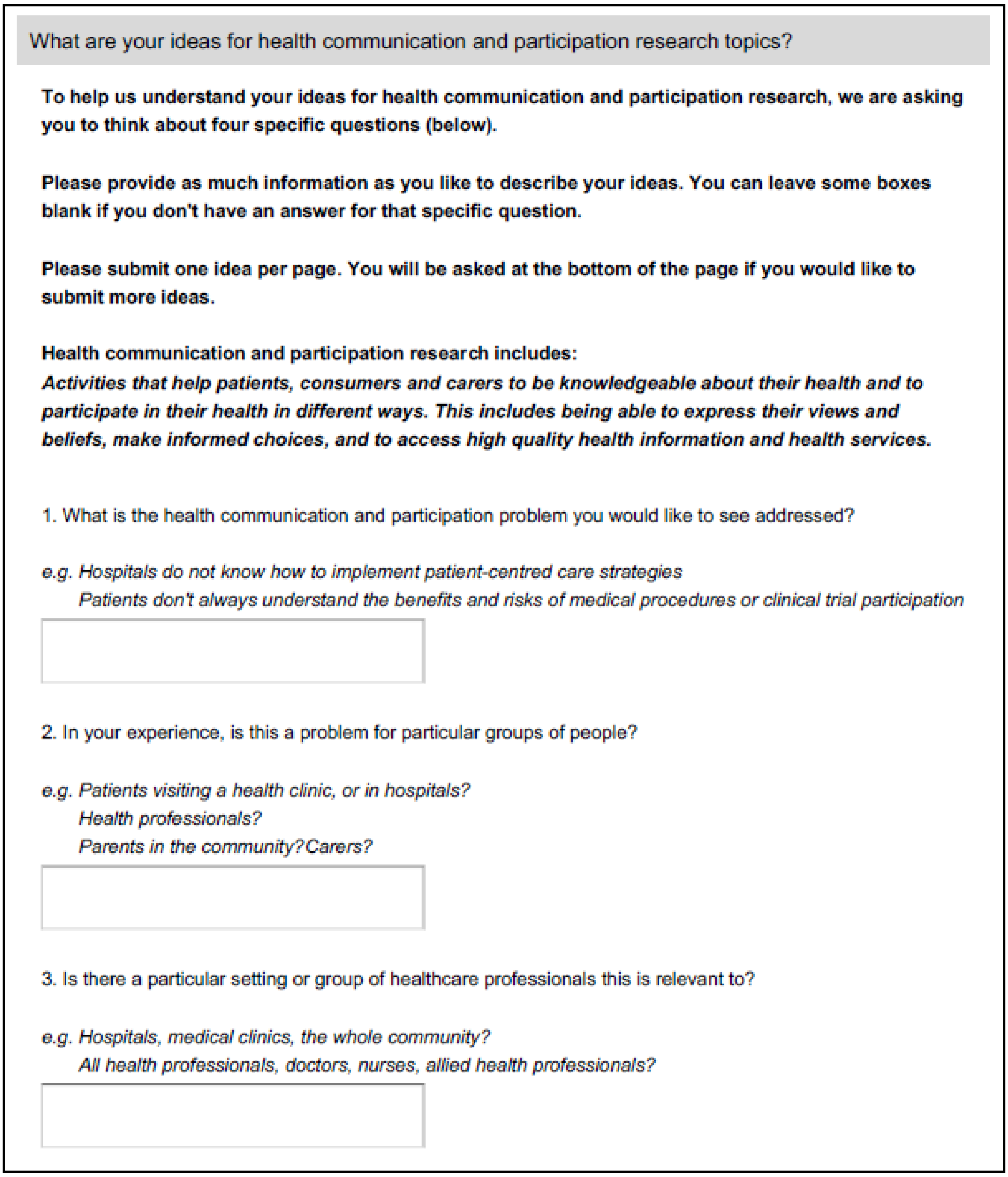
SUPPLEMENTARY FILE

S1. Online survey



What are your ideas for health communication and participation research topics?

