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TITLE

Stakeholder priorities for research in communication and participation in health: an international survey

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ABSTRACT

OBJECTIVE: To identify stakeholder priorities for research to inform Cochrane Reviews in the area of communication and participation in health (which includes concepts such as patient experience, shared decision making and health literacy).

SETTING: International

PARTICIPANTS: We included anyone with an interest in communication and participation in health. 151 participants across 12 countries took part, including 48 consumers (patients, carers, consumer representatives) and 75 professionals (health professionals, policymakers, researchers) (25 people identified as both).

METHODS: We invited people to submit their research ideas via an online survey. We used inductive thematic analysis to generate priority research topics, then classified these into broader themes.

RESULTS: Participants submitted 200 research ideas, which we grouped into 21 priority topics. These topics most frequently addressed: insufficient consumer involvement in research (19 responses), ‘official’ health information that is contradictory and hard to understand (18 responses), communication and coordination breakdowns in health services (15 responses), health information provision being a low priority for health professionals (15 responses), insufficient eliciting of patient preferences (14 responses), health services that poorly understand or implement patient-centred care (14 responses), lack of holistic care impacting health care quality and safety (13 responses), and inadequate involvement of consumers in service design (11 responses). The priority topics cut across acute and community health settings, and had implications for policy and research. Priority populations included people from diverse cultural and linguistic backgrounds, carers, and people with low educational attainment, or mental illness. Most frequently suggested interventions focussed on training and cultural change activities for health services and health professionals.

CONCLUSIONS: Stakeholders want evidence about interventions to address myriad issues in communication and participation in health, with considerable focus on organisational or governance changes with health services. Solutions should be devised in partnership with consumers, with particular focus on the needs of vulnerable groups.

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STRENGTHS AND LIMITATIONS OF THIS STUDY

- We partnered with consumers and other stakeholders, and used a systematic process, to identify 21 international priority topics for research in the area of communication and participation in health.
- Nearly 50% of stakeholders who suggested research priorities identified as consumers, carers or consumer representatives.
- We have demonstrated the feasibility of priority setting with stakeholders in complex areas, and detail a research-based approach to analysing and categorising participant responses.
- Over 90% of stakeholders were from Australia or other high-income, English-speaking countries, limiting generalisability beyond these countries.
- Some of the examples we used in the survey may have influenced the responses we received.

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INTRODUCTION

People have the right to be actively involved in their health care, and should be provided with high quality, culturally appropriate and timely information, support and services, allowing them to be knowledgeable about, and to participate in their health in different ways.[1-3] Recognised as critical aspects of a well-functioning health system, health funders and deliverers are increasingly seeking to measure and apply concepts such as shared decision-making and person-centred care,[3, 4] patient experience-led improvement,[5] health literacy,[6, 7] or the co-design of health services, policy and research.[8, 9] We refer to these concepts collectively, as experiences of, or activities to improve, 'communication and participation in health'.

Despite considerable efforts, people's experiences of communication and participation in health are often less than optimal.[10, 11] Aside from obvious ethical imperatives, poor communication and inadequate participation in health impacts upon health care quality and safety.[12, 13] For example, poor patient experience and low health literacy are associated with poorer health outcomes, adverse events, increased hospital length of stay and readmissions, reduced adherence to treatment and lower use of preventive services.[12, 14]

In this context, efforts to identify solutions to complex problems in both healthcare and research are increasingly being undertaken in partnership with the people and groups affected by the issues.[1, 15] Often termed 'stakeholders', this includes consumers (patients and their families or carers, those receiving services and the public)[15], and health professionals, managers, policy makers, research funders and researchers.[16] Research priority setting with stakeholders is thought to both align research with the needs of those who it affects,[17] and reduce research waste.[18]

Within the area of communication and participation in health, overarching stakeholder priorities for research are unknown, with the exception of medication adherence[19] and patient safety in primary care.[20] Research priority setting partnerships are typically conducted in discrete clinical areas and settings [17, 21]. However, it is notable that concepts like doctor-patient communication, information and education, consumers as partners, and self-management, are frequently identified as research priorities. For example, one or more of these topics was a top priority in asthma,[22] dementia,[23] palliative care,[24] pre-term birth,[25] and type 1 diabetes.[26] Given potential solutions to these problems are complex[27] and common across conditions,[28] an in-depth exploration of research priorities in this area across health conditions and contexts is valuable.

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In March 2015, we commenced a research priority setting project to identify future Cochrane Intervention Review topics in communication and participation in health.[29] Project aims were to (1) identify stakeholder priorities for research in communication and participation in health, broadly, and (2) use this list to identify five priority topics for Cochrane Reviews. Here we describe the project's first stage (meeting the first aim), using an international online survey.[28]

METHODS

The methods were informed by guidance from the James Lind Alliance,[30] and Cochrane Priority Setting Methods Group.[31, 32] In this first stage, we conducted an online survey.

We worked in partnership with stakeholders to plan and undertake all project stages.[33] Our approach was informed by the principles of co-production (i.e. stakeholders are active agents with respected expertise, blurred roles between researchers and stakeholders, with mutually-beneficial and reciprocal relationships).[34, 35] We reported activities and data against the relevant sections of a 32-item research priority setting appraisal checklist.[36, 37] The study was approved by the La Trobe University Science Health and Engineering College Human Ethics Sub-Committee (S15-52).

Context of the priority setting partnership

The project was initiated by researchers at the Centre for Health Communication and Participation ('the Centre'), La Trobe University, Australia. At this Centre, Cochrane Consumers and Communication (CCC) coordinates the preparation and publication of Cochrane Reviews of interventions that affect the way people interact with healthcare professionals, services and researchers.[28] Conducted as part of a suite of stakeholder engagement activities, the project also coincided with new strategic directions within Cochrane, which encouraged prioritisation of Cochrane Reviews.[38]

Project steering group

We convened a 14-member steering group at project commencement.[30] The group included people representing: the Australian Commission for Safety and Quality in Health Care; the National Health and Medical Research Council, Safer Care Victoria; Victorian health services (with people in

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clinical and managerial positions); health consumer organisations; health consumer representatives; and Cochrane Australia. Two researchers with priority-setting expertise also joined the group. Steering group input was sought to define project scope; advise on participant selection and recruitment; refine identified priorities at key points; and plan and assist with dissemination. We held three face-to-face steering group meetings (some joined by teleconference), with ad hoc input over email.

Scope of the priorities being set

The steering group recommended the project scope reflect the scope of CCC reviews (i.e. 'interventions that affect the way people interact with healthcare professionals, services and researchers').[39] Making sense of research in this area is challenging; interventions are complex[27] with innumerable related and inconsistently-defined concepts,[40, 41] and international variations in terminology and meaning.[42, 43] To aid clarity in survey promotion, we used the term 'health communication and participation research', defined as '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'.[44] We provided examples clarifying that this included broader participation in health services, policy and research. We sought international priorities that could be answered in, or scoped to inform, intervention reviews, given Cochrane's global reach and predominant focus on intervention effectiveness.

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Participants and recruitment

We sought wide participation in the survey internationally; inviting people aged 18 years and over who identified as 'patients, consumers, carers, and their advocates, health professionals, policy makers, researchers, funders, and anyone with an interest in the area'. English-language proficiency was implied given the survey was only available in English.

In May 2015 we promoted the survey by email and in newsletters. Participants could request to complete the survey by post or phone. Organisations and individuals who received the email included consumer groups, government health departments and health networks, medical and nursing colleges, national health organisations and advocacy groups, researchers and CCC authors and other contributors. Additional efforts, in the form of phone calls and facilitated introductions, were made to organisations working with or representing Indigenous people and people from diverse cultural and linguistic backgrounds. We sent weekly reminders over three weeks.

Collecting the priorities

We invited people to share their ‘ideas for future research topics in the area of health communication and participation’ via an online survey (see Supplementary File S1) using SurveyMonkey[45]. We advised that their ideas would inform topic selection of ‘reviews of the latest evidence’. We used the following set of questions: (1) What is the health communication and participation problem you would like to see addressed?, (2) In your experience, is this a problem for particular groups of people?, (3) Is there a particular setting or group of health professionals this is relevant to?, and (4) Do you have any particular solutions you would like to see tested? If so, please describe. Participants could submit up to four research ideas.

The aforementioned survey questions were devised in response to the complexity and breadth of project scope, and in consideration of the diversity of respondents’ familiarity with the topic and terminology. We opened with the ‘problem’ question to (1) provide participants a conceptual ‘anchor’ to enter the survey, (2) generate a description of the context or rationale to inform a potential review;[27, 28] and (3) allow participants to describe what they would like to see research address, without needing to be familiar with the wide range of potential interventions to solve the problem. Subsequent questions allowed participants to share information relevant to generating systematic review questions (i.e. participants, settings and interventions).[46] We took this approach because systematic reviews in communication and participation in health are frequently framed to capture a range of interventions which share a common goal addressing a known issue or problem, for example, interventions to improve safe and effective medicines use by consumers[47] or interventions for providers to promote a patient-centred approach in clinical consultations.[48] We avoided technical research terms (e.g. ‘systematic reviews’, ‘Cochrane reviews’, ‘interventions’) given consumers are often unfamiliar with these terms.[49, 50]

We piloted the survey with four consumers, one health professional and one policy maker. After completing the survey, they participated in a telephone interview, describing the experience and suggesting improvements. The survey structure was endorsed by these participants, and we made minor wording and format changes.

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Analysing and grouping the priorities

We conducted an inductive thematic analysis, using a taxonomy method for analysing qualitative health services research.[51] Taxonomies classify ‘multifaceted, complex phenomena according to a set of common conceptual domains and dimensions’[51] (p.1761), and are well suited to grouping like interventions in communication and participation in health.[52, 53] We used both conceptual (key communication and participation in health concept domains and their essential dimensions) and participant characteristic (identifying characteristics of stakeholders) codes.[51] Two researchers independently coded data, with a third to resolve disagreements (AS, JN, DL). Data was coded iteratively, and we compared interpretations and agreed on a set of codes, then topics and themes.[54, 55]

First, we downloaded data into Microsoft Excel and edited extraneous language to focus on key concepts.[53] For each participant, we coded their data against three conceptual codes: the problem they wanted addressed; who the problem affects (the ‘participants’ in PICO); and potential solutions to be tested in research (the ‘interventions’ in PICO). Given participants were asked to submit their research ideas using four related questions per idea, their answers to these four questions were treated as a single unit (or research idea) in the analysis. At this stage, research ideas that were agreed to be out of scope for future reviews were excluded, while those that contained one of more distinct conceptual problem code were split into two.

