neither important nor unimportant |
| <input type="radio"/> Not very important | <input type="radio"/> Not at all important | <input type="radio"/> Don't know |

g. Having a sense of my own worth or value

- | | | |
|--|--|---|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important | <input type="radio"/> Neither important nor unimportant |
| <input type="radio"/> Not very important | <input type="radio"/> Not at all important | <input type="radio"/> Don't know |

h. Being off machines that extend life, such as life support

- | | | |
|--|--|---|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important | <input type="radio"/> Neither important nor unimportant |
| <input type="radio"/> Not very important | <input type="radio"/> Not at all important | <input type="radio"/> Don't know |

i. Dying a natural death

- | | | |
|--|--|---|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important | <input type="radio"/> Neither important nor unimportant |
| <input type="radio"/> Not very important | <input type="radio"/> Not at all important | <input type="radio"/> Don't know |



Draft

The Lyon Advance Care Planning Survey - Patient Version
Form #

-

Family #

Person #

Visit#:

Date: / /

MM

DD

YYYY

20. If death were likely to happen in the next few weeks, and you could choose where to die, where would you MOST want to die?

- ☐ At home
- ☐ In an assisted-living facility
- ☐ In a hospital
- ☐ In a nursing home
- ☐ In a residential hospice (hospice services provided by a hospice-owned facility)
- ☐ Don't know

21. Below are some statements related to pain near the end-of-life that have been expressed by people. How strongly do you agree or disagree with each statement?

a. I am afraid the doctor may not believe I am in pain and treat my pain

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree or disagree
- ☐ Disagree
- ☐ Strongly disagree
- ☐ Don't know

b. I would only take pain medicines when the pain is severe

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree or disagree
- ☐ Disagree
- ☐ Strongly disagree
- ☐ Don't know

c. I am afraid I will become addicted to the pain medicines over time

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree or disagree
- ☐ Disagree
- ☐ Strongly disagree
- ☐ Don't know

Completed by: Initials



Draft

The Lyon Advance Care Planning Survey - Patient Version

Form

☐ Site 1 ☐ Site 2 ☐ Site 3 ☐ Site 4

Study ID:

☒ Adolescent

Date: / /
 MM DD YYYY

Family # - Person #

Participant initials:

Visit#:

d. I would take the lowest amount of medicine possible to save larger doses for later when the pain is worse

- ☐ Strongly agree ☐ Agree ☐ Neither agree or disagree
☐ Disagree ☐ Strongly disagree ☐ Don't know

e. I am afraid I would be given too much pain medicine

- ☐ Strongly agree ☐ Agree ☐ Neither agree or disagree
☐ Disagree ☐ Strongly disagree ☐ Don't know

22. Have you heard of hospice services?

- ☐ Yes
☐ No (If no, skip Q23 and Q24)

23. How did you learn about hospice services?

- ☐ I know someone who used hospice services
☐ I have used hospice services myself
☐ I am/was a hospice volunteer
☐ I heard from a health care professional
☐ I read literature/newspaper/TV/radio/other media
☐ I heard from others
☐ No response

24. If you were dying, would you want hospice support?

- ☐ Yes ☐ No ☐ Don't know/not sure ☐ No response

Spiritual Well -Being

25. Do you consider yourself...? (If not religious/spiritual, skip Q26 and Q27)

- ☐ Very religious/spiritual ☐ Somewhat religious/spiritual ☐ Not very religious/spiritual
☐ Not religious/spiritual ☐ No response
☐ Don't know



Draft

The Lyon Advance Care Planning Survey - Patient Version

Form

-

Family # Person #

Visit#

Date: / /

MM

DD

YYYY

26. How often do you attend religious or spiritual services?

- ☐ Always ☐ Very often ☐ Sometimes ☐ Rarely ☐ Never ☐ Don't now

27. How often does religion or spirituality help you face your fears or do what you were afraid to do?

- ☐ Everyday ☐ A few times a week ☐ A few times a month ☐ Rarely ☐ Never ☐ Don't know

About You

28. How many times in your life have you been seen at an emergency room?

Number of emergency room visits

29. How many times in your life have you ever been hospitalized?

29a. How many nights have you spent in a hospital in the last year?

