

Appendix 3 (as supplied by the authors): iDECIDE CPR Decision Aid Tool Baseline Data Collection Forms



PATIENT DEMOGRAPHIC FORM

1. Date of Birth: _____ / _____ / _____
 DD MM YYYY

2. Sex:
 Male Female

3. What is your current marital status? (√) Choose one
 Married or living as married
 Widowed
 Never married
 Divorced or separated; not remarried

4. Where have you been living in the last month? (√) Choose one
 At your own home (apartment, townhouse, bungalow, etc.)
 Retirement Residence
 Long-Term Care or Nursing Home
 Rehabilitation Facility
 Hospital
 Other (specify): _____

5. Do you live alone?
 Yes No

6. Is the location of your residence (√) Choose one
 Rural(Country) Urban(City)

7. Does a health care professional come to your home or residential setting to provide health care?
 Yes No

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8. Which of the following best describes the highest level of education you have completed? (√) Choose one

- Did not complete secondary school or high school
- Completed secondary or high school
- Had some university education or completed a community college, technical college, or post-secondary program (for example; trade, technical or vocational school, CEGEP)
- University degree (for example; BA, BSc, BSN)
- Graduate degree (for example; MD, DDS, DMD, DVM, OD, Master's, or PhD)

9. How important is spirituality or religion in your life? (√) Choose one

- Extremely important
- Very important
- Somewhat important
- Not very important
- Not at all important
- Don't know

10. Do you identify with a formal religious group or practice? (√) Choose one

- Protestant (includes Anglican, Baptist, United, Methodist)
- Catholic
- Jewish
- Muslim
- Sikh
- Other (specify): _____
- None

11. Do you see yourself as: (√) Choose one

- Asian/Pacific Islander
- African/Black North American
- Caucasian/White
- East Indian
- First Nations/Inuit/Metis or Aboriginal
- Other (specify): _____

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12. How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy? (√) Check one

- 1 - Never
- 2 - Rarely
- 3 - Sometimes
- 4 - Often
- 5 - Always

13. Thinking about your wishes for medical care in the future when you are seriously ill, which of the following options best describes how much information you would like to receive to help you make the best decision about the kinds of medical treatments that would be right for you?

- 1 – I would want a lot of information
- 2 – I would want some information
- 3 – I would want just a little information
- 4 – I would not want any information

14. Do you have a computer at home?

- 1 – Yes
- 2 – No

15. Do you use the internet at home?

- 1 – Yes
- 2 – No

16. Please indicate your level of agreement with the following statement:

“I am comfortable using the internet”

- 1 – Strongly Disagree
- 2 – Disagree
- 3 – Neither Agree nor Disagree
- 4 – Agree
- 5 – Strongly Agree
- 6 – Don't know

17. Which language do you speak on a daily basis?

- English
- French
- Other (Specify): _____

18. In general, how would you rate your overall quality of life?

- Excellent Very Good Good Fair Poor

19. In the last 6 months, how many times have you seen your family doctor, not including today/this hospital stay?

Enter Number: _____ don't know

20. In the last 6 months, how many times have you seen a specialist or a surgeon, not including today/this hospital stay?

Enter Number: _____ don't know

21. In the last 6 months, how many times have you been admitted to the hospital, not including today/this hospital stay?

Enter Number: _____ don't know

22. Comorbidities – Please indicate if you currently have the problems below. Check 'Yes' for all that apply.

Heart Disease	<input type="checkbox"/> Yes	<input type="checkbox"/> No
High Blood Pressure	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Lung Disease (non-cancer)	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Diabetes	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Ulcer or stomach disease	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Kidney disease (non-cancer)	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Liver disease (non-cancer)	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Anemia or other blood disease (non-cancer)	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Cancer	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Depression	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Osteoarthritis, degenerative arthritis	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Back pain	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Rheumatoid arthritis	<input type="checkbox"/> Yes	<input type="checkbox"/> No

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Questions for Cancer patients only:

23. Cancer diagnosis: _____

24. Treatment (check all that apply):









- Chemotherapy
- Radiation Therapy
- None

25. Intent of treatment (Choose one):

- To Cure Cancer (Curative)
- To control the cancer because it cannot be cured (Palliative)
- Unsure

26. These categories describe different levels of fitness and frailty. You do not have to read each one. Scroll down the pictures and decide which is more consistent with your condition.