We grouped ‘like’ conceptual problem codes together to form priority research topics,[51] which were then aggregated into groups labelled with simple descriptive themes using straightforward health systems language,[56] and that stayed close to the elements specified by respondents.[57] We developed and applied this method of categorising topics because the analysis commenced with the contextual problem (Q1, which was mandatory) and because this aids identification of potential interventions to address this problem or meet this goal but in a non-prescriptive way. This is in contrast to the more commonly used frame of “what is the effect of intervention X for people with Y on outcomes Z” which is used in clinical, condition-specific areas.[30] We retained the terminology used by participants to devise the topics, meaning synonymous terms were included (e.g. consumers and patients.

For the participant characteristics code, we collapsed the 10 stakeholder groups into three; ‘consumer or carer’, ‘health care professionals, policy makers and researchers’ and ‘both’ (see

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Supplementary file, table S1 for definitions) to allow narrative comparison of demographic characteristics and research priorities between stakeholder groups.

We listed the priority topics, grouped by descriptive themes, and included the number of responses coded to each topic. We elected not to present specific interventions and populations suggested for each theme given the considerable overlap in interventions and populations suggested across topics and the sometimes small number of responses per theme.

RESULTS

Participant characteristics

In total, 151 participants from 12 countries took part (see Table 1). Participants were from Australia (n = 110, 74%), United Kingdom (n = 13, 9%), Canada (n = 7, 5%), the United States (n = 6, 4%), and 12 other countries (8%). The mean age (± SD) was 48.9 ± 12.8 years (range 18 to 80 years), and 117 (79%) were female. Nearly all (n = 148, 98%) completed the survey online. The stakeholder groups most commonly nominated were that of consumer/patient advocate, representative or volunteer (n = 57, 38%), then health professional (n = 55, 36%), person with a health condition (n = 51, 34%), carer or family member of someone with a health condition (n = 49, 33%), and researcher (n = 43, 29%).

Table 1. Participant characteristics (N=151)

Characteristic	**TOTAL**[1] n (%)
Age (years; mean ± SD, range)	49 ± 13 (18 – 80)
Female	117 (79)
Stakeholder perspective[2]	
Person *without* a health condition	32 (21)
Person *with* a health condition	51 (34)
Carer/family member of someone with a health condition	49 (33)
Consumer/patient advocate, representative or volunteer	57 (38)
Health professional	55 (36)
Health service manager or staff	19 (13)
Policy maker	10 (7)
Researcher	43 (29)
Research funder	1 (1)
Other[3]	11 (7)
No response provided	3 (2)

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Country	
Australia	110 (74)
United Kingdom	13 (9)
Canada	7 (5)
United States	6 (4)
All other[4]	12 (8)

[1] The total number of participants was n = 151, but the denominator for most items was n = 148 given n = 3 participants did not provide any demographic information

[2] Participants could tick more than one ‘perspective’ so numbers and percentages for each item do not add up 100%.

[3] 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.

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

Many participants nominated more than one stakeholder perspective. We therefore grouped all stakeholders into three main groups: Consumers or carers (n = 48; 32%), Health care professionals, policy makers and researchers (n = 75; 51%), and a group where people identified as both (n = 25; 17%). In Table 1 we present the demographic characteristics for the 151 participants because there did not appear to be any meaningful differences between stakeholder groups (see Supplementary file, table S1). Additional demographic details that were only asked of Australian participants only are presented in Supplementary file, table S2.

Results of the coding process

Overall, 191 ideas for communication and participation in health research were submitted. Ten were removed for being out of scope (n = 8) or lacking sufficient clarity (n = 2). Several remaining ideas were split, as they contained more than one distinct problem. As such, there were 200 research ideas that were coded and grouped into one of 21 research priority topics, and then into one of six overarching priority themes (see Table 2).

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Table 2. Priority topics, grouped by descriptive themes for scoping future systematic reviews of interventions in communication and participation in health

	Number of responses (n =)
Theme 1: Health service-level issues	64
Breakdowns in **communication and coordination** of care between and within health services are common	15
The term **patient-centred care is poorly understood** and implemented by health services and health professionals	14
The **quality and safety of patient care** can be compromised by health services (particularly hospitals) not treating patients **holistically**	13
Cultural safety is not well-embedded in health services	10
Informed consent for treatment and research does not always happen	6
Not enough time is given to allow good communication between health professionals and patients	6
Theme 2: Health professional-level issues	50
Some health professionals **don't understand or ask patients** about their **preferences and priorities**	14
Some health professionals **don't provide enough information** to patients (some don't think it's a priority)	15
Health professionals don't always provide enough **support for patient decision-making**	10
There are often two-way **barriers to adequate communication and participation** (e.g. disability of individual plus discomfort of health professional)	7
Health professionals don't always know how to **gauge how much their patients understand**	4
Theme 3: Consumers and carer issues in their own care	37
Patients don't always **understand their health problems, treatment options or their rights**	10
Consumers and carers don't always **know about all the options or services** that exist	9
Consumers and carers aren't always able to **participate actively** in their care	5
The general public doesn't always have enough **health literacy** to navigate the health system and make health decisions	5
Patients often experience **information overload** and are unable to retain the important information	4
Consumers and carers have difficulty **understanding key medication** information	4
Theme 4: Issues for broader consumer and carer involvement	30
Health researchers don't adequately **involve patients** in research, nor share their findings	19
Health services don't properly **involve consumers and carers** in **health service planning and design**	11
Theme 5: Accessibility of high quality health information	18
'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**	18
Theme 6: Ageing and end of life care	8
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	8

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Priority themes and topics in communication and participation in health

The priority themes were issues at (1) health service level, (2) health professional level; and (3) for consumers and carers in their own care; along with (4) broader consumer and carer involvement; (5) accessibility of high quality health information; and (6) ageing and end-of-life care (see Table 2). The latter topic is more specific than others but our coding was both pragmatic and reflective of respondents' answers, and it is a feature of many health systems that communication with older people or people who are dying are treated as separate issues and interventions designed accordingly.[58, 59] The 21 research priority topics are broadly scoped priority issues to be addressed in research, some of which are not mutually exclusive given the overlap in concepts in communication and participation in health.

The most commonly cited priority topics, i.e. the communication and participation in health problems that stakeholders most wanted research to address include: insufficient consumer involvement in research (19 responses); 'official' health information that is contradictory and hard to understand (18 responses); communication and coordination breakdowns in health services (15 responses);, health information provision being a low priority for health professionals (15 responses); insufficient eliciting of patient preferences (14 responses); health services that poorly understand or implement patient-centred care (14 responses); lack of holistic care impacting quality and safety (13 responses); and inadequate involvement of consumers in service design (11 responses).

Below is a description of the priority themes and topics for all stakeholders, followed by priority populations and potential interventions. See Supplementary file, table S3 for the number of responses to each of the priority topics broken down by main stakeholder group, with example quotes.

Priority theme 1: Health service level issues

The theme on health service level issues contained six topics. The most frequently cited topics were breakdowns in communication and coordination between and within health services, poor understanding and/or embedding of 'patient-centred care' and cultural safety within health services and that the safety and quality of health care can be comprised by not treating patients holistically.

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Priority theme 2: Health professional level issues

Within health professional level issues, the five priority topics centred on individual health professional-patient communication issues. For example, stakeholders suggested some health professionals don’t understand or ask about patients about preferences and priorities, nor do they always know how to gauge how much their patients understand. Other suggested that health professionals do not provide enough information, or decision-making support.

Priority theme 3: Consumer and carer issues in their own care

Stakeholders identified six priority topics related to issues for consumers and carers in their own care. These focussed predominantly on issues related to a lack of understanding or awareness on the part of consumers and carers about their health, treatment options, rights and available services, affecting their ability to participate in their own care.

Priority themes 4 to 6: Broader consumer and carer involvement in services; accessibility of high quality health information access; and ageing and end-of-life care

Stakeholders identified two priority topics in theme 4; that researchers and health services do not properly involve consumers and carers in (1) research, or (2) service planning and design. The final two themes each included only one priority topic, that publically available health information can be contradictory, hard to understand, and hard to find and assess (theme 5) and that there is insufficient support and understanding about older people’s needs and end of life decisions (theme 6).

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Populations affected (across priority themes and topics)

Participants stated that certain people or groups were more likely to be affected for each idea or problem, but acknowledged that everyone can experience poor communication and participation in health. Those identified as more vulnerable were people: from diverse cultural and linguistic backgrounds, with limited English, with caring responsibilities, with limited education and/or limited literacy and numeracy, from low socioeconomic areas, with mental illness, older people, with dementia and cognitive issues, with chronic illness or multi-morbidity, from rural and regional areas, from Indigenous backgrounds, and with disability.

Possible interventions (across priority themes and topics)

Participants suggested a range of interventions could be researched to address the problems identified. Potential interventions included communication skills training for health professionals, training and cultural change activities for hospital and health professionals about involving consumers and carers in health services, and personally controlled electronic health records (see Box 1; interventions are described in order of the frequency with which they were mentioned).

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Box 1. Suggested interventions to address communication and participation in health priority themes and topics

- Training for health professionals and health services personnel, in how to:
  - Better involve patients and carers in their individual care
  - Communicate with patients and carers, particularly people from diverse cultural and linguistic backgrounds
  - Involve consumers and carers in the health service more broadly
- Cultural change activities for hospitals and health professionals
- Electronic health records (accessible by patients and carers)
- Support for patients and family members to negotiate health care services, for example patient advocates in hospital or peer support workers
- Better information for general public, patients and family members, including written and online formats that are easy to read, standardised and present risks and harms
- Community education campaigns about when and how to access health service, and understanding key health concepts
- Training for researchers and consumers in how to involve consumers in research and share research findings in understandable ways

DISCUSSION

We identified 21 priority topics highlighting a wide range of potential systematic review questions in communication and participation in health from an international survey of 151 consumers, health professionals and others. Notable amongst the myriad suggestions is the degree to which stakeholders want evidence about interventions which address structural and cultural barriers to communication and participation within health services (e.g., addressing the lack of holistic, patient-centred and culturally safe care) or building health professionals' communication skills and practices. Stakeholders also want to identify solutions to consumers' and carers' lack of understanding and awareness about their health, or know about treatment options or their rights. Importantly, respondents suggested consumers and carers work in partnership with researchers and health services to devise these solutions. The priorities identified cut across acute and community health settings, with relevance for policy and research, and across population groups and health conditions. The most frequently suggested interventions focussed on training and cultural change activities for health services and health professionals. Stakeholders emphasised that poor communication and participation can affect everyone, but disproportionately affect people from diverse cultural and linguistic backgrounds (relevant to the dominant culture and language of any country), carers, people with low education/literacy levels, and people with mental illness, among others.

