

Project title: *Making health decisions on behalf of others: A national survey of knowledge, attitudes and intentions of Australian adults on substitute decision-making*

SURVEY QUESTIONS

DEMOGRAPHICS

Below are some questions about you

- a) What is your gender?
 - Male
 - Female
 - Prefer not to say
 - Other: specify

- b) In what year were you born?

- c) Are you of Aboriginal or Torres Strait Islander origin?
 - Neither Aboriginal or Torres Strait Islander
 - Aboriginal
 - Torres Strait Islander
 - Aboriginal and Torres Strait Islander
 - Prefer not to say

- d) In what country were you born?
 - Australia
 - Other: please specify

- e) How many years have you lived in Australia? (If other is selected)

- f) In which state do you live?
 - Australian Capital Territory
 - New South Wales
 - Northern Territory
 - Queensland
 - South Australia
 - Tasmania
 - Victoria
 - Western Australia

- g) What is your postcode?

- h) What is your relationship status?
 - Married/de facto
 - Separated
 - Divorced
 - Widowed
 - Single

- In a relationship

i) Do you have any children?

- Yes – please complete the table (j)
- No

j) What is the age and gender of your child or children? Please indicate whether or not they have been adopted.

Child:	Age	Gender (Male, Female)	Adopted (Yes, No)
1			
2			
3			
4			
5			
6			

k) What is your religion?

- Anglican (Church of England)
- Baptist
- Buddhism
- Catholic
- Greek Orthodox
- Hinduism
- Islam
- Uniting Church
- No religion
- Other: specify

l) What is your highest of level of education?

- Years 1-6
- Years 7-10
- Years 11-12
- Certificate III/IV
- Diploma/Advanced Diploma
- Bachelor degree (including Honours)
- Graduate Diploma/Graduate certificate
- Postgraduate degree (Master, PhD, Doctorate)

m) What is current employment status?

- Full-time
- Part-time
- Not employed
- Retired

n) Have you worked in any of the following professions?

- Aged Care
- Financial planning services
- Funeral services
- Health care
- Legal practice
- Social services
- None of the above

o) Do you speak any languages other than English at home?

- Yes: please specify
- No

KNOWLEDGE: Advance Care Planning and Substitute Decision-Making

1. *Do you know about ways you can plan for your future medical care and what would happen if you could not make decisions or speak for yourself?*

- Yes -
- No – go to 1.11

1.1 Advance Care Planning description/definition (If Yes to Q1)

This is known as advance care planning. Advance care planning is a process which focuses on understanding your values and preferences regarding your future medical decisions. Your preferences then inform medical decisions if you are ever unable to decide or speak for yourself. You may choose to record your preferences in a legally binding document, which is called an advance care directive, also known as Advance Health Directive, Health Direction or Advance Personal Plan (depending on your state or territory).

1.1.1 Advance Care Planning description/definition (if No to Q1)

You can plan for your future medical care through advance care planning. Advance care planning is a process which focuses on understanding your values and preferences regarding your future medical decisions. Your preferences then inform medical decisions if you are ever unable to decide or speak for yourself. You may choose to record your preferences in a legally binding document, which is called an advance care directive, also known as Advance Health Directive, Health Direction or Advance Personal Plan (depending on your state or territory).

1.2 Prior to this survey, had you previously heard of advance care planning?

- Yes
- No (go to Q2)

1.3 From which of the following source(s) did you learn or hear about advance care planning? Please select all that apply (if Yes to Q1)

- An event: please specify
- Family or friends
- Traditional media (go to Q2.1) (TV, radio, newspaper, magazines, flyers/brochures/booklets, signs/billboards)
- New media (social media, e.g. Facebook, Twitter, website, smartphones)
- Health care professional (e.g. nurse, GP)
- Legal professional
- Financial planner
- Other: please specify

1.3.1 From which traditional media did you learn or hear about advance care planning? (if Traditional Media is selected in Q1.3)

- Television
- Radio
- Newspaper
- Magazines
- Flyers/brochures/booklets
- Signs/billboards

1.3.2 From which new media did you learn or hear about advance care planning? (if New Media is selected in Q1.3)

- Facebook
- Twitter
- Website (excluding social media websites Facebook, Twitter, etc.)
- Smartphone apps (excluding social media apps Facebook, Twitter, etc.)
- Other: please specify

1.4 Have you ever had a discussion about advance care planning?

- Yes
- No (go to Q2)

1.5 Who of the following did you have a discussion about **your own** advance care planning with? Please select all that apply.