Please consider your overall condition 2 weeks prior to the clinic visit or hospital admission. How fit or frail were you at that time? Check ONE response only. (If you have trouble deciding between two options, choose the higher functioning level.)

(✓)		Description
<input type="checkbox"/>		Very Fit (category 1) People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.
<input type="checkbox"/>		Well (category 2) No active disease symptoms but less fit than people in category 1. Often, they exercise or are very active occasionally , e.g. seasonally. <i>Well</i> older adults share most attributes of the very fit, except for regular, vigorous exercise. Like them, some may complain of memory symptoms, but without objective deficits.
<input type="checkbox"/>		Managing Well (category 3) Medical problems are well controlled, but people in this category are not regularly active beyond routine walking. Those with treated medical problems who exercise are classed in categories 1 or 2.
<input type="checkbox"/>		Vulnerable (category 4) Not dependent on others for daily help, but often symptoms limit activities . A common complaint is being “ slowed up ” and/ or being tired during the day . Many people in this category rate their health as no better than “fair”. Memory problems, if present, can begin to affect function (e.g. having to look up familiar recipes, misplacing documents) but usually do not meet dementia criteria. Families often note some withdrawal – e.g. needing encouragement to go to social activities.
<input type="checkbox"/>		Mildly Frail (category 5) More evident slowing and individuals need help in “ high ” activities of daily living (finances, transportation, heavy housework, medications). Mildly frail people might have difficulty with shopping or walking outside alone, meal preparation, and housework. Often, they will have several illnesses and take multiple medications. This category includes people with mild dementia . Their common symptoms include forgetting the details of a recent event, even though they remember the event itself, asking the same question, or telling the same story several times a day and social withdrawal.
<input type="checkbox"/>		Moderately Frail (category 6) Individuals need help with all outside activities and with keeping house . Inside, they often have problems with stairs and need help with bathing and might need minimal assistance (cuing, standby) with dressing. If a memory problem causes the dependency, often recent memory will be very impaired, even though they seemingly can remember their past life events well.
<input type="checkbox"/>		Severely Frail (category 7) Completely dependent on others for all or most personal activities of daily living, such as dressing and feeding.
<input type="checkbox"/>		Very Severely Frail (category 8) Completely dependent, approaching the end of life. Typically, people in this category could not recover from even a minor illness.

**FAMILY MEMBER DEMOGRAPHIC FORM**

1. Date of Birth: _____ / _____ / _____
 DD MM YYYY

2. Sex:

Male Female

3. What is your current marital status? (√) Choose one

- Married or living as married
 Widowed
 Never married
 Divorced or separated; not remarried

4. Which of the following best describes the highest level of education you have completed? (√) Choose one

- Did not complete secondary school or high school
 Completed secondary or high school
 Had some university education or completed a community college, technical college, or post-secondary program (for example; trade, technical or vocational school, CEGEP)
 University degree (for example; BA, BSc, BSN)
 Graduate degree (for example; MD, DDS, DMD, DVM, OD, Master's, or PhD)

5. How important is spirituality or religion in your life? (√) Choose one

- Extremely important
 Very important
 Somewhat important
 Not very important
 Not at all important
 Don't know

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6. Do you identify with a formal religious group or practice? (√) Choose one

- Protestant (includes Anglican, Baptist, United, Methodist)
 Catholic
 Jewish
 Muslim
 Sikh
 Other(specify): _____
 None

7. Do you see yourself as: (√) Choose one

- Asian/Pacific Islander
 African/Black North American
 Caucasian/White
 East Indian
 First Nations/Inuit/Metis or Aboriginal
 Other (specify): _____

8. How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy? (√) Check one

- 1- Never
 2- Rarely
 3- Sometimes
 4- Often
 5- Always

9. Which language do you speak on a daily basis?

- English
 French
 Other (Specify): _____

10. What is your relationship to the patient?

STUDY ID

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iDECIDE

Improving Decision Making for Goals of Care
for Hospitalized Elderly Patients

CPR Knowledge Questionnaire (Pre CPR Video)

Date Completed: _____ / _____ / _____
 DD MM YYYY

What do you know about Cardiopulmonary Resuscitation (CPR)?