To help us understand your ideas for health communication and participation research, we are asking you to think about four specific questions (below).

Please provide as much information as you like to describe your ideas. You can leave some boxes blank if you don't have an answer for that specific question.

Please submit one idea per page. You will be asked at the bottom of the page if you would like to submit more ideas.

Health communication and participation research includes:
Activities that help patients, consumers and carers to be knowledgeable about their health and to participate in their health in different ways. This includes being able to express their views and beliefs, make informed choices, and to access high quality health information and health services.

1. What is the health communication and participation problem you would like to see addressed?

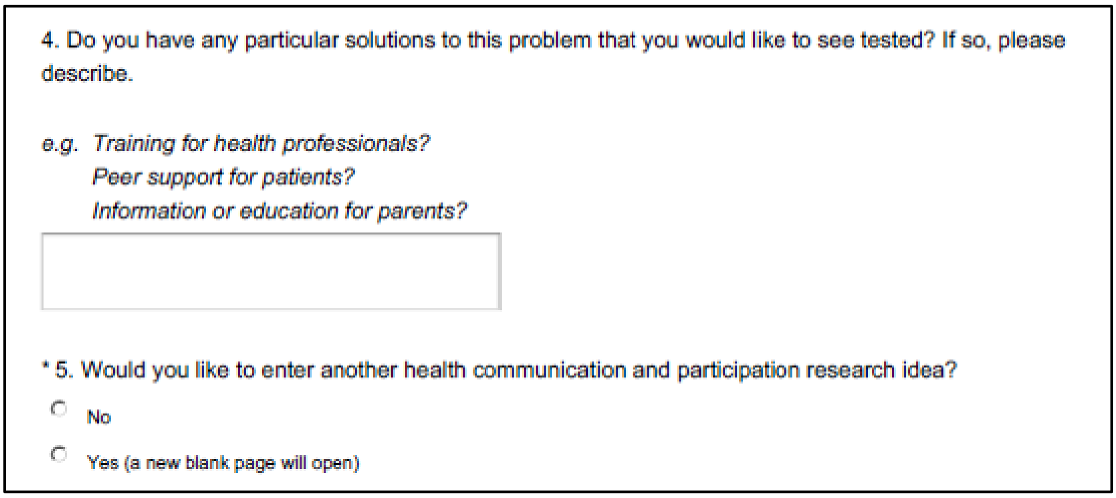
e.g. Hospitals do not know how to implement patient-centred care strategies
Patients don't always understand the benefits and risks of medical procedures or clinical trial participation

2. In your experience, is this a problem for particular groups of people?

e.g. Patients visiting a health clinic, or in hospitals?
Health professionals?
Parents in the community?Carers?

3. Is there a particular setting or group of healthcare professionals this is relevant to?

e.g. Hospitals, medical clinics, the whole community?
All health professionals, doctors, nurses, allied health professionals?