We conducted what we believe is the first research priority setting partnership with stakeholders (nearly 50% of whom identified as consumers, carers or consumer representatives) across communication and participation in health. We have not only identified a broad range of issues to inform future systematic reviews, but our list could be scoped by others, or subsequently prioritised in local contexts or health conditions, to inform a strategic research agenda. In doing so, we make three contributions to priority setting research methods; (1) demonstrating feasibility of priority setting with stakeholders in a complex area; (2) offering a novel approach to framing priority-setting survey questions and; (3) detailing a research-based approach to analysing and categorising suggested priorities, a step which lacks clear guidance.[30, 60]

There is considerable resonance between the research priorities we identified and policy priorities for improving the quality and safety of health services and systems in Australia,[1] the United Kingdom,[2] the United States[61] and globally.[4] For example, Australia has strategic goals and standards around partnering with consumers in their own care and in health service governance and evaluation.[1, 62] Similarly, the WHO's Framework on Integrated, People-Centred Health Services outlines strategic goals that include people being empowered and engaged, and improved coordination between and within health services.[4] For this reason, our steering group suggested this broadly scoped priority list could be used by health decision makers, and consumer

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representatives or organisations, to support strategic policy or implementation activities, or advocacy efforts, respectively.

There are also synergies between our priorities and those in three aligned priority-setting activities in medication adherence, [19] patient safety in primary care[20] and palliative and end of life care[24]. All three identified research priorities addressing the information and support needs of patients and families, plus health professional training in patient-centred care,[19] improved communication and coordination between services,[24] and addressing the needs of vulnerable groups.[24] Given the exponential growth of prioritisation activities,[21] there is an opportunity to build up an international picture of communication and participation priorities, in which the differences and similarities could be analysed.

One potential criticism of our approach is a lack of inclusiveness;[63] over 90% of participants were from Australia or other high-income, English-speaking countries and we lacked representative numbers of Australians from diverse cultural and linguistic backgrounds,[64] Indigenous people,[65] and people without a university degree [66]. This is important given consumers' perceptions of health communication can differ based on such characteristics.[67] Our steering group encouraged recruitment of these groups using face-to-face methods but despite our efforts we were limited by time and resource constraints. A counter to this point, however, is the resonance between our research priorities and international policy priorities, and that stakeholders singled out these population groups, and others, as deserving particular focus in future systematic reviews.

We acknowledge limitations related to online survey wording. First, participants may have been influenced by some of the examples we provided. Of note is that 'training for health professionals' used as an example response for, 'Do you have any particular solutions to this problem that you would like to see tested?' and this was the most commonly received response. Second, we asked participants to nominate all stakeholder perspectives that applied to them, rather than their 'main' perspective, meaning our three stakeholder categories may not reflect how participants would describe themselves.

Decisions about undertaking new research should be informed by the needs of potential users of this research, but also by what is already known[18]. Given this, research priority setting activities will typically refine and prioritise the initial, 'interim' priorities and undertake an assessment of the existing evidence, to determine which priorities are true 'research uncertainties'.[30] We

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subsequently convened a full-day workshop with stakeholders and undertook an evidence mapping exercise to complete these steps,[29] which will be reported separately. Additionally, to inform systematic reviews, the priorities must be ultimately be framed as searchable and answerable questions,[46] which most of our priorities are not. While interpretive analytic approaches[57] facilitate such a transformation of the data, we felt that given the potential for misinterpretation, subsequent scoping of answerable research questions should be done in partnership with stakeholders.

CONCLUSIONS

Stakeholders identified a broad mix of research priorities in communication and participation in health, with considerable focus on organisational or governance changes with health services. Solutions to these problems must be devised in partnership with consumers, and should particularly focus on the needs of vulnerable groups.

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COMPETING INTERESTS STATEMENT

The authors have no competing interests to declare.

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AUTHOR'S CONTRIBUTIONS

AS led the study design, data collection, analysis and interpretation and manuscript preparation. As steering group members, PB, LH DK, DG, SM, NP, NB, NL, DV, SO, and KC contributed to study design and interpretation, and commented on manuscript drafts. DL contributed to data analysis and interpretation, and commented on manuscript drafts. JN contributed to study design, data analysis and interpretation, and commented on manuscript drafts. MO contributed to study design, data collection and commented on manuscript drafts. AT contributed to data interpretation and critically revised the manuscript for important content. SH contributed to study design, analysis and interpretation, and critically revised the manuscript for important content. All authors approved the final version of the manuscript.

For peer review only

REFERENCES

1. Australian Commission on Safety and Quality in Health Care, *National Safety and Quality Health Service Standards (September 2012).* 2012, ACSQHC: Sydney.
2. National Institute for Health and Care Excellence, *Patient experience in adult NHS services: improving the experience of care for people using adult NHS services. NICE guideline (CG138)*. February 2012.
3. Institute of Medicine (US) Committee on Quality of Health Care in America, *Chapter 2. Improving the 21st-century Health Care System*, in *Crossing the Quality Chasm: A New Health System for the 21st Century*. 2001, National Academies Press (US): Washington (DC).
4. World Health Organization, *Framework on integrated, people-centred health services, A69/39*, S.-N.W.H. Assembly, Editor. 2016.
5. Raleigh, V., et al., *Patients' experience of using hospital services: An analysis of trends in inpatient surveys in NHS acute trusts in England, 2005–13*. 2015, The Kin's Fund and Picker Institute Europe: London, United Kingdom.
6. Australian Commission on Safety and Quality in Health Care (ACSQHC), *National Statement on Health Literacy*. n.d., ACSQHC: Sydney.
7. Brega, A., et al., *AHRQ Health Literacy Universal Precautions Toolkit, Second Edition*. 2015, Agency for Healthcare Research and Quality: Rockville, MD.
8. Boyd, H., S. McKernon, and A. Old, *Health Service Co-design: working with patients to improve healthcare services.* 2010, Waitemata District Health Board: Auckland, New Zealanad.
9. Health Canada and the Public Health Agency of Canada, *Guidelines on Public Engagement*. 2016, Health Canada: Ottawa.
10. Harrison, R., M. Walton, and E. Manias, *Patients' experiences in Australian hospitals: an Evidence Check rapid review brokered by the Sax Institute (www.saxinstitute.org.au) for the Australian Commission on Safety and Quality in Health Care*. 2015.
11. Care Quality Commission. *Better care in my hands: A review of how people are involved in their care*. 2016. London.
12. Doyle, C., L. Lennox, and D. Bell, *A systematic review of evidence on the links between patient experience and clinical safety and effectiveness.* BMJ Open, 2013. **3**(1).
13. Street Jr, R.L., et al., *How does communication heal? Pathways linking clinician–patient communication to health outcomes.* Patient Education and Counseling, 2009. **74**(3): p. 295-301.

For peer review only

14. Coulter, A. and E. J, *Patient-focussed interventions: A review of the evidence*. 2006, The Health Foundation: London, United Kingdom.

15. National Health and Medical Research Council and Consumers Health Forum of Australia, *Statement on consumer and community involvement in health and medical research*, Commonwealth of Australia, Editor. 2016.

16. Concannon, T.W., et al., *A New Taxonomy for Stakeholder Engagement in Patient-Centered Outcomes Research.* Journal of General Internal Medicine, 2012. **27**(8): p. 985-991.

17. Crowe, S., et al., *Patients', clinicians' and the research communities' priorities for treatment research: there is an important mismatch.* Research Involvement and Engagement, 2015. **1**(1): p. 1-10.

18. Chalmers, I., et al., *How to increase value and reduce waste when research priorities are set.* The Lancet, 2014. **383**(9912): p. 156-165.

19. McMullen, C.K., et al., *Patient-centered priorities for improving medication management and adherence.* Patient Education and Counseling, 2015.

20. NIHR Greater Manchester Primary Care Patient Safety Translational Research Centre *Patient Safety in Primary Care Research PSP*. 2017 13 June 1017]; Available from: http://research.bmh.manchester.ac.uk/PatientSafetyPSP/Top10/.

21. Domecq, J.P., et al., *Patient engagement in research: a systematic review.* BMC health services research, 2014. **14**.

22. Elwyn, G., et al., *Identifying and prioritizing uncertainties: patient and clinician engagement in the identification of research questions.* Journal of Evaluation in Clinical Practice, 2010. **16**(3): p. 627-631.

23. Kelly, S., et al., *Dementia priority setting partnership with the James Lind Alliance: using patient and public involvement and the evidence base to inform the research agenda.* Age and Ageing, 2015. **44**(6): p. 985-993.

24. Smith, R., S. Best, and B. Noble, *Identifying palliative and end-of-life care research priorities: a UK approach to consult end users.* European Journal of Palliative Care, 2015. **22**: p. 114-117.

25. Petit-Zeman, S. and S. Uhm, *Identifying research priorities in preterm birth.* Infant, 2012. **8**.

26. Gadsby, R., et al., *Setting research priorities for Type 1 diabetes.* Diabetic Medicine, 2012. **29**(10): p. 1321-1326.

27. Craig, P., et al., *Developing and evaluating complex interventions: the new Medical Research Council guidance.* BMJ, 2008. **337**.

For peer review only

28. Hill, S., Lowe, D, Ryan, R, *Interventions for communication and participation; their purpose and practice*, in *The Knowledgeable Patient* S. Hill, Editor. 2011, Wiley-Blackwell: London, UK.

29. Synnot, A., *Stakeholder priorities for research in health communication and participation: Findings from the Cochrane Consumers and Communication priority setting project*. 2016, Centre for Health Communication and Participation, La Trobe University: Melbourne.

30. The James Lind Alliance, *The James Lind Alliance Guidebook (version 6)*. 2016, National Institutes for Health Research.

31. Nasser, M., et al., *Evidence in agenda setting: new directions for the Cochrane Collaboration.* Journal of Clinical Epidemiology, 2013. **66**(5): p. 469-471.

32. Nasser, M., et al., *Ensuring relevance for Cochrane reviews: evaluating processes and methods for prioritizing topics for Cochrane reviews.* Journal of Clinical Epidemiology, 2013. **66**(5): p. 474-482.

33. IAP2 Australasia, *Quality Assurance Standard For Community and Stakeholder Engagement*. 2015, International Association for Public Participation Australasia (IAP2): Wollongong, Australia.

34. Ocloo, J. and R. Matthews, *From tokenism to empowerment: progressing patient and public involvement in healthcare improvement.* BMJ Qual Saf, 2016. **25**(8): p. 626-32.

35. Heaton, J., J. Day, and N. Britten, *Collaborative research and the co-production of knowledge for practice: an illustrative case study.* Implementation Science, 2016. **11**(1): p. 20.

36. Tong, A., et al., *Research priority setting in organ transplantation: a systematic review.* Transplant International, 2017: p. n/a-n/a.

37. Synnot, A.T., A; Hill, S; Craig, J, *Practical approaches to undertaking research priority setting in health [Workshop].* , in *Australasian Cochrane Symposium*. 2015: Melbourne, Australia.

38. Cochrane, *Strategy to 2020.* 2016, Cochrane: London, UK.

39. Cochrane Consumers and Communication. *Scope of our work*. 2017 24 July 2017]; Available from: http://cccrg.cochrane.org/scope-our-work.

40. Kitson, A., et al., *What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing.* Journal of Advanced Nursing, 2013. **69**(1): p. 4-15.