29b. How many of those hospitalizations were psychiatric hospitalizations? For example, for behavior problems or depression.

29c. How many nights have you spent psychiatrically hospitalized in the past year?

DURING THE PAST 30 DAYS

30. HOW MANY NIGHTS did you stay in a hospital?

- ☐ 0 ☐ 1-2 ☐ 3-5 ☐ 6-10 ☐ 11-20 ☐ >20

31. How healthy are you feeling right now?

- ☐ Excellent health ☐ Very good health ☐ Good health
☐ Fair health ☐ Poor health ☐ Don't know

32. Is your mother alive? ☐ Yes ☐ No ☐ Don't know

32. a. Is your father alive? ☐ Yes ☐ No ☐ Don't know



Draft

The Lyon Advance Care Planning Survey - Patient Version

Form

			0
--	--	--	---

Family #

Person #

--	--

Visit#

Date:

 /

 /

MM

DD

YYYY

F. Transition/End of Session

Thank you. That was the last question. I want to let you know 3 things.

First, patients do have a right to change their minds. People do change their minds sometimes as they become more ill.

Second, patients do have a right to important treatments like pain and comfort care, even if they decide to allow a natural death, that is, not to be kept alive by machines or feeding tubes.

Third, patients are not abandoned by their health care team if they decide they want to allow a natural death. Patients may still have regular visits at the hospital and be seen at home.

Do you have any questions? Now you are going to meet with our Research Assistant to answer some questions about how you experienced this session.

Acknowledgements

I would like to acknowledge AARP Knowledge Management (<http://research.aarp.org>) who gave me permission to adapt their North Carolina End of Life Survey of their adult members, so that I could expand an earlier survey of adolescents.

I would also like to acknowledge Edinger & Smucker whose 1992 advance directives survey of adult outpatients (J Fam Pract 1992/ 35:650-653) was also adapted with their permission, so that I could study adolescents.

This form may be reproduced for personal use. (c)Lyon 2006

For correspondence, please contact Maureen E. Lyon, PhD email: mlyon@childrensnational.org

Completed by:

 Initials



Draft

The Lyon Advance Care Planning Survey - Surrogate/Proxy Form

☐ Site 1 ☐ Site 2 ☐ Site 3 ☐ Site 4

Study ID:

Date:

 / /
MM DD YYYY

☐ Surrogate/proxy(1)

☐ Surrogate/proxy(2)

 -

Family # Person #

Participant initials:

Visit#:

Advance Planning and Preparation

1. Has _____ (youth) ever written down any thoughts about his or her future health plans?

☐ Yes, definitely ☐ Very probably ☐ Probably ☐ Probably not ☐ Definitely no ☐ Don't know

2. Advance directives allow people to make their health care choices known before becoming very ill or dying.

a. Has _____ (youth) ever heard about and completed a Health Care Power of Attorney (HCPA), in which he/she names someone to make decisions about his/her health care in case he/she could not?

☐ Have heard about and completed ☐ Have heard about but not completed

☐ Have not heard about ☐ Don't know

b. Has _____ (youth) ever heard about and completed an Advance Directive, such as the Five Wishes?

☐ Have heard about and completed ☐ Have heard about but not completed

☐ Have not heard about ☐ Don't know

3a. Whether _____ (youth) has completed any advance directives/pre-plans or not, has he/she talked about his/her wishes for care at the end of life with anyone? Select all that apply.