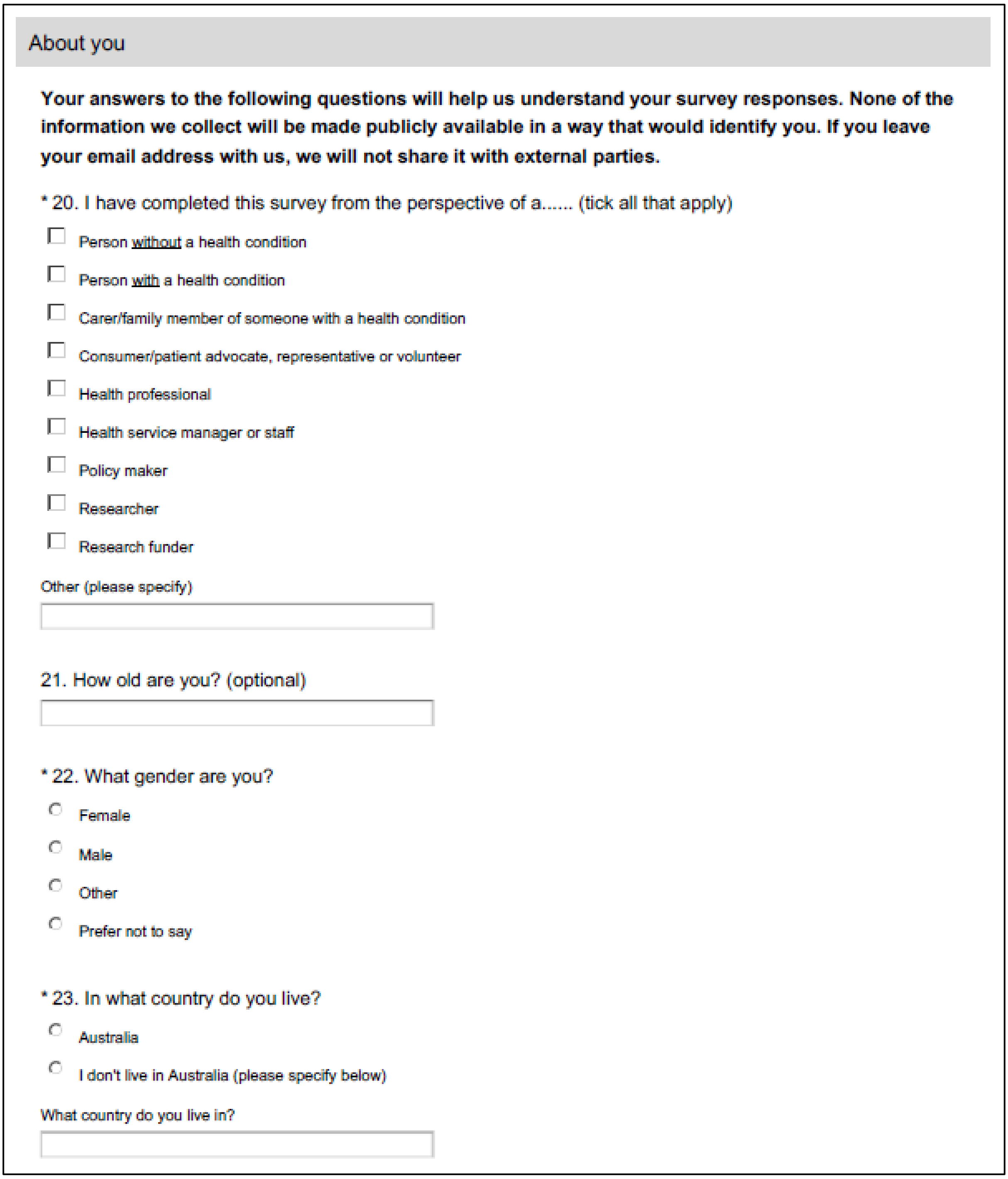
4. Do you have any particular solutions to this problem that you would like to see tested? If so, please describe.

e.g. Training for health professionals?
Peer support for patients?
Information or education for parents?

* 5. Would you like to enter another health communication and participation research idea?

○ No

○ Yes (a new blank page will open)



About you

Your answers to the following questions will help us understand your survey responses. None of the information we collect will be made publicly available in a way that would identify you. If you leave your email address with us, we will not share it with external parties.

* 20. I have completed this survey from the perspective of a...... (tick all that apply)

☐ Person without a health condition

☐ Person with a health condition

☐ Carer/family member of someone with a health condition

☐ Consumer/patient advocate, representative or volunteer

☐ Health professional

☐ Health service manager or staff

☐ Policy maker

☐ Researcher

☐ Research funder

Other (please specify)

21. How old are you? (optional)

* 22. What gender are you?

