Patient and population preferences for intensive care: Integrating the person into decisions around care



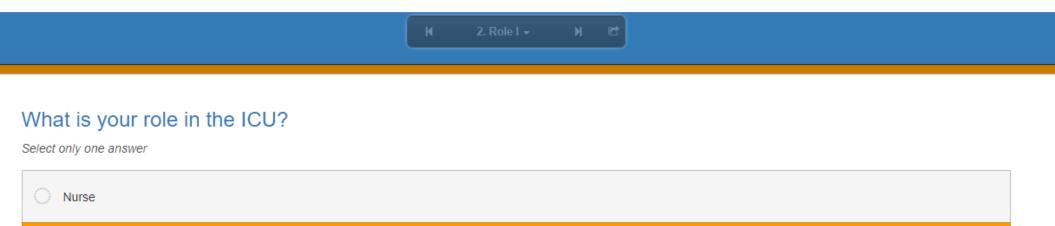
Welcome

We are inviting you to participate in a study about how people value health in the context of care within an Intensive Care Unit (ICU). We are exploring whether the way doctors and nurses feel about the health of people in ICU is the same as the rest of the population. The survey is going to ask you to imagine that you are critically ill and what your wishes would be in a variety of different hypothetical outcomes. Your responses to these hypothetical questions will be used to help us understand what is most important to people when considering their health. This study is being undertaken by researchers based at Sir Charles Gairdner Hospital in Perth, and Curtin University. If you would like to speak to someone about the study or this survey, please call Dr Richard Norman on (08) 92661327. If the questions in the survey make you feel anxious or depressed, we recommend you consult your GP or call Beyond Blue on 1300 22 4636 or Lifeline 13 11 14.

The survey will take about 15 minutes. Your participation in this study is entirely voluntary. By completing the survey you are voluntarily agreeing to participate. You can also choose to withdraw from the study at any time without any consequences. The survey software has been designed to protect your privacy and is secure. The survey is anonymous and confidential. No one will be able to identify you or your answers, and no one will know whether or not you participated in the study. Your survey responses will be stored for the purposes of analysis, and combined with those from other participants and analyzed as a group.

Please enter your site code





What is your medical specialty?

) Inte	ensive care specialist
O ICU	U trainee
O Car	reer medical officer
O No	n-ICU trainee (resident or registrar)

Page 4 consists of background survey logic and is not shown to respondents

You were admitted to hospital as you were very ill and a doctor decided that in order for you to survive, you needed to be admitted to the Intensive Care Unit, placed in an induced coma and put on a ventilator while you received treatment for your illness.

It has now been 1 week since you were admitted and you HAVE NOT improved as the doctors would have hoped.

The following questions show the likely outcomes from here.

Situation 1

With ongoing treatment, if you survive, you would be expected to require ongoing uncomfortable and potentially painful treatment in hospital for a further	7 weeks
With continued treatment, your chance of death is	Low risk (i.e. 20%)
If you do survive, your likelihood of permanent problems with your memory and concentration (such that you cannot function independently) is	Moderate risk (i.e. 50%)
If you do survive, your chance of ending up needing assistance caring for yourself (requiring help with toileting and feeding) is	Low risk (i.e. 20%)
If you do survive, your chance of needing full time nursing residential care is	High risk (i.e. 80%)