- Your family
- Friends
- Health professional(s)
- Legal practitioner
- Other: please specify

1.6 After the discussion, what was the outcome? Please select all that apply.

- I told my family, friends or doctor about medical treatments I would or would not want if I could no longer tell them
- I completed a document outlining my future medical treatment and care preferences in writing
- I completed a form appointing someone to make medical decisions on my behalf in case I could no longer tell them in the future
- I decided not to complete advance care planning
- Other: please specify

1.7 Have you ever been involved in a discussion with your family, friends or other people about **their** preferences regarding advance care planning?

- Yes
- No

2. Do you know that a person can choose to legally appoint someone to make medical decisions on their behalf if they can no longer decide for themselves?

- Yes
- No

2.1 Substitute Decision-Maker description/definition

These people are known as substitute decision-makers. Depending on the state or territory you live in, they might be called an attorney, enduring guardian, or medical treatment decision-maker but they refer to a person who is legally appointed to make medical decisions on someone's behalf if they are ever unable to make these decisions for themselves due to illness or injury. We will refer to this role as 'Substitute Decision Maker' for the remainder of the survey.

3. Below are statements regarding substitute decision-makers. Please indicate whether you think these are true or false (or don't know where applicable).

	True	False	Don't Know
1 To help them to make their decisions, substitute decision-makers can access all information about the person they are making decisions for, from healthcare provider(s).	X		
2 Substitute decision-makers cannot seek a second opinion from other healthcare providers to help inform them when making decisions on someone's behalf		X	
3 Where I live, there are no laws about substitute decision-makers		X	
4 Substitute decision-makers are limited in who they can consult in helping them make their decisions		X	

5 Once a person has been legally appointed as a substitute decision-maker, they cannot resign from that appointment		X	
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***correct answers**

4. Have you ever made medical decisions on an adult's behalf after you were appointed by them as their substitute decision-maker?

Yes – go to 4.1

No – go to question 5A

4.1 What type of medical decisions did you have to make?

4.2 What were the most challenging aspects of making these decisions (if any)?

4.3 What type of support (if any) did you access to help you with your decisions?

ATTITUDES: Substitute Decision-Making

5A. Below are statements about appointing or being appointed a substitute decision-maker. Please indicate your level of agreement to each of the statements, with 1 being strongly agree and 5 being strongly disagree.

Statements	1 Strongly agree	2 Agree	3 Neither disagree or agree	4 Disagree	5 Strongly disagree
Appointing a substitute decision-maker is not a priority for me at the moment					
If I was appointed, I would feel confident in my role as a substitute decision maker (<u>only if No to Q4</u>)					
Making medical decisions on someone's behalf would be a difficult and stressful experience for me (<u>only if No for Q4</u>)					
Making medical decisions on someone's behalf can be a difficult and stressful experience for me (<u>only if Yes to Q4</u>)					

It is best if only family members are appointed as substitute decision makers.					
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5B. Below are statements about how substitute decision-makers should make their decisions. Please indicate your level of agreement to each of the statements, with 1 being strongly agree and 5 being strongly disagree.

Statements	1	2	3	4	5
	Strongly agree	Agree	Neither disagree or agree	Disagree	Strongly disagree
It is important for substitute decision-makers to:					
consider a person's past values and preferences when making decisions on their behalf					
consistently follow the preferences outlined in advance care directives (a document outlining the person's preferences in writing)					
consider advice from health care providers when making decisions on someone's behalf					
consider a person's past values and preferences, as well as the advice of health care providers when making decisions on someone's behalf					
know where to seek support when needed					

NEEDS, CONCERNS AND INTENTIONS: Substitute Decision-Making

6. Please read the following scenario carefully and answer the following questions as honestly as you can. There are no right or wrong answers.

Scenario 1

Julia is 72 years old. She has advanced breast cancer, but she is still able to make plans regarding her future medical care. She is thinking about appointing a substitute decision maker to make medical decisions on her behalf in case she becomes too unwell and can no longer decide for

herself. She is married and lives with her husband. She has two children, a son and daughter. Julia plans to appoint her son, Ryan, the younger of the children to be her substitute decision-maker.

6.1 What do you think were Julia's main considerations when weighing up who to appoint as her substitute decision maker? Please rank in order of importance, with 1 being the most important.

- The person appointed is caring
- The person appointed will be able to cope with the substitute decision-maker role
- The person appointed is honest
- The person appointed is someone she trusts to make decisions that she would make herself
- The person appointed knows about her preferences for medical care
- The person appointed has a similar outlook to herself
- The person appointed will make the right decision
- The person appointed knows about health care and the decisions to be made
- Other: please specify

6.2 What do you think would be Julia's main concerns when deciding about who to appoint as her substitute decision maker? Please rank in order of importance, with 1 being the most important.

