

**eAppendix A.** Specific Advance Care Planning Questions Presented to Participants During Focus Groups

<b>Category</b>	<b>Question for Group</b>	<b>Materials for Review</b>
Patient Education	Everyone agrees that we should hand out educational materials to our patients. What do you think of our materials?	Participants were directed to a packet of institutional ACP materials when asking this question.
Personal Goals and Values for Maintaining Quality of Life	We need to know what gives your life meaning and quality. These questions have been used by others. Do you like any of these questions? How would you ask this in your own words?	What does living well mean to you? What gives your life meaning? What fears or worries do you have about your medical care or your disease? What sustains you when you face serious challenges in life? What makes your life good right now? Can you imagine a time where life would be so unbearable that you would not want medical treatments to keep you alive longer?
Selection of a Healthcare Proxy	We recommend that you pick someone to speak for you in case you are too sick to speak for yourself.  How can we find out from you who that person is?	Do you have someone assigned to make medical decisions for you in case you become too sick to speak for yourself? Would this person be: 1) willing to accept the responsibility, and 2) able to make difficult decisions under stress? Have you talked to this person about your goals, values, and beliefs? Will the person make decisions that honor your wishes? How closely should they follow your wishes (vs doing what they think is best for you when decisions are made)? Is there anyone you specifically would NOT want involved in helping to make healthcare decisions on your behalf?
Belief System	Often, your beliefs influence how you want to be cared for when you are very ill.	Think about what is important to you in relation to your health. What, if any, religious or personal beliefs do you have about sickness, healthcare decision-making, or dying?
Past Experiences	Your past experiences with loved ones with serious illness can shape how you wish to be cared for.	Have you or other people you know faced difficult medical treatment decisions during times of serious illness? How did you feel about those situations and any choices that were made?

ACP indicates advanced care planning.

Questions similar to these sample questions are used by others in guided discussions (programs such as, *The Health Values Questionnaire*, *Respecting Choices* and *Making Your Wishes Known*).<sup>1-3</sup>

#### **eAPPENDIX REFERENCES**

1. Levi BH, Green MJ. Too soon to give up: re-examining the value of advance directives. *Am J Bioeth.* 2010;10(4):3-22. doi: 10.1080/15265161003599691.
2. Karel MJ, Powell J, Cantor MD. Using a values discussion guide to facilitate communication in advance care planning. *Patient Educ Couns.* 2004;55(1):22-31.
3. Hammes BJ, Rooney BL, Gundrum JD. A comparative, retrospective, observational study of the prevalence, availability, and specificity of advance care plans in a county that implemented an advance care planning microsystem. *J Am Geriatr Soc.* 2010;58(7):1249-1255. doi: 10.1111/j.1532-5415.2010.02956.x.

## eAppendix B. PHR-Delivered ACP Framework

Dear [Patient Name],

As a routine part of your healthcare, we would like you to answer some questions. These questions help us know how we should take care of you in case you ever get too sick to speak for yourself. Your answers will be filed into your chart to help guide your future care. You can change your answers at any time.

Please think about these questions and talk about them with your loved ones. Send us back your answers when you are done.

If you are too sick to speak for yourself, who should make medical decisions for you?

Is there anyone you specifically would NOT want to make medical decisions for you?

What activities give your life quality?

What helps you cope during hard times (like the death of a loved one or a serious illness)?

If you would like to discuss your answers more with your physician during an appointment, please let us know. Our office has more resources to help you put your wishes in writing. Ask us for more information the next time you visit the clinic.

Thank you for your answers.

Sincerely,

[Physician Name], MD

[Nurse Name], RN

(Follow-up framework omitted)

ACP indicates advanced care planning; PHR, personal health record.