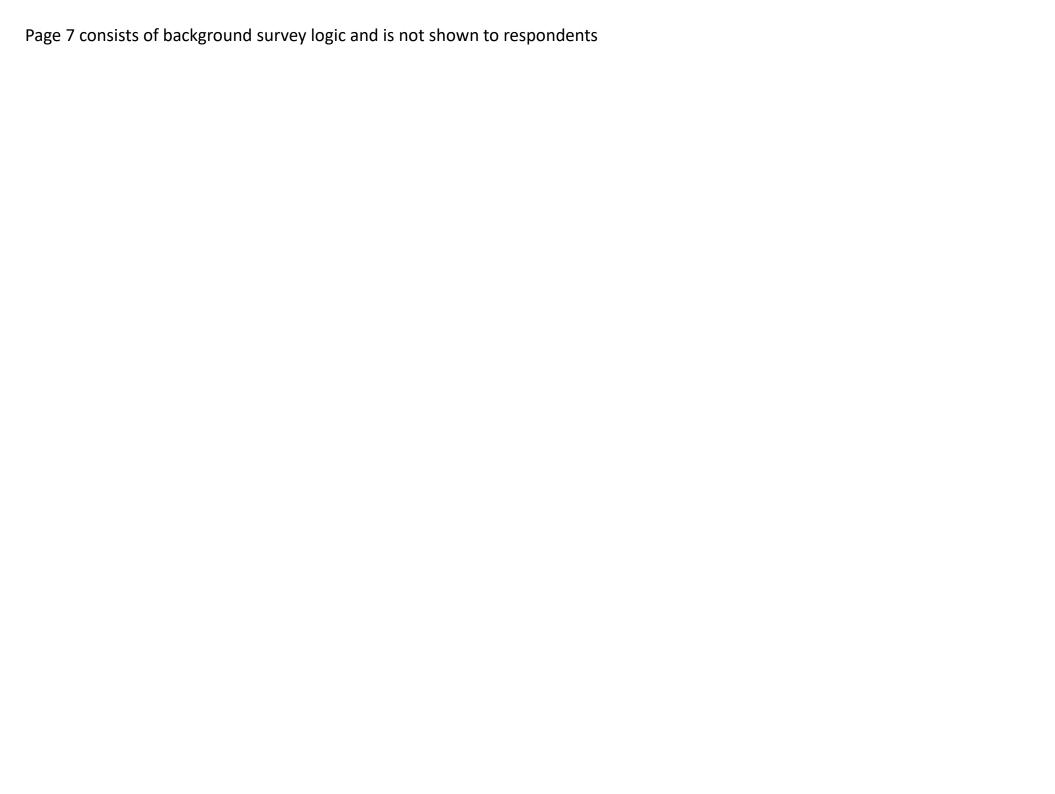
If you were asked, would you want to continue life support treatments in the ICU, or would you rather stop life support (with a high likelihood of death) and have care focused on your comfort and dignity?

Select only one answer

Continue life support



\bigcirc	Continuing to actively treat the patient
0	Talking to the family about stopping active treatment



You were admitted to hospital as you were very ill and a doctor decided that in order for you to survive, you needed to be admitted to the Intensive Care Unit, placed in an induced coma and put on a ventilator while you received treatment for your illness.

It has now been 1 week since you were admitted and you HAVE NOT improved as the doctors would have hoped.

The following questions show the likely outcomes from here.

Situation 2

With ongoing treatment, if you survive, you would be expected to require ongoing uncomfortable and potentially painful treatment in hospital for a further	7 weeks
With continued treatment, your chance of death is	Moderate risk (i.e. 50%)
If you do survive, your likelihood of permanent problems with your memory and concentration (such that you cannot function independently) is	Moderate risk (i.e. 50%)
If you do survive, your chance of ending up needing assistance caring for yourself (requiring help with toileting and feeding) is	High risk (i.e. 80%)
If you do survive, your chance of needing full time nursing residential care is	Low risk (i.e. 20%)

If you were asked, would you want to continue life support treatments in the ICU, or would you rather stop life support (with a high likelihood of death) and have care focused on your comfort and dignity?

Select only one answer

Continue life support

()	Continuing to actively treat the patient
0	Talking to the family about stopping active treatment



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It has now been 1 week since you were admitted and you HAVE NOT improved as the doctors would have hoped. The following questions show the likely outcomes from here.

Situation 3

With ongoing treatment, if you survive, you would be expected to require ongoing uncomfortable and potentially painful treatment in hospital for a further	1 week
With continued treatment, your chance of death is	High risk (i.e. 80%)
If you do survive, your likelihood of permanent problems with your memory and concentration (such that you cannot function independently) is	High risk (i.e. 80%)
If you do survive, your chance of ending up needing assistance caring for yourself (requiring help with toileting and feeding) is	Low risk (i.e. 20%)
If you do survive, your chance of needing full time nursing residential care is	Moderate risk (i.e. 50%)

If you were asked, would you want to continue life support treatments in the ICU, or would you rather stop life support (with a high likelihood of death) and have care focused on your comfort and dignity?

Select only one answer

Continue life support

0	Continuing to actively treat the patient
0	Talking to the family about stopping active treatment

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You were admitted to hospital as you were very ill and a doctor decided that in order for you to survive, you needed to be admitted to the Intensive Care Unit, placed in an induced coma and put on a ventilator while you received treatment for your illness.

It has now been 1 week since you were admitted and you HAVE NOT improved as the doctors would have hoped. The following questions show the likely outcomes from here.

Situation 4

With ongoing treatment, if you survive, you would be expected to require ongoing uncomfortable and potentially painful treatment in hospital for a further	1 week
With continued treatment, your chance of death is	Low risk (i.e. 20%)
If you do survive, your likelihood of permanent problems with your memory and concentration (such that you cannot function independently) is	Moderate risk (i.e. 50%)
If you do survive, your chance of ending up needing assistance caring for yourself (requiring help with toileting and feeding) is	High risk (i.e. 80%)
If you do survive, your chance of needing full time nursing residential care is	Moderate risk (i.e. 50%)

If you were asked, would you want to continue life support treatments in the ICU, or would you rather stop life support (with a high likelihood of death) and have care focused on your comfort and dignity?