- ☐ Spouse/partner ☐ Parents ☐ Siblings (brother/sister) ☐ Friends
☐ Boyfriend/girlfriend ☐ Lawyer ☐ Primary physician ☐ Clergy (such as iman, minister, rabbi, etc.)
☐ Other, please describe

☐ Have not talked with anyone

☐ Don't know

3b. Does _____ (youth) have any children? ☐ Yes (proceed to question 3c)

☐ No (proceed to question 4)



Draft

The Lyon Advance Care Planning Survey - Surrogate/Proxy Form

			-	
--	--	--	---	--

Family # Person #

--	--

Visit#

Date:

--	--

 /

--	--

 /

--	--	--	--

MM

DD

YYYY

3c. If _____ (youth) has children, has _____ (youth) talked about plans for who will take care of the child/children, if _____ (youth) is not able to? Select all that apply.

- ☐ Spouse/partner ☐ Parents ☐ Siblings (brother/sister) ☐ Friends
☐ Boyfriend/girlfriend ☐ Lawyer ☐ Primary physician ☐ Clergy (such as minister, rabbi, iman etc.)
☐ Other, please describe

--

☐ Have not talked with anyone
☐ Don't know

4. If _____ (youth) was very ill and knew that he/she would not get better, who would _____ (youth) want to be involved in decisions about his/her end-of-life care? Select all that apply.

- ☐ Him/herself ☐ His/her family ☐ His/her doctor
☐ Someone else, please specify:

--

5. When do you think _____ (youth) thinks is the best time to bring up end-of-life decisions?

- ☐ Before getting sick, while healthy
☐ When first diagnosed with a life-threatening illness
☐ When first sick from a life-threatening illness
☐ When first hospitalized with a life-threatening illness
☐ If dying
☐ All of the above
☐ Don't know
☐ Other

--

6. Who do you think _____ (youth) thinks are the best people/best person on the treatment team to bring it up with him/her? Select all that apply.

- ☐ Physician ☐ Nurse practitioner ☐ Nurse ☐ Social worker ☐ Psychologist
☐ Case manager ☐ Chaplain ☐ Other

--



Draft

The Lyon Advance Care Planning Survey - Surrogate/Proxy Form

-
Family # Person #

Visit#

Date: / /
MM DD YYYY

7. Do you believe that _____ (youth) believes that once he/she makes an important medical decision, for example, to be put on a respirator, a machine that breathes for him/her, that _____ (youth) would be able to change his/her mind?

☐ Yes, definitely ☐ Very probably ☐ Probably ☐ Probably not ☐ Definitely no ☐ Don't know

8. Do you think that _____ (youth) thinks the doctor or the hospital will respect _____ (youth)'s wishes, that is, do what _____ (youth) wants about medical care?

☐ Yes, definitely ☐ Very probably ☐ Probably ☐ Probably not ☐ Definitely no ☐ Don't know

9. Do you think that _____ (youth) thinks you understand _____ (youth)'s wishes?

☐ Yes, definitely ☐ Very probably ☐ Probably ☐ Probably not ☐ Definitely no ☐ Don't know

10. Do you think that _____ (youth) thinks you will respect _____ (youth)'s wishes, that is, do what he/she wants about his/her medical care?

☐ Yes, definitely ☐ Very probably ☐ Probably ☐ Probably not ☐ Definitely no ☐ Don't know

Thoughts about Death and Dying

11. How often has death and dying been talked about in _____ (youth's) family?

☐ Very often ☐ Often ☐ Occassionally ☐ Rarely ☐ Never ☐ Don't know

12. How comfortable is _____ (youth) with talking about death?

☐ Very comfortable
☐ Somewhat comfortable
☐ Neither comfortable or uncomfortable
☐ Not at very comfortable
☐ Not at all comfortable
☐ Don't know



Draft

The Lyon Advance Care Planning Survey - Surrogate/Proxy Form

Family # - Person #

Visit#

Date: MM / DD / YYYY

13. How likely is _____ (youth) to ...

Very likely Somewhat likely Neither likely or unlikely Not very likely Not at all likely Don't know

a. Attend funerals or memorial services when a loved one or friend dies

☐ ☐ ☐ ☐ ☐ ☐

b. Avoid medical checkups because _____ (youth) is afraid the doctor will find "something serious"