41. Kaufman, J., et al., *Face to face interventions for informing or educating parents about early childhood vaccination.* Cochrane Database of Systematic Reviews, 2013(5).

42. IAPO, *What is Patient-Centred Healthcare? A Review of Definitions and Principles*. 2007, International Alliance of Patients' Organization: London, United Kingdom.

For peer review only

43. Boote, J., R. Telford, and C. Cooper, *Consumer involvement in health research: a review and research agenda.* Health Policy, 2002. **61**(2): p. 213-236.

44. Ryan, R.E. and S.J. Hill, *Improving the experiences and health of people with multimorbidity: exploratory research with policymakers and information providers on comorbid arthritis.* Australian Journal of Primary Health, 2014. **20**(2): p. 188-196.

45. SurveyMonkey Inc, *SurveyMonkey*. San Mateo, California, USA.

46. O'Connor, D., S. Green, and J.P. Higgins, *Chapter 5: Defining the review question and developing criteria for including studies*, in *Cochrane Handbook for Systematic Reviews of Interventions Version 5.1.0 [updated March 2011]*, J. Higgins and S. Green, Editors. 2011, The Cochrane Collaboration, Available from www.handbook.cochrane.org.

47. Ryan, R., et al., *Interventions to improve safe and effective medicines use by consumers: an overview of systematic reviews.* Cochrane Database of Systematic Reviews, 2014. **4**.

48. Dwamena, F., et al., *Interventions for providers to promote a patient-centred approach in clinical consultations.* Cochrane Database of Systematic Reviews, 2012. **12**.

49. Synnot, A.J., et al., *The evolution of Cochrane evidence summaries in health communication and participation: seeking and responding to stakeholder feedback.* Evidence & policy, 2017. **Fast track online**.

50. Glenton, C., et al., *Presenting the results of Cochrane Systematic Reviews to a consumer audience: a qualitative study.* Med Decis Making, 2010. **30**(5): p. 566-77.

51. Bradley, E.H., L.A. Curry, and K.J. Devers, *Qualitative data analysis for health services research: developing taxonomy, themes, and theory.* Health Serv Res, 2007. **42**(4): p. 1758-72.

52. Lowe, D., et al., *Development of a taxonomy of interventions to organise the evidence on consumers' medicines use.* Patient Education and Counseling, 2011. **85**(2): p. e101-e107.

53. Willis, N., et al., *"Communicate to vaccinate": the development of a taxonomy of communication interventions to improve routine childhood vaccination.* BMC international health and human rights, 2013. **13**: p. 23.

54. Braun, V. and V. Clarke, *Successful qualitative research: a practical guide for beginners*. 2013, London, UK: Sage Publications.

55. Liamputtong, P., *Rigour and Ethics in Qualitative Research*, in *Qualitative research methods (4th ed)*. 2013, Oxford University Press: South Melbourne, Australia.

56. Lohr, K. and D. Steinwachs, *Health Services Research: An Evolving Definition of the Field.* Health Services Research, 2002. **37**: p. 15-17.

For peer review only

57. Thomas, J. and A. Harden, *Methods for the thematic synthesis of qualitative research in systematic reviews.* BMC Med Res Methodol, 2008. **8**: p. 45.

58. Cross, A., R. Elliott, and J. George, *Interventions for improving medication-taking ability and adherence in older adults prescribed multiple medications (Protocol).* Cochrane Database of Systematic Reviews, 2016. **10**: p. Art. No.: CD012419

59. Australian Commission on Safety and Quality in Health Care, *National Consensus Statement: essential elements for safe and high‑quality end-of-life care.* 2015, ACSQHC: Sydney.

60. Morris, C., et al., *Setting research priorities to improve the health of children and young people with neurodisability: a British Academy of Childhood Disability-James Lind Alliance Research Priority Setting Partnership.* BMJ Open, 2015. **5**.

61. AHRQ, *National Healthcare Quality and Disparities Report and 5th Anniversary Update on the National Quality Strategy*. 2016, Agency for Healthcare Research and Quality: Rockville, MD.

62. Australian Commission on Safety and Quality in Health Care, *Australian Safety and Quality Framework for Health Care*, C. ACSQHC, Editor. 2010.

63. Viergever, R.F., et al., *A checklist for health research priority setting: nine common themes of good practice.* Health Research Policy and Systems, 2010. **8**.

64. Australian Bureau of Statistics, *Reflecting a Nation: Stories from the 2011 Census, 2012–2013 , cat. no. 2071.0,* *http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/2071.0main+features902012-2013*. 2012.

65. Australian Bureau of Statistics, *Estimates of Aboriginal and Torres Strait Islander Australians, June 2011, cat. no. 3238.0.55.001, viewed 1 May 2017,* *http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3238.0.55.001June%202011?OpenDocument*. 2013.

66. Australian Bureau of Statistics, *Education and Work, Australia, May 2016, 'Table 29 Highest non-school qualification: Bachelor Degree level or above, By age and sex, 1982 to 2016', data cube: Excel spreadsheet, cat. no. 6277.0, viewed 1 May 2016,* *http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/6227.0Main+Features1May%202016?OpenDocument*. 2016.

67. DeVoe, J.E., L.S. Wallace, and G.E. Fryer, *Measuring patients' perceptions of communication with healthcare providers: Do differences in demographic and socioeconomic characteristics matter?* Health Expectations, 2009. **12**: p. 70-80.

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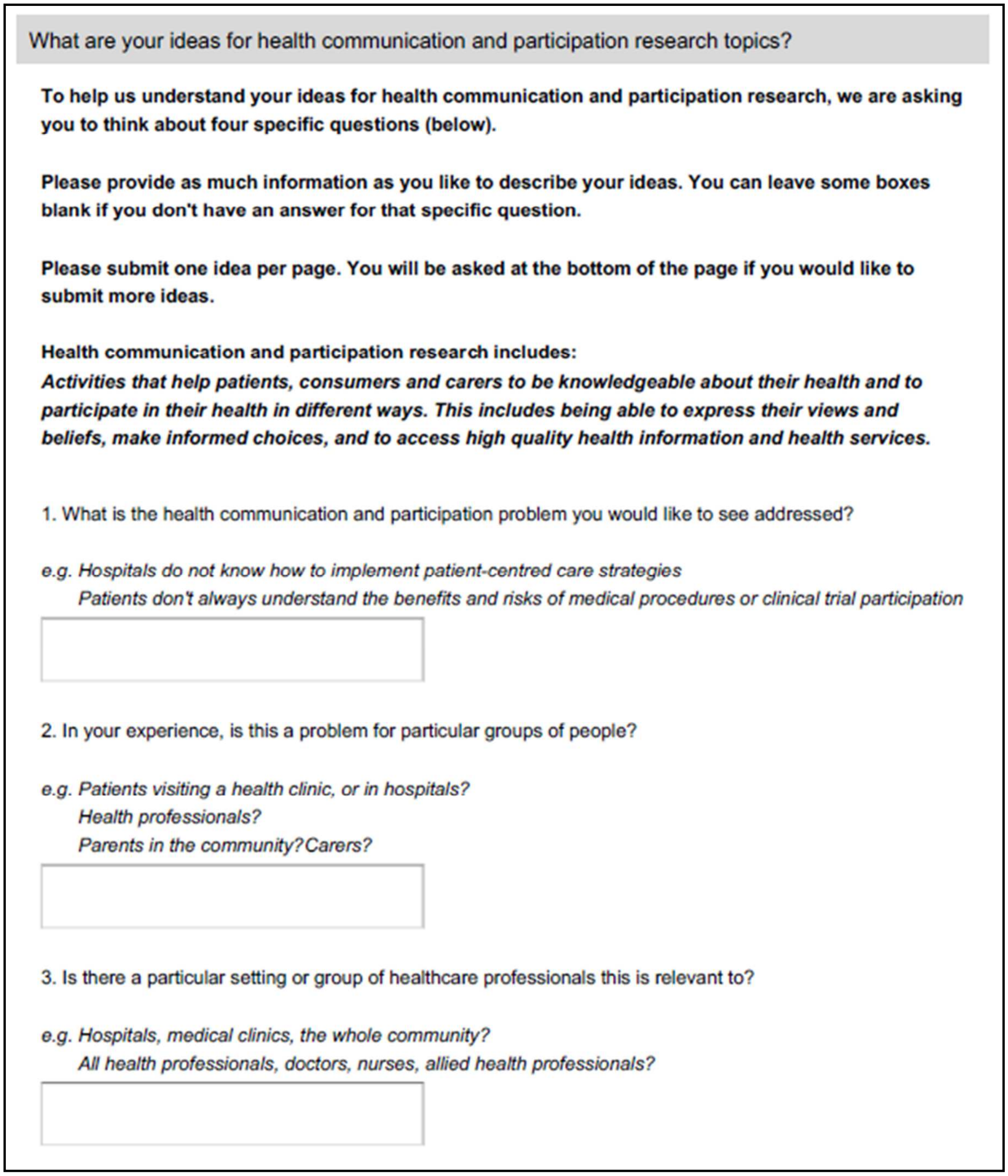
SUPPLEMENTARY FILE

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?

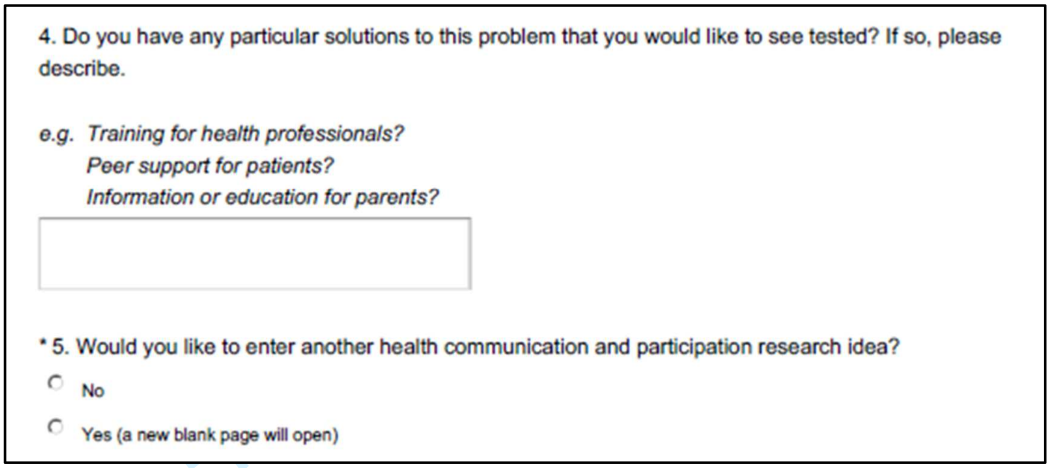
e.g. Hospitals do not know how to implement patient-centred care strategies
Patients don't always understand the benefits and risks of medical procedures or clinical trial participation

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)