Select only one answer

Continue life support

0	Continuing to actively treat the patient
0	Talking to the family about stopping active treatment



You were admitted to hospital as you were very ill and a doctor decided that in order for you to survive, you needed to be admitted to the Intensive Care Unit, placed in an induced coma and put on a ventilator while you received treatment for your illness.

It has now been 1 week since you were admitted and you HAVE NOT improved as the doctors would have hoped.

The following questions show the likely outcomes from here.

Situation 5

With ongoing treatment, if you survive, you would be expected to require ongoing uncomfortable and potentially painful treatment in hospital for a further	4 weeks
With continued treatment, your chance of death is	High risk (i.e. 80%)
If you do survive, your likelihood of permanent problems with your memory and concentration (such that you cannot function independently) is	Moderate risk (i.e. 50%)
If you do survive, your chance of ending up needing assistance caring for yourself (requiring help with toileting and feeding) is	Low risk (i.e. 20%)
If you do survive, your chance of needing full time nursing residential care is	Low risk (i.e. 20%)

If you were asked, would you want to continue life support treatments in the ICU, or would you rather stop life support (with a high likelihood of death) and have care focused on your comfort and dignity?

Select only one answer

Continue life support

0	Continuing to actively treat the patient
0	Talking to the family about stopping active treatment



You were admitted to hospital as you were very ill and a doctor decided that in order for you to survive, you needed to be admitted to the Intensive Care Unit, placed in an induced coma and put on a ventilator while you received treatment for your illness.

It has now been 1 week since you were admitted and you HAVE NOT improved as the doctors would have hoped. The following questions show the likely outcomes from here.

Situation 6

With ongoing treatment, if you survive, you would be expected to require ongoing uncomfortable and potentially painful treatment in hospital for a further	4 weeks
With continued treatment, your chance of death is	Low risk (i.e. 20%)
If you do survive, your likelihood of permanent problems with your memory and concentration (such that you cannot function independently) is	Low risk (i.e. 20%)
If you do survive, your chance of ending up needing assistance caring for yourself (requiring help with toileting and feeding) is	Moderate risk (i.e. 50%)
If you do survive, your chance of needing full time nursing residential care is	High risk (i.e. 80%)

If you were asked, would you want to continue life support treatments in the ICU, or would you rather stop life support (with a high likelihood of death) and have care focused on your comfort and dignity?

Select only one answer

Continue life support



0	Continuing to actively treat the patient
\bigcirc	Talking to the family about stopping active treatment

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You were admitted to hospital as you were very ill and a doctor decided that in order for you to survive, you needed to be admitted to the Intensive Care Unit, placed in an induced coma and put on a ventilator while you received treatment for your illness.

It has now been 1 week since you were admitted and you HAVE NOT improved as the doctors would have hoped. The following questions show the likely outcomes from here.

Situation 7

With ongoing treatment, if you survive, you would be expected to require ongoing uncomfortable and potentially painful treatment in hospital for a further	4 weeks
With continued treatment, your chance of death is	Moderate risk (i.e. 50%)
If you do survive, your likelihood of permanent problems with your memory and concentration (such that you cannot function independently) is	High risk (i.e. 80%)
If you do survive, your chance of ending up needing assistance caring for yourself (requiring help with toileting and feeding) is	Low risk (i.e. 20%)
If you do survive, your chance of needing full time nursing residential care is	High risk (i.e. 80%)

If you were asked, would you want to continue life support treatments in the ICU, or would you rather stop life support (with a high likelihood of death) and have care focused on your comfort and dignity?

Select only one answer

Continue life support

0	Continuing to actively treat the patient
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Situation 8

With ongoing treatment, if you survive, you would be expected to require ongoing uncomfortable and potentially painful treatment in hospital for a further	1 week
With continued treatment, your chance of death is	Moderate risk (i.e. 50%)
If you do survive, your likelihood of permanent problems with your memory and concentration (such that you cannot function independently) is	Low risk (i.e. 20%)
If you do survive, your chance of ending up needing assistance caring for yourself (requiring help with toileting and feeding) is	High risk (i.e. 80%)
If you do survive, your chance of needing full time nursing residential care is	High risk (i.e. 80%)

If you were asked, would you want to continue life support treatments in the ICU, or would you rather stop life support (with a high likelihood of death) and have care focused on your comfort and dignity?

Select only one answer

Continue life support

ं	Continuing to actively treat the patient
\circ	Talking to the family about stopping active treatment

You were admitted to hospital as you were very ill and a doctor decided that in order for you to survive, you needed to be admitted to the Intensive Care Unit, placed in an induced coma and put on a ventilator while you received treatment for your illness.