☐ ☐ ☐ ☐ ☐ ☐

c. Speak freely to loved ones about death and dying

☐ ☐ ☐ ☐ ☐ ☐

d. Visit or telephone a friend or relative who has recently lost a loved one in order to see how they are doing

☐ ☐ ☐ ☐ ☐ ☐

e. Preplan his/her own funeral, for example, choose someone to speak or choose the music he/she would like

☐ ☐ ☐ ☐ ☐ ☐

14. How afraid, if at all, is he/she of...

Very afraid Somewhat afraid Neither afraid nor not afraid Not very afraid Not at all afraid Don't know

a. Dying from a long term illness

☐ ☐ ☐ ☐ ☐ ☐

b. Dying suddenly, such as an accident, or being killed

☐ ☐ ☐ ☐ ☐ ☐

c. Dying alone

☐ ☐ ☐ ☐ ☐ ☐

d. Dying in an institution such as a

☐ ☐ ☐ ☐ ☐ ☐

e. Dying painfully

☐ ☐ ☐ ☐ ☐ ☐

Completed by: Initials



Draft

The Lyon Advance Care Planning Survey - Surrogate/Proxy Form

☐ Site 1 ☐ Site 2 ☐ Site 3 ☐ Site 4

Study ID:

Date:

☐ Surrogate/proxy(1)

☐ Surrogate/proxy(2)

MM

DD

YYYY

Participant initials:

Visit#:

Family # Person #

15. How strongly do you think _____(youth) would agree or disagree that...

a. Dying is an important part of life

- ☐ Strongly agree ☐ Agree ☐ Neither agree or disagree
☐ Disagree ☐ Strongly disagree ☐ Don't know

b. If someone could tell _____(youth) when he/she would die, _____(youth) would want to know.

- ☐ Strongly agree ☐ Agree ☐ Neither agree or disagree
☐ Disagree ☐ Strongly disagree ☐ Don't know

16. When _____youth thinks about death and dying, how concerned do you think _____(youth) is that...

a. The family's money won't last

- ☐ Very concerned ☐ Concerned ☐ Neither concerned nor unconcerned
☐ Not concerned ☐ Not at all concerned ☐ Don't know

b. He/she will be a burden to, or overload, family or friends

- ☐ Very concerned ☐ Concerned ☐ Neither concerned nor unconcerned
☐ Not concerned ☐ Not at all concerned ☐ Don't know

17. Which of the following health problems, if any, do you think _____ (youth) thinks are worse than death? Select all that apply.

- ☐ Living with great pain
☐ Total physical dependency on others, for example, being in a wheelchair
☐ Not being able to communicate his/her wishes and/or care for family members, for example, being in a coma
☐ None are worse than death



Draft

The Lyon Advance Care Planning Survey - Surrogate/Proxy Form

Family #

Person #

Visit#

Date:

MM

DD

YYYY

Dealing with Dying

18. How important would each of the following be to _____ (youth) if _____ (youth) was dealing with dying?

a. Family/friends visiting

☐ Very important

☐ Not very important

☐ Somewhat important

☐ Not at all important

☐ Neither important nor unimportant

☐ Don't know

b. Being able to stay in his/her own home

☐ Very important

☐ Not very important

☐ Somewhat important

☐ Not at all important

☐ Neither important nor unimportant

☐ Don't know

c. Honest answers from the doctor

☐ Very important

☐ Not very important

☐ Somewhat important

☐ Not at all important

☐ Neither important nor unimportant

☐ Don't know

d. Comfort from church services or persons such as a minister, priest, imam, or rabbi