○ Female

○ Male

○ Other

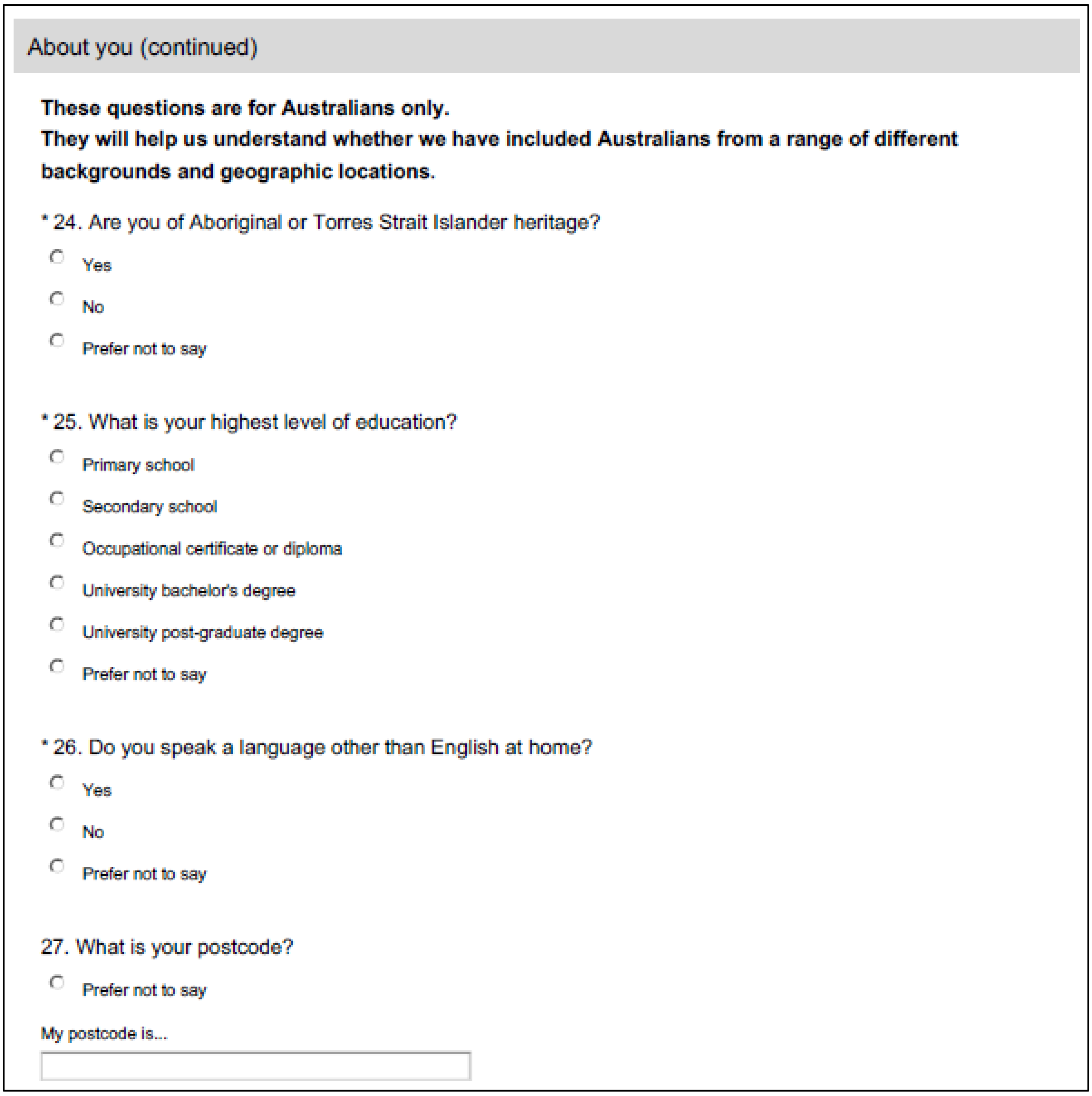
○ Prefer not to say

* 23. In what country do you live?

○ Australia

○ I don't live in Australia (please specify below)

What country do you live in?