It has now been 1 week since you were admitted and you HAVE NOT improved as the doctors would have hoped. The following questions show the likely outcomes from here.

Situation 9

With ongoing treatment, if you survive, you would be expected to require ongoing uncomfortable and potentially painful treatment in hospital for a further	1 week
With continued treatment, your chance of death is	Moderate risk (i.e. 50%)
If you do survive, your likelihood of permanent problems with your memory and concentration (such that you cannot function independently) is	High risk (i.e. 80%)
If you do survive, your chance of ending up needing assistance caring for yourself (requiring help with toileting and feeding) is	Moderate risk (i.e. 50%)
If you do survive, your chance of needing full time nursing residential care is	Low risk (i.e. 20%)

If you were asked, would you want to continue life support treatments in the ICU, or would you rather stop life support (with a high likelihood of death) and have care focused on your comfort and dignity?

Select only one answer

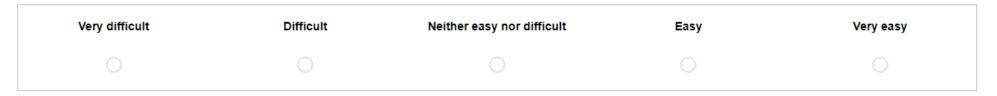
Continue life support



Continuing to actively treat the patient	
Talking to the family about stopping active treatment	



How difficult was it to choose whether to receive the intervention or not?



Section C: Information about you

You have now completed the main part of the experiment. Thank you.

Before we finish, we need you to answer a few more questions about you. This is to ensure we have a good spread of respondents.

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v v	ı ıaı		voui	sex?
			,	

Select only one answer	
○ male	
○ female	
What is your current ago (in years)?	

What is your current age (in years)?

What is your country of birth?

O Australia
Other English-speaking country
Other NON-English-speaking country

What is your main language?

Select only one answer					
○ English					
Other					
Which of these describe your current living arrangements? Tick all that apply Select all that apply					
I live alone					
I live with my spouse/partner					
I live with my children					
I live with my parent(s)					
I live with my sibling(s)					
I live with other adult family members					
I live with other adults (not family members)					

How many children do you have in the following age ranges?

Select one response from each row

	No children in this age range	1 child	2 children	3 or more children
Less than five years old	0	\circ	0	0
Five to eighteeen years old	0	0	0	0

() V	/ery religious
() s	Somewhat religious
() N	lot religious
O v	/ery non religious

As far as you know, do you have any of the following health conditions at the present time?

Select all that apply

Asthma, emphysema, or chronic bronchitis
Arthritis or rheumatism
Cancer diagnosed in last 3 years
Diabetes
Digestive problems (such as ulcer, colitis, or gallbladder disease)
Heart trouble (such as angina, congestive heart failure, or coronary artery disease)
HIV illness or AIDS
Kidney disease
Liver problems (such as cirrhosis)
Stroke
None of these

Have you ever been admitted to an Intensive Care Unit?

Select only one answer						
○ Yes						
○ No						
Has a member of your immediate family ever been admitted to an Intensive Care Unit? Select only one answer						
○ Yes						
○ No						
prev	next					
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PAIN / DISCOMFORT: Please select the one option that best describes your health TODAY

Select only one answer

○ I have no pain or discomfort	
I have slight pain or discomfort	
I have moderate pain or discomfort	
I have severe pain or discomfort	
I have extreme pain or discomfort	

ANXIETY / DEPRESSION: Please select the one option that best describes your health TODAY

○ I am not anxious or depressed
○ I am slightly anxious or depressed
○ I am moderately anxious or depressed
○ I am severely anxious or depressed
○ I am extremely anxious or depressed

In general would you say that your health is:

Select only one answer

Excellent	Very good	Good	Fair	Poor
	\circ	\circ	\circ	\circ

Do you agree or disagree with the following statements?

Select one response from each row

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know/refuse
I am asked to do an excessive amount of work.	0	\circ	0	0	0	0
I have thoughts about leaving my current position/job.	0	0	\circ	\circ	\circ	0
In my ICU, death is perceived as a treatment failure, so decisions to withdraw or withhold therapy are seldom made.	0	0	0	0	0	0
In general, I think that the ICU is the best place to provide a good death. prev	0	0	0	0		nex

Thank you

You have now finished the task. We appreciate your time and your contribution. To help us improve this survey, we would value your thoughts about how you answered this survey, any aspects you found difficult, or any other thoughts.

If you have any specific comments relating to the survey, we would really valuable your input in the box below.

Enter text below	
	,

prev

Thank You

That concludes the survey

prev

submit answers and finish