- 1) When the heart stops beating brain death will occur in:
 - a) One hour
 - b) Several minutes
 - c) Immediately
 - d) Don't know

- 2) CPR includes the following treatments:
 - a) Pressing hard and fast on the breast bone to pump blood through the heart to the body
 - b) Putting a breathing tube through the mouth and into the lungs to get air into the lungs
 - c) Giving the person antibiotics for a lung infection
 - d) Don't know

- 3) If CPR is successful and the heart restarts the person:
 - a) Is able to resume their usual activities
 - b) Usually needs to rest in bed for a few days
 - c) Usually needs a machine to help with breathing, medicines, and fluids while trying to recover in ICU (Intensive Care Unit)
 - d) Don't know

- 4) The most serious possible harm from the heart stopping and needing to have CPR is:
 - a) Having bruised or broken ribs from pressing on the chest
 - b) Severe brain damage from lack of oxygen
 - c) It is frightening to watch
 - d) None of the above
 - e) Don't know



- 5) When CPR is effective it will:
- a) Restart the heart and improve most health conditions and improve ability to live
 - b) Restart the heart but have absolutely no effect on other medical conditions
 - c) Don't know
- 6) If 100 people have a chronic condition (heart failure, kidney failure, chronic lung disease) and their hearts stop, how many will survive CPR and recover well enough to leave the hospital?
- a) Everyone survives (100 out of 100)
 - b) About half of the people (50 out of 100)
 - c) Very few people (10 out of 100)
 - d) Don't know
- 7) If the patient decides NOT to have CPR:
- a) They can receive treatments to relieve suffering AND for other medical conditions if wanted
 - b) They can only receive treatment to relieve suffering but NOT for other medical conditions
 - c) They will be discharged from hospital because there is nothing more to do
 - d) Don't know
- 8) The healthcare team wants to talk to hospitalized patients about the CPR decision because:
- a) The right decision about CPR depends on what is most important to the individual patient in addition to the patient's medical conditions
 - b) The patient can order CPR to be done in any situation
 - c) The doctor doesn't want to be sued for not asking the patient
 - d) Don't know
- 9) Of all the people who survive CPR, how many will have serious problems with their ability to think?
- a) All survivors
 - b) More than half of survivors
 - c) A few survivors
 - d) Don't know

STUDY ID

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Date Completed: _____ / _____ / _____
 DD MM YYYY



Decisional Conflict Scale (Pre-CPR Video)

A. Which option do you prefer? Please check one.

- a. **Have CPR if the heart stops**
- b. **No CPR (and continue to receive care)**
- c. **Unsure**

B. **How much difficulty are you having in making this choice?**

B. Considering the option you prefer, please answer the following questions:

	Yes	Unsure	No
	[0]	[2]	[4]
1. Do you know which options are available?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Do you know the benefits of each option?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Do you know the risks and side effects of each option?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Are you clear about which benefits matter most to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Are you clear about which risks and side effects matter most to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Do you have enough support from others to make a choice?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Are you choosing without pressure from others?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Do you have enough advice to make a choice?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Are you clear about the best choice for you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Do you feel sure about what to choose?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

iDECIDE CPR Decision Aid Tool
Post Video Data Collection Forms

STUDY ID

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iDECIDE
Improving Decision Making for Goals of Care
for Hospitalized Elderly Patients

CPR Decision Aid Acceptability Questionnaire

Today's Date:

_____/_____/_____
DD MM YYYY

What did you think about the video decision aid called *Cardio-Pulmonary Resuscitation (CPR): A Video Decision Aid for Patients and Their Families?*

Please check one answer for each question.

1. Did you watch the entire video decision aid?

- Yes
- No

2. Did anyone else (such as family or friends) watch the video decision aid?

- Yes What is their relation to you?: _____
- No

3. How would you rate the amount of information in the video decision aid?

- Much less than I needed
- A little less than I needed
- About the right amount
- A little more than I needed
- A lot more than I needed

4. How balanced was the video decision aid's information about CPR?

- Clearly slanted towards **having** CPR
- A little slanted towards **having** CPR
- Completely balanced
- A little slanted towards **not** having CPR
- Clearly slanted towards **not** having CPR

5. How clear was the information in the video decision aid?

- Everything was clear
- Most things were clear
- Some things were clear
- Many things were unclear

STUDY ID

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6. How helpful was the video decision aid in helping you make decisions about CPR?