About you (continued)

These questions are for Australians only.
They will help us understand whether we have included Australians from a range of different backgrounds and geographic locations.

* 24. Are you of Aboriginal or Torres Strait Islander heritage?

○ Yes

○ No

○ Prefer not to say

* 25. What is your highest level of education?

○ Primary school

○ Secondary school

○ Occupational certificate or diploma

○ University bachelor's degree

○ University post-graduate degree

○ Prefer not to say

* 26. Do you speak a language other than English at home?

○ Yes

○ No

○ Prefer not to say

27. What is your postcode?

○ Prefer not to say

My postcode is...

Table S1. Participant characteristics (by broad stakeholder group)

Characteristics	Broad stakeholder group		
	Consumer/ carer[1] n (%)	**Professional**[2] n (%)	**Both**[3] n (%)
Age (years; mean ± SD, range)	53 ± 14 (18 to 80)	44 ± 11 (24 to 65)	53 ± 11 (25 to 67)
Female	39 (81)	59 (79)	19 (76)
Stakeholder perspective[4]			
Person *without* a health condition	8 (17)	19 (25)	5 (20)
Person *with* a health condition	25 (52)	13 (17)	13 (52)
Carer/family member of someone with a health condition	19 (40)	19 (25)	11 (44)
Consumer/patient advocate, representative or volunteer	32 (67)	0 (0)	25 (100)
Health professional	0 (0)	40 (53)	15 (60)
Health service manager or staff	0 (0)	13 (17)	6 (24)
Policy maker	0 (0)	6 (8)	4 (16)
Researcher	0 (0)	34 (45)	9 (36)
Research funder	0 (0)	1 (1)	0 (0)
Other[5]	6 (13)	3 (4)	2 (8)
Country			
Australia	38 (79)	51 (68)	21 (84)
United Kingdom	3 (6)	10 (13)	0 (0)
Canada	2 (4)	4 (5)	1 (4)
United States	2 (4)	3 (4)	1 (4)
Other[6]	3 (6)	7 (9)	2 (8)

[1] Included those who selected one or more of the following 'stakeholder perspectives': Person without a health condition, Person with a health condition, Carer/family member of someone with a health condition, Consumer/patient advocate, representative or volunteer or Other (in the instances that they described a non-professional role in health). This category only included participants who did not tick any of the health care, policy or research professional categories.

[2] Included those who selected one or more of following 'stakeholder perspectives': Health professional, Health service manager, Policy maker, Researcher or Other (in the instances that they described currently or previously holding a professional role in health). Participants who also ticked one or more of: Person without a health condition, Person with a health condition, Carer/family member of someone with a health condition, were also coded into this category.

[3] Included people who selected one or more of the Professional 'stakeholder perspectives' and the Consumer/patient advocate, representative or volunteer perspective

[4] Participants could tick more than one 'stakeholder perspective' so numbers and percentages for each item do not add up 100%.

[5] Included responses such as retired health care, policy or research professionals and consumers who worked at, or with, national or state-based health organisations or advocacy groups.

[6] Included Belgium, Germany, India, Ireland, Malaysia, Netherlands, New Zealand and Sri Lanka.

Abbreviations: n = number of participants, SD = standard deviation

Table S2. Additional demographic characteristics for Australian participants only

Characteristic	**TOTAL** (N = 110, %)[1]
Age (mean ± SD, range)	48.7 ± 13.3 (18 to 80)
Gender (n = , % female)	88 (80)
Highest education level	
Primary school	0 (0)
Secondary school	2 (2)
Occupational certificate or diploma	12 (13)
University bachelor's degree	25 (27)
University post-graduate degree	64 (68)
Identify as Indigenous (yes,)	2 (2)
Non-English speaking background (yes,)	15 (15)
Area of residence[2]	
Metropolitan	74 (85)
Non-metropolitan	13 (15)
Location of residence, by state or territory	
Victoria	34 (39)
New South Wales / Australian Capital Territory	18 (21)
South Australia	17 (20)
Queensland	9 (10)
Western Australia	4 (5)
Tasmania	4 (5)

[1] Not all participants answered all demographic questions, therefore totals numbers for each demographic characteristic do not always add up to n = 110.

