

Appendix

ACOVE-1 Interview Questions

1. Sometimes older people don't want certain types of medical care. For example, they might decide that they don't want to have surgery. Or maybe they decide that they don't want to be admitted to the hospital. Have you ever thought about things like this? (*yes, no, don't know, refuse*)

2. Have you ever talked about this with your doctor? (*yes, no, don't know, refuse*)

3. (if "yes" to #2): What decisions did you make with your doctor? (*choices include not to stay in the hospital, not to have a big surgery, not to have CPR if the heart stops, not to have a feeding tube, not to be attached to a ventilator, other decision made, or no decision made*).

(*Patients answering that they had chosen to limit the care they would receive with their doctor were not asked the applicable question among questions 4–9 below.*)

4. Now I would like to ask you about the kind of medical care you want if you get sick. Some people want every medical treatment that might help them. Others only want treatments that won't bother them too much. We ask these questions of every person that we interview. You don't need to answer them if you don't want to. If you were sick and needed hospital care, would you agree to go to the hospital? (*yes, no, don't know, refuse*)

5. (If "no, don't know, or refuse" to answer previous question) Would you stay away from the hospital, even if it meant that you might die sooner? (*yes, no, don't know, refuse*)

6. Let's say you were sick, and you needed a major operation. The operation would hurt a lot, and you would have to stay in the hospital for at least a week. Would you want the operation? (*yes, no, don't know, refuse*)

7. (If "no, don't know, or refuse" to answer previous question) Would you say no to the major operation, if not having surgery meant that you might die sooner? (*yes, no, don't know, refuse*)

8. Doctors can try to revive someone whose heart has stopped beating. This usually includes pressing on the chest and using a machine to help breathing. If your heart stopped beating, would you want doctors to try to revive you? That is, would you want the doctors to do CPR? (*yes, no, don't know, refuse*)

Probe: If you chose not to have CPR, your doctor will write a DNR order in your chart.

9. (If "no, don't know, or refuse" to answer previous question) Would you rather the doctors did NOT try to start your heart beating again, even if it meant that you might die sooner? (*yes, no, don't know, refuse*)

APPENDIX TABLE 1. HIERARCHY OF PREFERENCE INFORMATION ABSTRACTED FROM MEDICAL RECORDS

	ACOVE-1 (office, nursing home, hospital, emergency department)	ACOVE-1 (outpatient ancillary services)	ACOVE-2 (office only) ^a
Formal document (written advance directive such as durable power of attorney or living will)	X	X	X
Physician note of patient's preferences with respect to life-sustaining care	X		X
Note of discussion attempting to elicit patient's preferences	X		X
Note of patient refusal/reluctance to discuss preferences	X		
Note that patient's preferences are not known	X		
Evidence that advance directive exists but no copy could be found in record	X		X
Progress note documentation of "full code"	X		
Administrative documentation of "full code"	X		
Other/no data	X	X	X

This table contains the hierarchy of information collected by abstractors from medical records. Abstractors recorded the highest level of information in the hierarchy, with a formal document of preferences at the top and "no data" at the bottom.

^aACOVE-2 had an additional option pertinent to one of the sites, "patient notified of advance directive information on request."

APPENDIX TABLE 2. HIERARCHY OF SURROGATE INFORMATION ABSTRACTED FROM MEDICAL RECORDS

	ACOVE-1 (office, nursing home, hospital, emergency department)	ACOVE-1 (outpatient ancillary services)	ACOVE-2 (office only)
Name of surrogate identified in a formal document (written advance directive such as durable power of attorney)	X	X	X
Name of surrogate documented in notes	X		X
Note of discussion attempting to identify surrogate	X		X
Note of patient refusal/reluctance to discuss surrogate	X		
Note that surrogate is not known for this patient	X		
Other/No Data	X	X	X

This table contains the hierarchy of information collected by abstractors from medical records. Abstractors recorded the highest level of information in the hierarchy, with a formal document of surrogate at the top and "no data" at the bottom.

10. Do you know what an advance directive or durable power of attorney for health care is? (IF NO, An advance directive is a paper you sign telling your health provider or hospital what you want done if you are sick and can't talk for yourself. A durable power of attorney names someone to make decisions about medical treatment for you when you can't talk for yourself.)

11. Have you ever signed an advance directive or durable power of attorney for health care? (*yes, no, don't know, refuse*)

12. (*If "yes" to question above*) Have you given a copy of this to your health provider or hospital? (*yes, no, don't know, refuse*)

13. Have you completed a living will? (*yes, no, don't know, refuse*)

IF RESPONDENT DOESN'T KNOW WHAT THIS IS, EXPLAIN: A living will is a paper telling the health provider what you want done if you are very sick and can't talk for yourself.

14. (*If "yes" to question above*) Have you given a copy of this living will to your health provider or hospital? (*yes, no, don't know, refuse*)

15. (*If "yes" to question above*) When did you first give your [advance directive / living will] to your health care provider? Was it: (*since January 1st of this year, during 1999, before 1999, don't know, refuse*)

16. Have you told your health provider who could make decisions about medical treatment for you if ever you could not speak for yourself? (*yes, no, don't know, refuse*)

(*Patients answering that they had chosen to limit the care they would receive with their doctor were not asked the applicable question those questions below.*)

17. I am going to read you some situations that sometimes happen to people who are very sick. For each one, please tell me if you would prefer to live as long as possible in this condition, even if you would not get any better, or if you would prefer to die.

a. Being attached to a ventilator (machine that breathes for you) all the time. Would you . . . (*Prefer to live as long as possible in this condition, even if you would not get any better; prefer to die; don't know; refuse*)

b. Being fed through a tube into your stomach all the time. Would you . . . (*Prefer to live as long as possible in this condition, even if you would not get any better; prefer to die; don't know; refuse*)

c. Being unconscious or in a coma all the time. Would you . . . (*Prefer to live as long as possible in this condition, even if you would not get any better; prefer to die; don't know; refuse*)

ACOVE-2 Interview Questions

1. Do you know what an advance directive or durable power of attorney for health care is?

IF NO, READ: An advance directive is a paper you sign telling your health provider or hospital what you want done if you are sick and can't talk for yourself. A durable power of attorney names someone to make decisions about medical treatment for you when you can't talk for yourself.

2. Have you ever signed an advance directive or durable power of attorney for health care or living will?

3. (If yes to #2) Have you given a copy of this to a doctor or nurse?

4. Have you told a doctor or nurse about who could make decisions about medical treatment for you if you were unable to speak for yourself?