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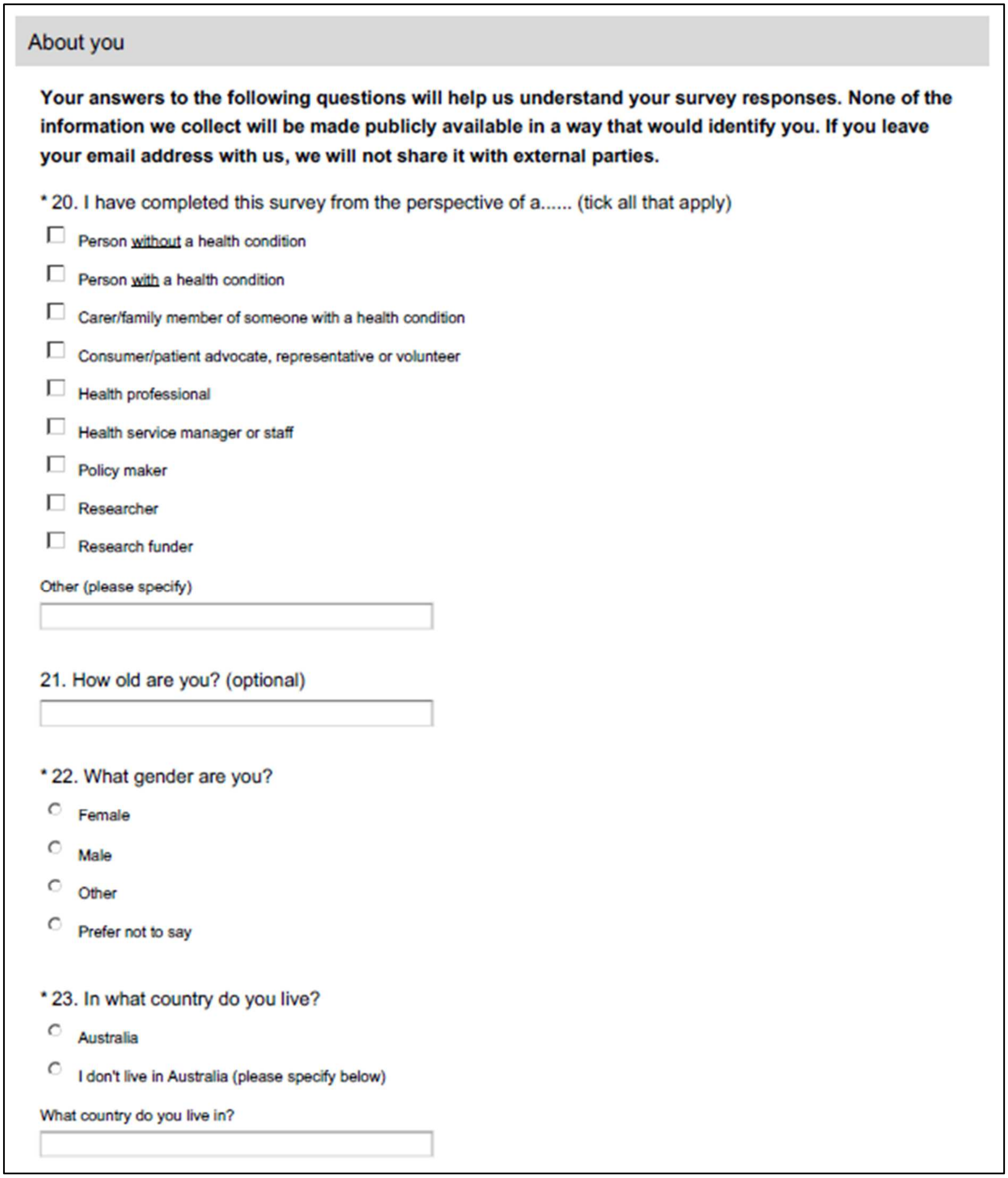


About you

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

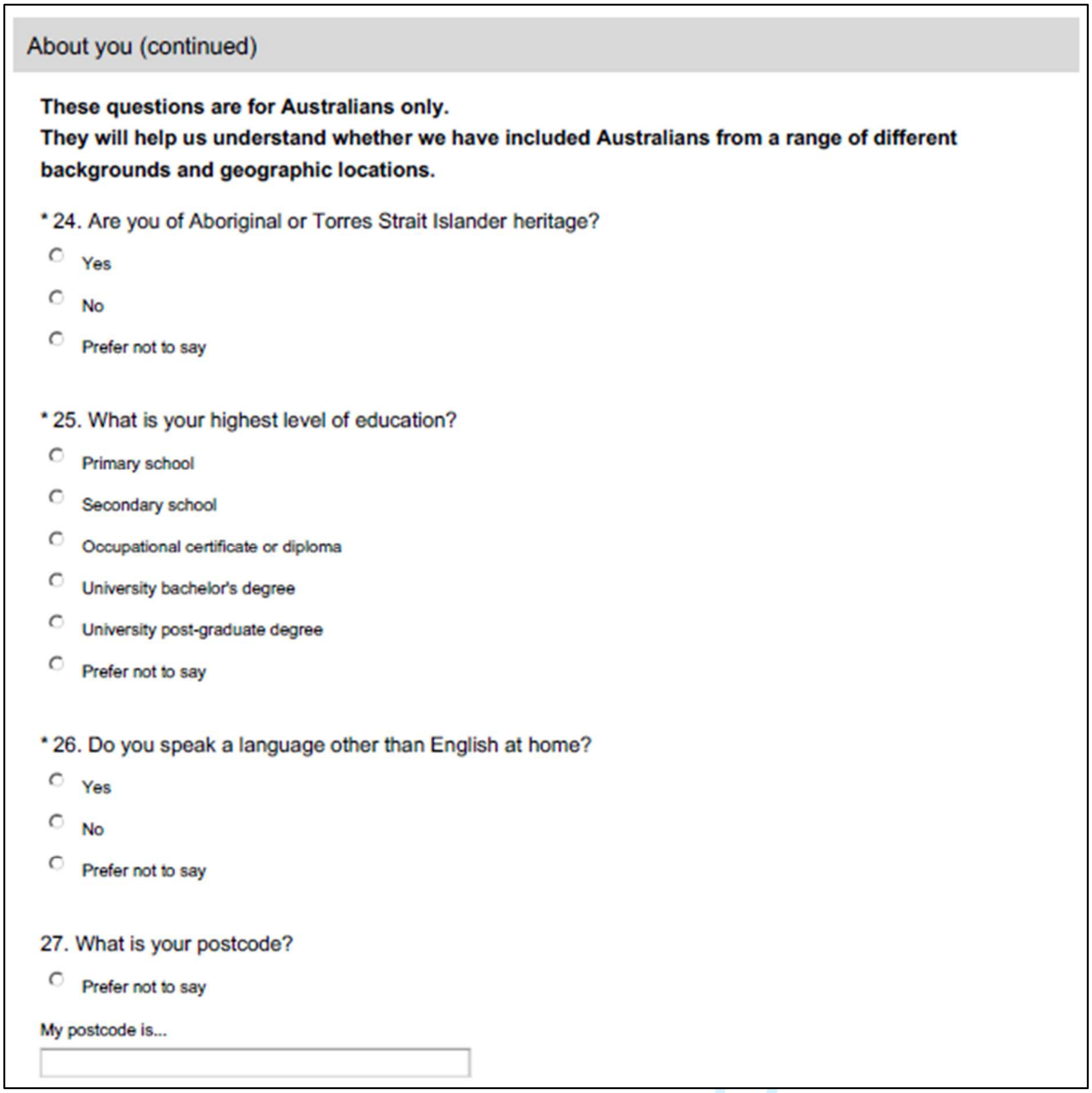
○ Prefer not to say

* 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...

only

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

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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

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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 themes and topics to inform systematic reviews in communication and participation in health, 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

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	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

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	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

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	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				

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	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				

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‘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

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Tong, A., Sautenet, B., Chapman, J. R., Harper, C., MacDonald, P., Shackel, N., Crowe, S., Hanson, C., Hill, S., Synnot, A. and Craig, J. C. (2017), Research priority setting in organ transplantation: a systematic review. Transpl Int, 30: 327–343. doi:10.1111/tri.12924

Available in Supplementary Material at: http://onlinelibrary.wiley.com/doi/10.1111/tri.12924/abstract

SDC Materials and Methods: Appraisal framework

ID	Item	Descriptor and/or examples	Page no.
A.	**Context and scope**		
1	Define geographical scope	*Global, regional, national, institutional, health service*	6
2	Define health area or focus	*Disease or condition specific, healthcare delivery*	7
3	Define end-users of research	*General population, patients*	7
4	Define the target audience	*Policy makers, funders, researchers, industry*	7
5	Identify the research focus	*Public health, health services, clinical, basic science; primary research, systematic reviews, guidelines*	6
6	Identify the type of research question	*Etiology, diagnosis, prevention, treatment, prognosis, health services, psychosocial, education, QOL, economic evaluation*	7
7	Define the time frame	*Short term or long term priorities*	NR
B.	**Governance and team**		
8	Describe selection of the project leader/s and team	*Steering Committee, working group, coordinators*	6-7
9	Describe the characteristics of the project leader/team members	*Stakeholder group, organisations represented, characteristics*	6-7
10	Training or experience in research priority setting	*Involvement of JLA advisor*	7
C.	**Inclusion of stakeholders/participants**		
11	Define the inclusion criteria for stakeholder groups involved in the PSP	*Stakeholder group*	7
12	State the strategy or method for identifying and engaging stakeholders	*Partnerships, social media, recruitment through hospitals*	7
13	Indicate the number of participants and/or organisations involved	*Individuals, organisations*	10
14	Describe the characteristics of stakeholders	*Name of stakeholder group e.g. clinicians, patients, policy makers*	10-11
15	Reimbursement for participation	*Cash, vouchers, certificates, acknowledgement*	NR
D.	**Identification and collection of research topics/questions**		
16	Describe methods for collecting all research topics or questions	*Technical data (burden of disease, incidence), systematic reviews, reviews of guidelines/other documents, surveys, interviews, focus groups, meetings, workshops*	8
17	Describe methods for collating and/or categorising topics or questions	*Taxonomy, framework, used to organised and aggregate topics or questions*	9
18	Describe methods or reason for initial removal or topics or questions	*Beyond scope, lack of clarity and ill-defined, duplicative, number of submissions*	9 & 11
19	Describe methods for refining research questions/topics	*Reviewed by Steering Committee*	9
20	Cross check to identify if research questions have been answered	*Systematic reviews, consultation with experts*	N/A (see footnote)

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21	Describe number of research questions/topics	*Report number of research questions at each stage of the process*	11
E.	**Prioritisation of research topics/questions**		
22	Describe methods for prioritising or achieving consensus on priority research areas, topics, or questions	*Consensus methods: Delphi, nominal group technique, workshops; define thresholds: ranking scores, proportions, votes (interim and final stage)*	N/A (see footnote)
23	Provide reasons for excluding research topics/questions	*Thresholds for ranking scores, proportions, votes (interim and final stage)*	N/A (see footnote)
F.	**Output**		
24	Define specificity of research priorities	*Area, topic, questions, PICO*	N/A (see footnote)
G.	**Evaluation and feedback**		
25	Describe how the research priorities exercise was evaluated	*Conduct a survey, interviews, debriefing session*	N/A (see footnote)
26	Describe how priorities were made accessible for review by stakeholders	*Circulate or upload a draft report*	N/A (see footnote)
27	State how feedback was integrated	*Describe changes made based on feedback*	N/A (see footnote)
28	Outline the strategy or action plans for implementing priorities	*Liaise with key partners*	N/A (see footnote)
29	Describe how impact will be measured	*Improved stakeholder understanding, shifted priorities, reallocation of resources, improved quality of decision-making, stakeholder acceptance and satisfaction*	N/A (see footnote)
30	State sources of funding	*Name of funders*	18
31	Outline the budget and/or cost	*Report project expenses*	N/A (see footnote)
32	Provide declaration of conflict of interest	*Statement of conflict of interest collected and reported*	18

Footnote: Given we report only the first stage of the priority setting project, several of the later items are not applicable as they were undertaken in the subsequent project stage.