[2] Area of residence was extrapolated from postcodes provided by participants using ARIA+ (Accessibility/Remoteness Index of Australia).[1]

Abbreviations: n = number of participants, SD = standard deviation

References

1. Hugo Centre, *Accessibility/Remoteness Index of Australia Plus 2011 (ARIA+ 2011).* . 2014, Hugo Centre for Migration and Population Research, the University of Adelaide: Adelaide, South Australia.

Table S3. Priority research themes and topics to inform systematic reviews in health communication and participation, split into stakeholder groups, with example quotes from stakeholders.

	Consumer/ carer[1] (n =)	**Professional**[2] (n =)	**Both**[3] (n =)	**NR**[4] (n =)
Theme 1: Health service-level issues				
Breakdowns in communication and coordination of care between and within health services are common *Communication is pretty awful. We've had specific issues around check-ups for a child over a number of years where the hospitals don't talk and the hospitals and GP don't talk. Sometimes the hospital doesn't even talk to itself!* (Person who identified as both consumer/carer and professional)	4	9	2	0
The term patient-centred care is poorly understood and implemented by health services and health professionals *There is no aligned understanding of 'patient-centred care'. Each sector, stakeholder group has a different understanding. Without a common understanding ' patient-centred care' has no practical implementation benefits* (Person who identified as both consumer/carer and professional)	4	4	5	1
The quality and safety of patient care can be compromised by health services (particularly hospitals) not treating patients holistically *I would like to see patient comfort attended to holistically. When a patient attends hospital for any procedure there is a financial component either with medical costs or financial issues at home. This causes stress if not addressed appropriately thus impacting on patient recovery* (Consumer/carer)	8	5	0	0
Cultural safety is not well-embedded in health services	4	4	2	0

	Consumer/ carer[1] (n =)	**Professional**[2] (n =)	**Both**[3] (n =)	**NR**[4] (n =)
Health professionals are not always able to take into consideration language and cultural needs of patients (Consumer/carer) *Cultural safety is not embedded well in health services and as a result our Aboriginal population struggles even further to access services required* (Professional)				
Informed consent for treatment and research does not always happen *Patients don't always understand the benefits and risks of medical procedures or clinical trial participation as true informed consent has not been obtained* (Professional)	0	5	1	0
Not enough time is given to allow good communication between health professionals and patients *Doctors don't always give patients time to express themselves during consultations (due to time constraints). Creates a tension with expectations and can lead to misdiagnosis* (Professional)	0	5	1	0
Theme 2: Health professional-level issues				
Some health professionals don't understand or ask patients about their preferences and priorities *It is really hard to open up the discussion with your GP of what kind of treatment you would like to receive or not from my experience. It is common practice that GPs prescribe something and there are no options given or explained* (Consumer/carer)	5	4	5	0
Some health professionals don't provide enough information to patients (some don't think it's a priority) *Doctors do not explain why they prescribe treatments and interventions, nor ask about patient preferences regarding treatment and outcomes* (Consumer/carer)	8	3	4	0

	Consumer/ carer[1] (n =)	**Professional**[2] (n =)	**Both**[3] (n =)	**NR**[4] (n =)
Health professionals don't always provide enough support for patient decision-making *The patient and carer (should be) treated as part of the decision and not only be on the receiving end of the decision that is reached by the caring team* (Person who identified as both consumer/carer and professional)	3	5	2	0
There are often two-way barriers to adequate communication and participation (e.g. disability of individual plus discomfort of health professional) *Those who are older or disabled (including young patients) [have a] fear…of going into hospital and whether they would get the same treatment as an 'able bodied person and/or younger healthier person* (Consumer/carer)	3	3	0	1
Health professionals don't always know how to gauge how much their patients understand *Health professionals in all settings (primary care, hospitals, private practice etc) all have significant issues gauging the health literacy capabilities of the range of clients they see, and altering their communication practices accordingly* (Professional)	1	2	1	0
Theme 3: Consumers and carer issues in their own care				
Patients don't always understand their health problems, treatment options or their rights *Improve patient understanding of their medical care (particularly for patients [who are] non-native English speakers)* (Consumer/carer)	4	5	0	1
Consumers and carers don't always know about all the options or services that exist	1	8	0	0