- Very helpful
- Somewhat helpful
- A little helpful
- Not helpful

7. Would you recommend this video decision aid to other people who are considering whether or not to have CPR?

- I would definitely recommend it
- I would probably recommend it
- I would probably not recommend it
- I would definitely not recommend

8. Overall, how would you rate the video decision aid?

- Poor
- Fair
- Good
- Very good
- Excellent

9. Based on your experience watching the video decision aid, what suggestions do you have to improve the video?

10. Thinking about the process of watching the video, completing the worksheet, and waiting to talk with your doctor about CPR, what suggestions do you have to make this process better?

STUDY ID

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11. What day did your doctor talk to you about CPR after you watched the video?

_____/_____/_____
DD MM YYYY

12. How satisfied are you with the conversation you had about CPR with your doctor *after* you watched the video?

- Not at all satisfied
- A little satisfied
- Somewhat satisfied
- Fairly satisfied
- Extremely satisfied

13. What could be done to make this conversation go better?

STUDY ID

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iDECIDE

Improving Decision Making for Goals of Care
for Hospitalized Elderly Patients

CPR Knowledge Questionnaire (Post CPR Video)

Date Completed: _____ / _____ / _____
 DD MM YYYY

What do you know about Cardiopulmonary Resuscitation (CPR)?

- 1) When the heart stops beating brain death will occur in:
 - a) One hour
 - b) Several minutes
 - c) Immediately
 - d) Don't know

- 2) CPR includes the following treatments:
 - a) Pressing hard and fast on the breast bone to pump blood through the heart to the body
 - b) Putting a breathing tube through the mouth and into the lungs to get air into the lungs
 - c) Giving the person antibiotics for a lung infection
 - d) Don't know

- 3) If CPR is successful and the heart restarts the person:
 - a) Is able to resume their usual activities
 - b) Usually needs to rest in bed for a few days
 - c) Usually needs a machine to help with breathing, medicines, and fluids while trying to recover in ICU (Intensive Care Unit)
 - d) Don't know

- 4) The most serious possible harm from the heart stopping and needing to have CPR is:
 - a) Having bruised or broken ribs from pressing on the chest
 - b) Severe brain damage from lack of oxygen
 - c) It is frightening to watch
 - d) None of the above
 - e) Don't know



- 5) When CPR is effective it will:
- Restart the heart and improve most health conditions and improve ability to live
 - Restart the heart but have absolutely no effect on other medical conditions
 - Don't know
- 6) If 100 people have a chronic condition (heart failure, kidney failure, chronic lung disease) and their hearts stop, how many will survive CPR and recover well enough to leave the hospital?
- Everyone survives (100 out of 100)
 - About half of the people (50 out of 100)
 - Very few people (10 out of 100)
 - Don't know
- 7) If the patient decides NOT to have CPR:
- They can receive treatments to relieve suffering AND for other medical conditions if wanted
 - They can only receive treatment to relieve suffering but NOT for other medical conditions
 - They will be discharged from hospital because there is nothing more to do
 - Don't know
- 8) The healthcare team wants to talk to hospitalized patients about the CPR decision because:
- The right decision about CPR depends on what is most important to the individual patient in addition to the patient's medical conditions
 - The patient can order CPR to be done in any situation
 - The doctor doesn't want to be sued for not asking the patient
 - Don't know
- 9) Of all the people who survive CPR, how many will have serious problems with their ability to think?
- All survivors
 - More than half of survivors
 - A few survivors
 - Don't know

STUDY ID

Four sets of empty boxes for entering the study ID number.