☐ Very important

☐ Not very important

☐ Somewhat important

☐ Not at all important

☐ Neither important nor unimportant

☐ Don't know

e. Planning his/her own funeral

☐ Very important

☐ Not very important

☐ Somewhat important

☐ Not at all important

☐ Neither important nor unimportant

☐ Don't know

f. Being able to complete an advance directive that would let loved ones know _____ (youth)'s wishes, if he/she were unable to speak for him/herself

☐ Very important

☐ Not very important

☐ Somewhat important

☐ Not at all important

☐ Neither important nor unimportant

☐ Don't know

g. Fulfilling personal goals/pleasures

☐ Very important

☐ Not very important

☐ Somewhat important

☐ Not at all important

☐ Neither important nor unimportant

☐ Don't know

h. Reviewing his/her life history with family

☐ Very important

☐ Not very important

☐ Somewhat important

☐ Not at all important

☐ Neither important nor unimportant

☐ Don't know

i. Having health care professionals visiting his/her home

☐ Very important

☐ Not very important

☐ Somewhat important

☐ Not at all important

☐ Neither important not unimportant

☐ Don't know

j. Understanding treatment choices

☐ Very important

☐ Not very important

☐ Somewhat important

☐ Not at all important

☐ Neither important nor unimportant

☐ Don't know



Draft

The Lyon Advance Care Planning Survey - Surrogate/Proxy Form

-
Family # Person #

Visit#

Date: / /
MM DD YYYY

19. How important do you think each of the following is to _____ (youth) when he/she thinks about dying?

a. Being physically comfortable

- | | | |
|--|--|---|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important | <input type="radio"/> Neither important nor unimportant |
| <input type="radio"/> Not very important | <input type="radio"/> Not at all important | <input type="radio"/> Don't know |

b. Being free from pain

- | | | |
|--|--|---|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important | <input type="radio"/> Neither important nor unimportant |
| <input type="radio"/> Not very important | <input type="radio"/> Not at all important | <input type="radio"/> Don't know |

c. Saying everything to people in his/her family

- | | | |
|--|--|---|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important | <input type="radio"/> Neither important nor unimportant |
| <input type="radio"/> Not very important | <input type="radio"/> Not at all important | <input type="radio"/> Don't know |

d. Being at peace spiritually

- | | | |
|--|--|---|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important | <input type="radio"/> Neither important not unimportant |
| <input type="radio"/> Not very important | <input type="radio"/> Not at all important | <input type="radio"/> Don't know |

e. Not being a burden to loved ones

- | | | |
|--|--|---|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important | <input type="radio"/> Neither important nor unimportant |
| <input type="radio"/> Not very important | <input type="radio"/> Not at all important | <input type="radio"/> Don't know |

f. Knowing how to say good bye

- | | | |
|--|--|---|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important | <input type="radio"/> Neither important nor unimportant |
| <input type="radio"/> Not very important | <input type="radio"/> Not at all important | <input type="radio"/> Don't know |

g. Having a sense of own worth or value

- | | | |
|--|--|---|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important | <input type="radio"/> Neither important nor unimportant |
| <input type="radio"/> Not very important | <input type="radio"/> Not at all important | <input type="radio"/> Don't know |

h. Being off machines that extend life, such as life support

- | | | |
|--|--|---|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important | <input type="radio"/> Neither important nor unimportant |
| <input type="radio"/> Not very important | <input type="radio"/> Not at all important | <input type="radio"/> Don't know |

i. Dying a natural death

- | | | |
|--|--|---|
| <input type="radio"/> Very important | <input type="radio"/> Somewhat important | <input type="radio"/> Neither important nor unimportant |
| <input type="radio"/> Not very important | <input type="radio"/> Not at all important | <input type="radio"/> Don't know |



Draft

The Lyon Advance Care Planning Survey - Surrogate/Proxy Form

			-	
--	--	--	---	--

Family # Person #

--	--

Visit#

Date:

--	--

 /

--	--

 /

--	--	--	--

MM

DD

YYYY

20. If death were likely to happen in the next few weeks, and _____ (youth) could choose where to die, where do you think he/she would MOST want to die?