	Consumer/ carer[1] (n =)	**Professional**[2] (n =)	**Both**[3] (n =)	**NR**[4] (n =)
[When] caring for ill/debilitated/incapacitated persons at home - carers are not told what choices are available for them, just told what they can have, and for carers, often you can't ask if you don't know (Consumer/carer)				
Consumers and carers aren't always able to participate actively in their care *Patients need to be encouraged to ask more questions and to be more assertive in their own care. And to understand the need for active involvement in their care as a partner with the healthcare team* (Professional)	1	2	2	0
The general public doesn't always have enough health literacy to navigate the health system and make health decisions *Health literacy. Many people do not have the skills/education or language skills to negotiate healthcare (and other) systems* (Professional)	2	2	1	0
Patients often experience information overload and are unable to retain the important information *Patients don't recall or understand, and can be confused by, verbal information provided by health professionals. This is because people's retention of oral information is low. Made worse by being unwell, stress related to serious illness, Dr's accent, medical terminology, conflicting information from other providers, being in a second language* (Health professional)	3	1	0	0
Consumers and carers have difficulty understanding key medication information *Decisions about medication use are often based on incomplete understanding of the potential for benefit and harm, particularly in terms of clinical outcomes of importance to health* (Professional)	0	2	2	0
Theme 4: Issues for broader consumer and carer involvement				

	Consumer/ carer[1] (n =)	**Professional**[2] (n =)	**Both**[3] (n =)	**NR**[4] (n =)
Health researchers don’t adequately involve patients in research, nor share their findings *Researchers don't know how (or why they should) involve patients and carers in designing and reporting their research* (Consumer/carer)	5	9	3	2
Health services don’t properly involve consumers and carers in health service planning and design *Frequently we ask consumers to review the material already produced or to be involved on a working group for a project health professionals have developed without asking the consumers what work needs to be done or even if the information being documented is what they want and in a format they want* (Professional)	4	7	0	0
Theme 5: Accessibility of high quality health information				

‘Official’ health information can be contradictory and hard to understand, both written and online. Consumers and professionals don’t know how to find and assess good quality information online *Standardised national leaflets about conditions provided by different sources (charities, NHS trusts, condition specific support groups), the information can vary wildly* (Consumer/carer)	3	11	4	0
Theme 6: Ageing and end of life care				
There is not enough support or understanding about the needs of older people and end of life decisions are poorly understood by patients, families and the community *Patients and their relatives are often unprepared for the possibility of death, and health professionals frequently perform poorly in managing communication around this issue (particularly in critical care environments)* (Professional)	5	2	0	1

[1] Included those who selected one or more of the following ‘stakeholder perspectives’: Person without a health condition, Person with a health condition, Carer/family member of someone with a health condition, Consumer/patient advocate, representative or volunteer or Other (in the instances that they described a non-professional role in health). This category only included participants who did not tick any of the health care, policy or research professional categories.

[2] Included those who selected one or more of following ‘stakeholder perspectives’: Health professional, Health service manager, Policy maker, Researcher or Other (in the instances that they described currently or previously holding a professional role in health). Participants who also ticked one or more of: Person without a health condition, Person with a health condition, Carer/family member of someone with a health condition, were also coded into this category.

[3] Included people who selected one or more of the Professional ’stakeholder perspectives’ and the Consumer/patient advocate, representative or volunteer perspective.

[4] Three people did not select any ‘stakeholder perspective’

Abbreviations: n = number of responses, NR = not reported