- The person appointed may not accept the role
- The person appointed might not be available when important decisions are needed to be made
- The person appointed might lack or misinterpret the information necessary to make an informed decision
- The person appointed might not be able to cope with the responsibilities
- The person appointed may not make the right decision
- If she chooses her youngest child she may upset her husband and / or her oldest child
- Other: please specify

6.3 What do you think Ryan was thinking or feeling about the possibility of becoming his mother's substitute decision maker?

6.4 What do you think would be Ryan's main considerations in accepting his appointment as a substitute decision maker? Please rank in order of importance, with 1 being the most important.

- He might not make the right decision for his mother
- He might feel uncertain about the outcomes of the decisions made
- He may not be able to cope with the stress that comes with the role
- The decisions he is expected to make might cause family conflict
- He is prepared to make important medical decisions when needed
- He is willing to act based on his mother's preferences
- He clearly understands his duties and responsibilities
- He knows where he can get help regarding his role if he needs it

- He feels he is the right person to be his mother's SDM
- He aims to be fair in his decisions so that family conflict is avoided
- Other: please specify

6.5 Based on the order of Ryan's considerations, do you think he should accept his appointment?

	<i>Strongly agree</i>	<i>Agree</i>	<i>Neither disagree or agree</i>	<i>Disagree</i>	<i>Strongly disagree</i>
<i>Ryan should accept his appointment</i>					

7. Please read the following scenario carefully and answer the following questions. There are no right or wrong answers.

Scenario 2

Mathew is 76 years old, and is in hospital after a stroke. His doctor has said that he requires minor surgery for tube feeding. He is currently unable to make his own decisions regarding his treatment. His daughter, Sarah, is his appointed substitute decision maker. Matthew has previously completed an Advance Care Directive and stated in this that he would not like to have life prolonging treatment, such as surgery, or tube feeding if he were to be in a situation such as this. Sarah is aware of the advance care directive and its contents. Mathew's son, Connor, has also been included in discussions with Sarah and Matthew's doctor. The preferences outlined in Mathew's advance care directive are new to Connor and he has not previously considered his father's treatment preferences.

7.1 What do you think Sarah was thinking or feeling about the possibility of following her father's preferences in his Advance Care Directive?

7.2 What do you think were some of the thoughts Sarah considered before making her decision? Please drag and drop to rank in order of importance.

- She should be actively involved to ensure that decisions are consistent with her father's preferences
- She should seek advice from another doctor
- She should let the doctor decide as she trusts his medical expertise
- She should talk to her brother about the decision
- She should resign as the substitute decision maker
- She should let Connor make the decision
- Other: please specify

7.3 What type of support could Connor/Sarah be offered after having made his/her decision?

RESOURCE DEVELOPMENT

8. If you wanted more information about how to support substitute decision-makers make their decisions, which of the following source(s) of information would you prefer?

- An event: please specify
- Discussion with a family member or friend
- Traditional media (go to Q8.1)
- New media (go to Q8.2)
- Health care professional (e.g. nurse, GP)
- Other: please specify

8.1 From which traditional media would you like to be informed about support for substitute-decision makers?

- Television
- Radio
- Newspaper
- Magazines
- Flyers/brochures/booklets
- Signs/billboards
- Other: please specify

8.1.1 Why did you rank this as the most preferred?

8.1.2 Please provide reasons for selecting this option

8.2 From which type of new media would like to be informed about support for substitute decision makers?

- Facebook
- Twitter
- Website (excluding social media websites Facebook, Twitter, etc.)
- Smartphone apps (excluding social media apps Facebook, Twitter, etc.)
- Other (e.g. USBs): please specify

8.2.1 Why did you rank this as the most preferred?

8.2.2 Please provide reasons for selecting this option

9. Which of the following information about substitute decision-makers would be most important to you? Please rank in order of importance, with 1 being the most important.

Themes	Rank
Traits and qualities of substitute decision-makers (e.g. over 18, trustworthy, willing and able, etc.)	
Rights and responsibilities of substitute decision-makers (e.g., follow instructions, right to access information about the person, right to resign, etc.)	

Limitations for substitute decision-makers (e.g. that medical substitute decision-makers cannot make legal or financial decisions unless authorised to do so)	
Benefits of being substitute decision-makers (e.g. knowing you are trusted, helping a person to have their preferences respected)	
Challenges of being substitute decision-makers (e.g. stress, family conflict, putting aside their own values)	
Needs and concerns of substitute decision-makers	
Support for substitute decision-makers (e.g. further information, advice, counselling)	

10. Why did you think X was the most important?

10.1 Please provide your reasons

11. Why did you think X was the least important?

11.1 Please provide your reasons

12. What other information do you think is important?