- ☐ At home
- ☐ In an assisted-living facility
- ☐ In a hospital
- ☐ In a nursing home
- ☐ In a residential hospice (hospice services provided by a hospice-owned facility)
- ☐ Don't know

21. Below are some statements related to pain near the end-of-life that have been expressed by people. How strongly do you think _____ (youth) agrees or disagrees with each statement?

a. _____ (youth) is afraid the doctor may not believe he/she is in pain and treat pain

- | | | |
|--------------------------------------|---|---|
| <input type="radio"/> Strongly agree | <input type="radio"/> Agree | <input type="radio"/> Neither agree or disagree |
| <input type="radio"/> Disagree | <input type="radio"/> Strongly disagree | <input type="radio"/> Don't know |

b. _____ (youth) would only take pain medicines when the pain is severe

- | | | |
|--------------------------------------|---|---|
| <input type="radio"/> Strongly agree | <input type="radio"/> Agree | <input type="radio"/> Neither agree or disagree |
| <input type="radio"/> Disagree | <input type="radio"/> Strongly disagree | <input type="radio"/> Don't know |

c. I am afraid I will become addicted to the pain medicines over time

- | | | |
|--------------------------------------|---|---|
| <input type="radio"/> Strongly agree | <input type="radio"/> Agree | <input type="radio"/> Neither agree or disagree |
| <input type="radio"/> Disagree | <input type="radio"/> Strongly disagree | <input type="radio"/> Don't know |

Completed by:

--	--	--

 Initials



Draft

The Lyon Advance Care Planning Survey - Surrogate/Proxy Form

☐ Site 1 ☐ Site 2 ☐ Site 3 ☐ Site 4

Study ID:

Date:

 / /

MM

DD

YYYY

 -

Family #

Person #

☐ Surrogate/proxy(1)

☐ Surrogate/proxy(2)

Participant initials:

Visit#:

d. I would take the lowest amount of medicine possible to save larger doses for later when the pain is worse

☐ Strongly agree

☐ Agree

☐ Neither agree or disagree

☐ Disagree

☐ Strongly disagree

☐ Don't know

e. I am afraid I would be given too much pain medicine

☐ Strongly agree

☐ Agree

☐ Neither agree or disagree

☐ Disagree

☐ Strongly disagree

☐ Don't know

22. Has _____ (youth) heard of hospice services?

☐ Yes

☐ No (If no, skip Q23 and Q24)

23. How did _____ (youth) learn about hospice services?

☐ know someone who used hospice services

☐ used hospice services

☐ was a hospice volunteer

☐ heard from a health care professional

☐ read literature/newspaper/TV/radio/other media

☐ heard from others

☐ No response

24. If _____ (youth) were dying, do you think he/she would you want hospice support?

☐ Yes

☐ No

☐ Don't know/not sure

☐ No response

Spiritual Well -Being

25. Do you think _____ (youth) considers him/herself? (If not religious/spiritual, skip Q26 and Q27)

☐ Very religious/spiritual

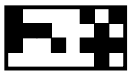
☐ Somewhat religious/spiritual

☐ Not very religious/spiritual

☐ Not religious/spiritual

☐ No response

☐ Don't know



Draft

The Lyon Advance Care Planning Survey - Surrogate/Proxy Form

 -

Family # Person #

Visit#

 Date: / /

MM

DD

YYYY

26. How often does _____ (youth) attend religious or spiritual services?

- ☐ Always
 ☐ Very often
 ☐ Sometimes
 ☐ Rarely
 ☐ Never
 ☐ Don't know

27. How often do you think _____ (youth) thinks religion or spirituality helps _____ (youth) face his/her fears or do what he/she was afraid to do?