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Research priorities in health communication and participation: International survey of consumers and other stakeholders

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TITLE

Research priorities in health communication and participation: International survey of consumers and other stakeholders

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ABSTRACT

OBJECTIVE: To identify research priorities of consumers and other stakeholders to inform Cochrane Reviews in 'health communication and participation' (including such concepts as patient experience, shared decision making and health literacy).

SETTING: International

PARTICIPANTS: We included anyone with an interest in health communication and participation. 151 participants (18 to 80 years; 117 female) across 12 countries took part, including 48 consumers (patients, carers, consumer representatives) and 75 professionals (health professionals, policymakers, researchers) (plus 25 people who identified as both).

DESIGN: Survey

METHODS: We invited people to submit their research ideas via an online survey open for four weeks. Using inductive thematic analysis, we generated priority research topics, then classified into broader themes.

RESULTS: Participants submitted 200 research ideas, which we grouped into 21 priority topics. Key research priorities included: insufficient consumer involvement in research (19 responses), 'official' health information is contradictory and hard to understand (18 responses), communication/coordination breakdowns in health services (15 responses), health information provision a low priority for health professionals (15 responses), insufficient eliciting of patient preferences (14 responses), health services poorly understand/implement patient-centred care (14 responses), lack of holistic care impacting healthcare quality and safety (13 responses), and inadequate consumer involvement in service design (11 responses). The priority topics encompassed acute and community health settings, with implications for policy and research. Priority populations of interest included people from diverse cultural and linguistic backgrounds, carers, and people with low educational attainment, or mental illness. Most frequently suggested interventions focussed on training and cultural change activities for health services and health professionals.

CONCLUSIONS: Consumers and other stakeholders want research addressing structural and cultural challenges in health services (e.g. lack of holistic, patient-centred, culturally safe care) and building health professionals' communication skills. Solutions should be devised in partnership with consumers, with particular focus on the needs of vulnerable groups.

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STRENGTHS AND LIMITATIONS OF THIS STUDY

- We partnered with stakeholders (nearly 50% of whom identified as consumers, carers or consumer representatives) and used a systematic process, to identify 21 international priority research topics in communication and participation in health.
- We have demonstrated the feasibility of priority setting with stakeholders in a complex healthcare area, and detail a research-based approach to analysing and categorising participant responses.
- Over 90% of stakeholders were from Australia or other high-income, English-speaking countries, limiting generalisability beyond high-income settings.
- The use of online-only methods may have resulted in inequitable participation, with less participation of people from vulnerable groups.
- Some of the examples we provided in the survey may have influenced the responses of participants.

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INTRODUCTION

People have the right to be actively involved in their healthcare, and should be provided with high quality, culturally appropriate and timely information, support and services, allowing them to be knowledgeable about, and to participate in their health in different ways.[1-3] Recognised as critical aspects of a well-functioning health system, health funders and deliverers are increasingly seeking to measure and apply concepts such as shared decision-making and person-centred care,[3, 4] patient experience-led improvement,[5] health literacy,[6, 7] and the co-design of health services, policy and research.[8, 9] In this study we define these concepts collectively, as experiences of, or activities to improve, 'health communication and participation'.

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Despite considerable efforts, people's experiences of health communication and participation are often less than optimal.[10, 11] Aside from obvious ethical imperatives, poor communication and inadequate patient participation in their health impacts upon healthcare quality and safety.[12, 13] For example, poor patient experience and low health literacy are associated with poorer health outcomes, adverse events, increased hospital length of stay and readmissions, reduced adherence to treatment and lower use of preventive services.[12, 14] Conversely, considerable international evidence now supports the use of numerous interventions to improve health communication and participation. For example, people exposed to decision aids feel better informed, better able to understand risks and are more active in the decision-making process.[15] The use of automated telephone communication systems in a wide variety of clinical contexts and settings can improve clinical outcomes and increase healthcare uptake, such as immunisation and appointment attendance,[16] and self-monitoring interventions can improve medication adherence, clinical outcomes and reduce mortality in some people.[17]

In this context, efforts to identify solutions to complex problems in both healthcare and research are increasingly being undertaken in partnership with the people and groups affected by the issues.[1, 18] Often termed 'stakeholders', this includes not only consumers (patients and their families or carers, those receiving services and the public)[18], but health professionals, managers, policy makers, research funders and researchers.[19] Research priority setting with stakeholders is thought to both align research with the needs of those who it affects,[20] and reduce research waste.[21] Increasingly, priority-setting methods are being applied not just for primary research, but to identify the most important questions for systematic reviews.[22] While existing research priority setting methods and frameworks (e.g. Viergever)[23] can be used for prioritising systematic reviews,[24] the final selection of priority systematic review topics may also be informed by their appropriateness and feasibility for systematic review teams.[25]

Within the area of health communication and participation, overarching research priorities of consumers and other stakeholders are unknown, with the exception of medication adherence[26] and patient safety in primary care.[27] Research priority setting partnerships are typically conducted for specific health conditions or clinical settings [20, 28]. However, it is notable that concepts like doctor-patient communication, information and education, consumers as partners, and self-management, are frequently identified as research priorities. For example, one or more of these topics was a top priority in asthma,[29] dementia,[30] palliative care,[31] pre-term birth,[32] and type 1 diabetes.[33] Given potential solutions to these problems are complex[34] and common across conditions,[35] an in-depth exploration of research priorities in this area across health conditions and contexts has the potential to add valuable information to healthcare policy making.

Study aim

In March 2015, we commenced a research priority setting project with the aim of identifying future Cochrane Intervention Review topics in health communication and participation.[36] In this paper, we report the first stage of the project, in which we used an international survey to identify priority topics.

METHODS

The methods were informed by guidance from the James Lind Alliance,[37] and Cochrane Priority Setting Methods Group.[22, 24] In this first stage, we conducted an online survey.

We worked in partnership with consumers and other stakeholders to plan and undertake all project stages.[38] Our approach was informed by the principles of co-production, i.e. recognising expertise, building on strengths, enabling shared control and mutually beneficial and supported relationships .[39, 40] We reported activities and data against the relevant sections of a 32-item research priority setting appraisal checklist.[41] The study was approved by the La Trobe University Science Health and Engineering College Human Ethics Sub-Committee.

Context of the priority setting partnership

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The project was initiated by researchers at the Centre for Health Communication and Participation ('the Centre'), La Trobe University, Australia. At this Centre, the Cochrane Consumers and Communication (CCC) Group coordinates the preparation and publication of Cochrane Reviews of interventions that affect the way people interact with healthcare professionals, services and researchers.[35] Conducted as part of a suite of stakeholder engagement activities, the project also coincided with new strategic directions within Cochrane, in which the organisation committed to engage with consumers and other stakeholders to identify their most relevant and important questions, and prioritising Cochrane Review topics accordingly .[42] (p.11).

Project steering group

We convened an 11-member steering group at project commencement.[37] The group was based in Australia and included people representing: the Australian Commission on Safety and Quality in Health Care (n = 1);[43] the National Health and Medical Research Council (n = 1);[44] Safer Care Victoria (n = 1);[45] Victorian health services (with people in clinical (n = 1) and managerial (n = 1) positions); health consumer organisations (n = 1); health consumer representatives (n = 2); and Cochrane Australia (n = 1).[46] Two researchers (one of whom was based in the UK) with priority-setting expertise also joined the group. Steering group input defined project scope; advised on participant selection and recruitment; refined identified priorities at key points; and planed and assisted with dissemination. We held three face-to-face steering group meetings (some joined by teleconference), with ad hoc input over email.

Scope of the priority setting

The steering group recommended the project scope reflect the scope of CCC reviews (i.e. 'interventions that affect the way people interact with healthcare professionals, services and researchers').[47] Making sense of research in this area is challenging; interventions are complex[34] with innumerable related and inconsistently-defined concepts,[48, 49] and international variations in terminology and meaning.[50, 51] To aid clarity in survey promotion, we used the term 'health communication and participation research', defined as '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'.[52] We provided examples to participants

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clarifying that this included broader participation in health services, policy and research. We sought international priorities that could be scoped to inform intervention reviews, given Cochrane's global reach and predominant focus on intervention effectiveness.

Participants and recruitment

We sought international participation in the online survey; inviting people aged 18 years and over who identified as 'patients, consumers, carers, and their advocates, health professionals, policy makers, researchers, funders, and persons interested in health communication and participation'. English-language proficiency was implied given the survey was only available in English. Participants were provided with the option to complete the survey by post or phone.

In May 2015 we undertook purposive and snowball sampling,[53] promoting the survey by email and in newsletters. Approximately 1,000 individuals and organisations were identified from the networks of the project team and steering group, and internet searches (for international patient groups, in particular), and were invited to forward the survey link to their networks or members. Those who received the email included consumer groups, Australian government health departments and health networks, medical and nursing colleges, national health organisations and advocacy groups, researchers and CCC authors and other contributors. Additional efforts, in the form of phone calls and facilitated introductions, were made to Australian organisations working with or representing Indigenous people and people from diverse cultural and linguistic backgrounds. We sent weekly email reminders while the survey was open.

Collecting research priorities

We invited people to share their 'ideas for future research topics in the area of health communication and participation' via an online survey (see Supplementary File S1) that was open for four weeks, using SurveyMonkey.[54] We advised that their ideas would inform topic selection of 'reviews of the latest evidence'. We used the following set of questions: (1) What is the health communication and participation problem you would like to see addressed?, (2) In your experience, is this a problem for particular groups of people?, (3) Is there a particular setting or group of health professionals this is relevant to?, and (4) Do you have any particular solutions you would like to see tested? If so, please describe. The online system permitted up to four research priority submissions

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per participant. To facilitate clarity, context and meaning each question was followed by illustrative examples (see Supplementary File S1).