Date Completed: _____ / _____ / _____
DD MM YYYY

Clinician Conversation with patient/family member about the CPR Decision Aid

- Occurred
- Did Not Occur



Decisional Conflict Scale (Post-CPR Video)

A. Which option do you prefer? Please check one.

- a. **Have CPR if the heart stops**
- b. **No CPR (and continue to receive care)**
- c. **Unsure**

B. **How much difficulty are you having in making this choice?**

B. Considering the option you prefer, please answer the following questions:

	Yes	Unsure	No
	[0]	[2]	[4]
1. Do you know which options are available?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Do you know the benefits of each option?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Do you know the risks and side effects of each option?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Are you clear about which benefits matter most to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Are you clear about which risks and side effects matter most to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Do you have enough support from others to make a choice?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Are you choosing without pressure from others?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Do you have enough advice to make a choice?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Are you clear about the best choice for you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Do you feel sure about what to choose?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

STUDY ID

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Clinician Conversation with patient/family member about the CPR Decision Aid

- Occurred
- Did Not Occur



PATIENT VERSION

Thinking about the conversation you had with [insert clinician] today about the CPR Decision Aid...

1. How much effort was made to help you understand your health issues?

0	1	2	3	4	5	6	7	8	9
No effort was made									Every effort was made

2. How much effort was made to listen to the things that matter most to you about your health issues?

0	1	2	3	4	5	6	7	8	9
No effort was made									Every effort was made

3. How much effort was made to include what matters most to you in choosing what to do next?

0	1	2	3	4	5	6	7	8	9
No effort was made									Every effort was made



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STUDY ID

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Clinician Conversation with patient/family member about the CPR Decision Aid

- Occurred
- Did Not Occur



FAMILY MEMBER VERSION

Thinking about the conversation you had with [insert clinician] today about the CPR Decision Aid...

1. How much effort was made to help you understand the patient’s health issues?

0	1	2	3	4	5	6	7	8	9
No effort at all									Every effort was made

2. How much effort was made to listen to the things that matter most to you about the patient’s health issues?

0	1	2	3	4	5	6	7	8	9
No effort at all									Every effort was made

3. How much effort was made to include what matters most to you in choosing what to do next for the patient?

0	1	2	3	4	5	6	7	8	9
No effort at all									Every effort was made



STUDY ID

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iDECIDE
Improving Decision Making for Goals of Care
for Hospitalized Elderly Patients

Chart Abstraction Tool

Date and time of admission to hospital

		M	M	M	2	0	Y	Y	H	H	M	M
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(24 hour clock)

Instructions for reporting CPR Orders

On the day the patient is enrolled into the study please document the CPR status recorded in the patient's chart, MD orders, progress notes.

Record the location in which the order was found (i.e. progress notes, MD orders)

Enter the date the order was written.

Record the details of the order.

One week or seven days after the date of enrollment, document all conversations regarding CPR/ resuscitation/ ICU/ Palliative care/ EOL goals of care recorded in the patient's chart, Kardex, MD orders and progress notes .

Record the location in which the order was found (i.e. progress notes, MD orders)

Enter the date the order was written.

Check one response below which reflects the details of the order:

1. Use machines and all possible measures including resuscitation (CPR) with a focus on keeping me alive at all costs.
2. Use machines and all possible measures with a focus on keeping me alive but if my heart stops, no resuscitation (CPR).
3. Use machines only in the short term to see if I will get better but if my illness is prolonged, change focus to comfort measures only. If my heart stops, no resuscitation (CPR).
4. Use full medical care to prolong my life but if my heart or breathing stops, no resuscitation (CPR) or breathing machines.
5. Use comfort measures only with a focus on improving my quality of life and comfort. Allow natural death and no artificial prolongation of life and no resuscitation.
6. Unsure, documentation unclear.
7. No documentation.
8. Other, specify:

STUDY ID

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Post Intervention

Looking at orders written/progress notes please document all conversations regarding CPR/ resuscitation/ ICU/ Palliative care/ EOL goals of care.

Location	Date	Details of Order						
<table border="1"><tr><td>D</td><td>D</td></tr></table>	D	D	<table border="1"><tr><td>2</td><td>0</td><td>Y</td><td>Y</td></tr></table>	2	0	Y	Y	
D	D							
2	0	Y	Y					
<table border="1"><tr><td>D</td><td>D</td></tr></table>	D	D	<table border="1"><tr><td>2</td><td>0</td><td>Y</td><td>Y</td></tr></table>	2	0	Y	Y	
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2	0	Y	Y					
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