- ☐ Everyday
 ☐ A few times a week
 ☐ A few times a month
 ☐ Rarely
 ☐ Never
 ☐ Don't know

About Youth

28. How many times in his/her life has _____ (youth) been seen at an emergency room?

Number of emergency room visits

29. How many times in his/her life has he/she ever been hospitalized?

29a. How many nights has youth spent in hospital in the last year?

29b. How many of those hospitalizations were psychiatric hospitalizations? For example, for behavior problems or depression.

29c. How many nights has youth spent psychiatrically hospitalized in the past year?

DURING THE PAST FOUR WEEKS

30. HOW MANY NIGHTS has (youth) stayed in a hospital?

- ☐ 0
 ☐ 1-2
 ☐ 3-5
 ☐ 6-10
 ☐ 11-20
 ☐ >20

31. How healthy do you think _____ (youth) thinks he/she feeling right now?

- ☐ Excellent health
 ☐ Very good health
 ☐ Good health
☐ Fair health
 ☐ Poor health
 ☐ No response

32. Is (name)'s mother alive? ☐ Yes ☐ No ☐ Don't know

32. a. Is (name)'s father alive? ☐ Yes ☐ No ☐ Don't know



Draft

The Lyon Advance Care Planning Survey - Surrogate/Proxy Form

 -

Family # Person #

Visit#

Date: / /

MM

DD

YYYY

Transition/End of Session

Thank you. That was the last question. I want to let you know 3 things.

First, patients do have a right to change their minds. People do change their minds sometimes as they become more ill.

Second, patients do have a right to important treatments like pain and comfort care, even if they decide to allow a natural death, that is, not to be kept alive by machines or feeding tubes.

Third, patients are not abandoned by their health care team if they decide they want to allow a natural death. Patients may still have regular visits at the hospital and be seen at home.

Do you have any questions? Now you are going to meet with our Research Assistant to answer some questions about how you experienced this session.

Acknowledgements

I would like to acknowledge AARP Knowledge Management (<http://research.aarp.org>) who gave me permission to adapt their North Carolina End of Life Survey of their adult members, so that I could expand an earlier survey of adolescents.

I would also like to acknowledge Edinger & Smucker whose 1992 advance directives survey of adult outpatients (J Fam Pract 1992/ 35:650-653) was also adapted with their permission, so that I could study adolescents.

This form may be reproduced for personal use. (c) Lyon 2006

For correspondence, please contact Maureen E. Lyon, PhD email: mlyon@childrensnational.org

Completed by: Initials



55182

FACE: Palliative Care
(PI: Maureen Lyon, PhD)
Satisfaction Questionnaire - Form 16

☐ CNMC ☐ Georgetown ☐ GW ☐ VA

Study ID:

Date:

☐ Surrogate (1)☐ Patient
 / /
☐ Surrogate (2)

MM

DD

YYYY

 -
Participant Initials: Visit#:

Family #

Person #

How did you feel about Session ☐ 1 ☐ 2

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1. It was useful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. It was helpful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. I felt scared or afraid	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. It felt like a load off my mind	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. It was too much to handle	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. I felt satisfied	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. It was harmful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. I felt angry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. It was something I needed to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. I felt sad	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. I felt courageous	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. It felt hurtful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. It was worthwhile	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Is there anything else you want to tell us about how you felt during this session?



15459

Family Centered Advance Care Planning: Teens Living with Cancer
(PI: Maureen Lyon, PhD)
The Quality of Patient-Interviewer Communication
(Surrogate/proxy)
Form - 18

Study ID:

4	0	3	2
---	---	---	---

Date:

		/			/				
--	--	---	--	--	---	--	--	--	--

MM

DD

YYYY

			-	
--	--	--	---	--

Family #

Person #

☐ Surrogate/proxy(1)☐ Surrogate/proxy(2)Participant Initials:

--	--	--

Visit#:

--	--

The following questions are to evaluate the discussion that you just had. Considering how you felt about the communication between you and the interviewer during this session, please respond to the following questions. The last question is to rate overall quality of the discussion you had. Your answers are confidential.