We used an online survey as it allowed international participation and is recommended by the James Lind Alliance process.[37] The online survey questions were devised in response to the complexity and breadth of project scope, and in consideration of the diversity of respondents' familiarity with the topic and terminology. We opened with the 'problem' question to (1) provide participants a conceptual 'anchor' to enter the survey, (2) generate a description of the context or rationale to inform a potential review;[34, 35] and (3) allow participants to describe what they would like to see research address, without needing to be familiar with the wide range of potential interventions to solve the problem. Subsequent questions allowed participants to share information relevant to generating systematic review questions (i.e. participants, settings and interventions).[55] We took this approach because systematic reviews in health communication and participation are frequently framed to capture a range of interventions which share a common goal addressing a known issue or problem, for example, interventions to improve safe and effective medicines use by consumers[17] or interventions for providers to promote a patient-centred approach in clinical consultations.[56] We avoided technical research terms (e.g. 'systematic reviews', 'Cochrane reviews', 'interventions') given consumers are often unfamiliar with these terms.[57, 58]

We piloted the survey with six people, including consumers (n = 4), a health professional (n = 1) and a policy maker (n = 1). After completing the survey, they participated in a telephone interview, describing the experience and suggesting improvements. The survey structure was endorsed by these participants, and we made minor wording and format changes.

Analysing and grouping research priorities

We conducted an inductive thematic analysis, using a taxonomy method for analysing qualitative health services research.[59] Taxonomies classify 'multifaceted, complex phenomena according to a set of common conceptual domains and dimensions'[59] (p.1761), and are well suited to grouping similar interventions in health communication and participation.[60, 61] We used both conceptual (key health communication and participation concept domains and their essential dimensions) and participant characteristic (identifying characteristics of stakeholders) codes.[59] Two researchers independently coded data, with a third to resolve disagreements (AS, JN, DL). Data was coded

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iteratively, and we compared interpretations and agreed on a set of codes, then topics and themes.[62, 63]

First, we downloaded data into Microsoft Excel and edited extraneous language to focus on key concepts.[61] For each participant, we coded their data against three conceptual codes: the problem they wanted addressed; who the problem affects (the 'participants' in the commonly used systematic review question-formation structure of Participants, Interventions, Comparisons and Outcomes (PICO)); and potential solutions to be tested in research (the 'interventions' in PICO). Given participants were asked to submit their research ideas using four related questions per idea, their answers to these four questions were treated as a single unit (or research idea) in the analysis. At this stage, research ideas that were agreed to be out of scope for future reviews were excluded, while those that contained one of more distinct conceptual problem code were split into two.

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We grouped similar conceptual problem codes together to form priority research topics,[59] which were then aggregated into groups labelled with simple descriptive themes using straightforward health systems language,[64], the aim being to adhere closely to the elements specified by respondents.[65] We developed and applied this method of categorising topics because the analysis commenced with the contextual problem (Q1, which was mandatory) and because this aids identification of potential interventions to address this problem or meet this goal but in a non-prescriptive way. This is in contrast to the more commonly used frame of "what is the effect of intervention X for people with Y on outcomes Z" which is used in clinical, condition-specific areas.[37] We retained the terminology used by participants to devise the topics, meaning synonymous terms were included (e.g. some themes refer to 'consumers' and others to 'patients').

For the participant characteristics code, we collapsed the 10 stakeholder groups into three mutually exclusive groups; 'consumer or carer', 'healthcare professionals, policy makers and researchers' and 'both' (see Supplementary file, table S1 for definitions) to allow narrative comparison of demographic characteristics and research priorities between stakeholders. We used Microsoft Excel to analyse the descriptive data.

We listed the priority topics, grouped by descriptive themes, and included the number of responses coded to each topic. We elected not to present specific interventions and populations suggested for each theme given the considerable overlap in interventions and populations suggested across topics and the sometimes small number of responses per theme.

RESULTS

Participant characteristics

In total, 151 participants from 12 countries took part (see Table 1). Participants were from Australia (n = 110, 74%), United Kingdom (n = 13, 9%), Canada (n = 7, 5%), the United States (n = 6, 4%), and 12 other countries (8%; denominator 148 given demographic data absent for three participants. The mean age (± SD) was 48.9 ± 12.8 years (range 18 to 80 years), and 117 (79%) were female. Nearly all (n = 148, 98%) completed the survey online. The stakeholder groups most commonly self-nominated were that of consumer/patient advocate, representative or volunteer (n = 57, 38%), then health professional (n = 55, 36%), person with a health condition (n = 51, 34%), carer or family member of someone with a health condition (n = 49, 33%), and researcher (n = 43, 29%).

Table 1. Participant characteristics (N=151)

Characteristic	TOTAL[1] n (%)
Age (years; mean ± SD, range)	49 ± 13 (18 – 80)
Female	117 (79)
Stakeholder perspective[2]	
Person *without* a health condition	32 (21)
Person *with* a health condition	51 (34)
Carer/family member of someone with a health condition	49 (33)
Consumer/patient advocate, representative or volunteer	57 (38)
Health professional	55 (36)
Health service manager or staff	19 (13)
Policy maker	10 (7)
Researcher	43 (29)
Research funder	1 (1)
Other[3]	11 (7)
No response provided	3 (2)
Country	
Australia	110 (74)
United Kingdom	13 (9)
Canada	7 (5)
United States	6 (4)
All other[4]	12 (8)

[1] The total number of participants was n = 151, but the denominator for most items was n = 148 given n = 3 participants did not provide any demographic information.

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

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

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

Many participants self-nominated more than one stakeholder perspective. To facilitate a meaningful comparison, we grouped all stakeholders into one of three mutually exclusive groups: Consumers or carers (n = 48; 32%), Healthcare professionals, policy makers and researchers (n = 75; 51%), and a group where people identified as both (n = 25; 17%). In Table 1 we present the demographic characteristics for the 151 participants because there did not appear to be any meaningful differences between stakeholder groups (see Supplementary file, table S1). Additional demographic details that were only asked of Australian participants only are presented in Supplementary file, table S2.

Results of the coding process

Overall, 191 ideas for health communication and participation research were submitted. Ten were removed for being out of scope (n = 8) or lacking sufficient clarity (n = 2). Several remaining ideas were split, as they contained more than one distinct problem. As such, there were 200 research ideas that were coded and grouped into one of 21 research priority topics, and then into one of six overarching priority themes (see Table 2).

Table 2. Priority topics, grouped by descriptive themes for scoping future systematic reviews of interventions in health communication and participation

	Number of responses (n =)
Theme 1: Health service-level issues	64
Breakdowns in **communication and coordination** of care between and within health services are common	15
The term **patient-centred care is poorly understood** and implemented by health services and health professionals	14
The **quality and safety of patient care** can be compromised by health services (particularly hospitals) not treating patients **holistically**	13
Cultural safety (e.g. language considerations and cultural needs) is not well-embedded in health services	10
Informed consent for treatment and research does not always happen	6
Not enough time is given to allow good communication between health professionals and patients	6
Theme 2: Health professional-level issues	50
Some health professionals **don't understand or ask patients** about their **preferences and priorities**	14

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Some health professionals **don't provide enough information** to patients (some don't think it's a priority)	15
Health professionals don't always provide enough **support for patient decision-making**	10
There are often two-way **barriers to adequate communication and participation** (e.g. disability of individual plus discomfort of health professional)	7
Health professionals don't always know how to **gauge how much their patients understand**	4
Theme 3: Consumers and carer issues in their own care	37
Patients don't always **understand their health problems, treatment options or their rights**	10
Consumers and carers don't always **know about all the options or services** that exist	9
Consumers and carers aren't always able to **participate actively** in their care	5
The general public doesn't always have enough **health literacy** to navigate the health system and make health decisions	5
Patients often experience **information overload** and are unable to retain the important information	4
Consumers and carers have difficulty **understanding key medication** information	4
Theme 4: Issues for broader consumer and carer involvement	30
Health researchers don't adequately **involve patients** in research, nor share their findings	19
Health services don't properly **involve consumers and carers** in **health service planning and design**	11
Theme 5: Accessibility of high quality health information	18
'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**	18
Theme 6: Ageing and end of life care	8
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	8

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Priority themes and topics in health communication and participation

The priority themes were issues at (1) health service level, (2) health professional level; and (3) for consumers and carers in their own care; along with (4) broader consumer and carer involvement; (5) accessibility of high quality health information; and (6) ageing and end-of-life care (see Table 2). The latter topic is more specific than others but our coding was both pragmatic and reflective of respondents' answers, and it is a feature of many health systems that communication with older people or people who are dying are treated as separate issues and interventions designed accordingly.[66, 67] The 21 research priority topics are broadly scoped priority issues to be addressed in research, some of which are not mutually exclusive given the overlap in concepts in health communication and participation.

The most commonly cited priority topics, i.e. the health communication and participation problems that stakeholders most wanted research to address include: insufficient consumer involvement in research (19 responses); ‘official’ health information that is contradictory and hard to understand (18 responses); communication and coordination breakdowns in health services (15 responses);, health information provision being a low priority for health professionals (15 responses); insufficient eliciting of patient preferences (14 responses); health services that poorly understand or implement patient-centred care (14 responses); lack of holistic care impacting quality and safety (13 responses); and inadequate involvement of consumers in service design (11 responses).

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Below is a description of the priority themes and topics for all stakeholders, followed by priority populations and potential interventions. See Supplementary file, table S3 for the number of responses to each of the priority topics broken down by main stakeholder group, with example quotes.

Priority theme 1: Health service level issues

The theme on health service level issues contained six topics. The most frequently cited topics were breakdowns in communication and coordination between and within health services, poor understanding and/or embedding of ‘patient-centred care’ and cultural safety (e.g. language considerations or cultural needs) within health services and that the safety and quality of healthcare can be comprised by not treating patients holistically.

Priority theme 2: Health professional level issues

Within health professional level issues, the five priority topics centred on individual health professional-patient communication issues. For example, stakeholders suggested some health professionals don’t understand or ask about patients about preferences and priorities, nor do they always know how to gauge how much their patients understand. Other suggested that health professionals do not provide enough information, or decision-making support.

Priority theme 3: Consumer and carer issues in their own care

Stakeholders identified six priority topics related to issues for consumers and carers in their own care. These focussed predominantly on issues related to a lack of understanding or awareness on the part of consumers and carers about: their health; treatment options; rights; and available services, affecting their ability to participate in their own care.

Priority themes 4 to 6: Broader consumer and carer involvement in services; accessibility of high quality health information access; and ageing and end-of-life care

Stakeholders identified two priority topics in theme 4; that researchers and health services do not properly involve consumers and carers in (1) research, or (2) service planning and design. The final two themes each included only one priority topic, that publically available health information can be contradictory, hard to understand, and hard to find and assess (theme 5) and that there is insufficient support and understanding about older people's needs and end of life decisions (theme 6).