1. Do you think that your attitudes are known by the interviewer?

☐ Definitely no☐ Probably no☐ Don't know☐ Probably yes☐ Definitely yes

2. Did you feel that the interviewer cared about you as a person?

☐ Definitely no☐ Probably no☐ Don't know☐ Probably yes☐ Definitely yes

3. Did you feel that the interviewer listened to what you said?

☐ Definitely no☐ Probably no☐ Don't know☐ Probably yes☐ Definitely yes

4. Did you feel that the interviewer gave you enough of her attention?

☐ Definitely no☐ Probably no☐ Don't know☐ Probably yes☐ Definitely yes**RATINGS**

5. How would you rate the overall quality of the discussions you just had with the interviewer ?

☐ Poor☐ Fair☐ Good☐ Very good☐ Excellent

Is there anything else you want to tell us about how you felt about the communication during this session?

--

[SAMPLE AGENDA]
NEXT STEPS ACP FACILITATOR CERTIFICATION
A disease-specific Advance Care Planning Program

AGENDA

Pre-course Assignment

1. Completion of Respecting Choices online ACP course
2. Completion of Next Steps ACP Facilitator Manual reading

DAY 1

8:00 am Introductions

- Welcome
- Introduction of faculty and participants

Overview of course

- Program description, objectives, and agenda
- Competency evaluation expectations

8:30 Advance Care Planning for patients with advanced illness

- Video, Carol Goodman
- Overview of end-stage chronic illness
- Next Steps ACP Interview: Program Development & Theoretical Underpinnings (NS manual, Chapter 2)

9:30 Break

9:45 Discuss disease-specific knowledge templates (NS manual, Chapter 3)

10:00 Next Steps ACP Interview: Purpose, stages, techniques

- Overview and introduction of tool
 - Stage 1: Assess illness beliefs, goals, and values
 - Stage 2: Explore experiences
 - Stage 3: Explain purpose of advance care planning
- Group practice of interview questions Stage 1 & 2
- Interview techniques to promote dialogue
 - Explore meaning of words/phrases
 - Paraphrase, clarify – ask “anything else?”
 - Listen
 - Reaffirm purpose of interview
 - Verbalize empathy

11:15 Video Role-Play Demonstration of Next Steps ACP Interview Stages 1 through 3 and Discussion

12:00 pm Lunch

- 12:30 Practice Next Steps ACP Interview Stages 1 through 3**
- 1:30** Debrief practice exercise
- 1:45 Next Steps ACP Interview Stage 4: Clarifying Goals for Life-Sustaining Treatment**
- Statement of Treatment Preference (SOTP) form
 - Understanding scenarios of “bad outcomes”
 - Strategies to promote dialogue and understanding
 - Guide to SOTP
- 2:45 Break**
- 3:00 Practice Next Steps ACP Interview Stage 4**
- 3:30 The CPR Discussion**
- Live Role Play: The CPR discussion
 - Video demonstration: The CPR discussion (if needed)
- 4:15 Summary, Question and Answer**
- Suggestions:**
- Practice reading aloud the Next Steps ACP Interview questions.
 - Review Day 2 agenda and expectations

DAY 2

- 8:00 am Question and Answer**
- 8:30 Group Activities**
- Next Steps role-play practice sessions
 - Videotaping of participants in role play
- 12:30 pm Lunch**
- 1:00 Debriefing and Difficult Situations**
- Lessons learned from group activities
 - Common themes and lessons learned in skill development
 - Difficult questions/situations
 - Documentation
- 2:30 Break**
- 2:45 Stages 5 and 6: Summary and Follow-up Plan**
- 3:00 Live Role Play: Stages 3 and 4**
- 3:45 What Comes Next?**
- Practice sessions
 - Video, Competency Validation
- 4:00 Program Evaluation and Adjourn**