Populations affected (across priority themes and topics)

Participants stated that certain people or groups were more likely to be affected for each health communication and participation research priority, but acknowledged that everyone can experience poor health communication and participation. Those identified as more vulnerable were people: from diverse cultural and linguistic backgrounds; with limited English; with caring responsibilities; with limited education and/or limited literacy and numeracy; from low socioeconomic areas; with mental illness; older people; with dementia and cognitive issues; with chronic illness or multi-morbidity; from rural and regional areas; from Indigenous backgrounds; and with disability.

Possible interventions (across priority themes and topics)

Participants suggested a range of interventions that could be researched to address the problems identified. Potential interventions included communication skills training for health professionals, training and cultural change activities for hospital and health professionals about involving consumers and carers in health services, and personally controlled electronic health records (see Box 1; interventions are described in order of the frequency with which they were mentioned).

Box 1. Suggested interventions to address health communication and participation priority themes and topics

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- Training for health professionals and health services personnel, in how to:
    - Better involve patients and carers in their individual care
    - Communicate with patients and carers, particularly people from diverse cultural and linguistic backgrounds
    - Involve consumers and carers in the health service more broadly
- Cultural change activities for hospitals and health professionals
- Electronic health records (accessible by patients and carers)
- Support for patients and family members to negotiate healthcare services, for example patient advocates in hospital or peer support workers
- Better information for general public, patients and family members, including written and online formats that are easy to read, standardised and present risks and harms
- Community education campaigns about when and how to access health services, and understanding key health concepts
- Training for researchers and consumers in how to involve consumers in research and share research findings in understandable ways

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DISCUSSION

We identified 21 priority topics highlighting a wide range of potential systematic review questions in health communication and participation from an international survey of 151 consumers, health professionals and others. Notable amongst the myriad suggestions is the degree to which stakeholders want evidence about interventions which address structural and cultural barriers to communication and participation within health services (e.g., addressing the lack of holistic, patient-centred and culturally safe care) or building health professionals' communication skills and practices. Stakeholders also want to identify solutions to consumers' and carers' lack of understanding and awareness about their health, treatment options and their rights. Importantly, respondents suggested consumers and carers work in partnership with researchers and health services to devise these solutions. The priorities identified encompassed acute and community health settings, with relevance for policy and research, and many population groups and health conditions. The most frequently suggested interventions focussed on training and cultural change activities for health services and health professionals. Stakeholders emphasised that poor communication and participation can affect everyone, but disproportionately affect people from diverse cultural and linguistic backgrounds (relevant to the dominant culture and language of any country), carers, people with low education/literacy levels, and people with mental illness, among others.

We conducted what we believe is the first research priority setting partnership with stakeholders (nearly 50% of whom identified as consumers, carers or consumer representatives) across health communication and participation. We have not only identified a broad range of issues to inform future systematic reviews, but our list could be scoped by others, or subsequently prioritised in local contexts or health conditions, to inform a strategic research agenda (see Box 2). In doing so, we make three contributions to priority setting research methods; (1) demonstrating feasibility of priority setting with stakeholders in a complex healthcare area; (2) offering a novel approach to framing priority-setting survey questions and; (3) detailing a research-based approach to analysing and categorising suggested priorities.

Box 2. Recommendations

Recommendations for health communication and participation researchers:

- Consumers and other stakeholders want research about interventions which address structural and cultural barriers to health communication and participation within health services; build health professionals communication skills and practices; and support consumers' and carers' to better understand their health, treatment options and rights.
- Research should focus on priority populations of interest, including people from diverse cultural and linguistic backgrounds, carers, people with low educational attainment and those with mental illness.
- Researchers should work in partnership with consumers and carers to devise interventions to address the research priorities, but the most frequently suggested interventions focussed on training and cultural change activities for health services and health professionals.

Recommendations for future priority-setting research in health communication and participation:

- Identify the health communication and participation research priorities of consumers and other stakeholders low and middle-income settings;
- Compare the similarities and differences in health communication and participation research priorities generated in this study with those generated in priority setting exercises in condition- and context-specific topics (i.e. asthma and intensive care).

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There is considerable consistency between the research priorities we identified and policy priorities for improving the quality and safety of health services and systems in Australia,[1] the United Kingdom,[2] the United States[68] and globally.[4] For example, Australia has strategic goals and standards for partnering with consumers in their own care and in health service governance and evaluation.[1, 69] Similarly, the WHO's Framework on Integrated, People-Centred Health Services outlines strategic goals that include people being empowered and engaged, and improved coordination between and within health services.[4] For this reason, our steering group suggested this broadly scoped priority list could be used by health decision makers, and consumer representatives or organisations, to support strategic policy or implementation activities, or advocacy efforts, respectively.

There are also synergies between our priorities and those in three aligned priority-setting activities in medication adherence,[26] patient safety in primary care[27] and palliative and end of life care.[31] All three identified research priorities addressing the information and support needs of patients and families, plus health professional training in patient-centred care,[26] improved communication and coordination between services,[31] and addressing the needs of vulnerable groups.[31] Given the exponential growth of prioritisation activities,[28] there is an opportunity to build up an international picture of communication and participation priorities, in which the differences and similarities could be analysed (see Box 2).

We acknowledge as a limitation that over 90% of participants were from Australia or other high-income, English-speaking countries. This is unsurprising given the project team and steering group were predominantly based in Australia, and the survey was only available in English. While there is variation in health communication and participation practices internationally,[70] studies show there can be considerable inter-country similarities[71] and differences[72] in patient preferences for involvement in their healthcare. As such, our results may be more applicable to higher income countries.

A second limitation relates to potential inequity in our priority-setting approach.[73]
Reflecting the PROGRESS-PLUS equity checklist (place of residence, race/ethnicity, occupation, gender, religion, education, socioeconomic status, social capital, age, sexual orientation, and disability)[74, 75] there was a low proportion of Australians from diverse cultural and linguistic backgrounds,[76], regional and rural areas,[77] Indigenous people,[78] and people without a university degree,[79] in our study. This is important given consumers' perceptions of health

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communication can differ based on such characteristics.[80] We also included more women than men. Given gender (relative to other demographic factors, like religion, ethnicity and age) is not a major predictor of healthcare preferences[81] we believe our results are broadly applicable across genders. While we made targeted efforts to recruit people from cultural and linguistically diverse backgrounds, and Indigenous people, we could only achieve what was feasible within the resources available. We note, however, that stakeholders themselves were equity-focussed, as they recommended these vulnerable population groups, and others, as deserving particular focus in future systematic reviews.

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Finally, we acknowledge limitations related to online survey wording. First, participants may have been influenced by some of the examples we provided. Of note is that 'training for health professionals' used as an example response for, 'Do you have any particular solutions to this problem that you would like to see tested?' and this was the most commonly received response. Second, we asked participants to nominate all stakeholder perspectives that applied to them, rather than their 'main' perspective, meaning our three stakeholder categories may not reflect how participants would describe themselves.

Decisions regarding new research should be informed by the needs of potential users of this research, but also by the existing evidence.[21] Given this, research priority setting activities will typically refine and prioritise the initial, 'interim' priorities and undertake an assessment of the existing evidence, to determine which priorities are true 'research uncertainties'.[37] We subsequently convened a full-day workshop with stakeholders and undertook an evidence mapping exercise to complete these steps,[36] which will be reported separately. Additionally, to inform systematic reviews, the priorities must be ultimately be framed as searchable and answerable questions,[55] which most of our priorities are not. While interpretive analytic approaches[65] facilitate such a transformation of the data, we felt that given the potential for misinterpretation, subsequent scoping of answerable research questions should be done in partnership with stakeholders.

CONCLUSIONS

Consumers and other stakeholders identified a broad mix of research priorities in health communication and participation. Notable amongst the myriad of priorities is the degree to which people want research addressing structural and cultural challenges in health services (e.g. lack of holistic, patient-centred, culturally safe care) and building health professionals' communication skills. Solutions should be devised in partnership with consumers, with particular focus on the needs of vulnerable groups.

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COMPETING INTERESTS STATEMENT

The authors have no competing interests to declare.

DATA SHARING STATEMENT

No additional unpublished data are available.

AUTHOR'S CONTRIBUTIONS

AS led the study design, data collection, analysis and interpretation and manuscript preparation. As steering group members, PB, LH, DK, DG, SM, NP, NB, NL, DV, SO, and KC contributed to study design and interpretation, and commented on manuscript drafts. DL contributed to data analysis and interpretation, and commented on manuscript drafts. JN contributed to study design, data analysis and interpretation, and commented on manuscript drafts. MO contributed to study design, data collection and commented on manuscript drafts. AT contributed to data interpretation and critically

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revised the manuscript for important content. SH contributed to study design, analysis and interpretation, and critically revised the manuscript for important content. All authors approved the final version of the manuscript.

For peer review only

REFERENCES

1. Australian Commission on Safety and Quality in Health Care, *National Safety and Quality Health Service Standards (September 2012).* 2012, ACSQHC: Sydney.
2. National Institute for Health and Care Excellence, *Patient experience in adult NHS services: improving the experience of care for people using adult NHS services. NICE guideline (CG138)*. February 2012.
3. Institute of Medicine (US) Committee on Quality of Health Care in America, *Chapter 2. Improving the 21st-century Health Care System*, in *Crossing the Quality Chasm: A New Health System for the 21st Century*. 2001, National Academies Press (US): Washington (DC).
4. World Health Organization, *Framework on integrated, people-centred health services, A69/39*, S.-N.W.H. Assembly, Editor. 2016.
5. Raleigh, V., et al., *Patients' experience of using hospital services: An analysis of trends in inpatient surveys in NHS acute trusts in England, 2005–13*. 2015, The Kin's Fund and Picker Institute Europe: London, United Kingdom.
6. Australian Commission on Safety and Quality in Health Care (ACSQHC), *National Statement on Health Literacy*. n.d., ACSQHC: Sydney.
7. Brega, A., et al., *AHRQ Health Literacy Universal Precautions Toolkit, Second Edition*. 2015, Agency for Healthcare Research and Quality: Rockville, MD.
8. Boyd, H., S. McKernon, and A. Old, *Health Service Co-design: working with patients to improve healthcare services.* 2010, Waitemata District Health Board: Auckland, New Zealanad.
9. Health Canada and the Public Health Agency of Canada, *Guidelines on Public Engagement*. 2016, Health Canada: Ottawa.
10. Harrison, R., M. Walton, and E. Manias, *Patients' experiences in Australian hospitals: an Evidence Check rapid review brokered by the Sax Institute (www.saxinstitute.org.au) for the Australian Commission on Safety and Quality in Health Care*. 2015.
11. Care Quality Commission. *Better care in my hands: A review of how people are involved in their care*. 2016. London.
12. Doyle, C., L. Lennox, and D. Bell, *A systematic review of evidence on the links between patient experience and clinical safety and effectiveness.* BMJ Open, 2013. **3**(1).
13. Street Jr, R.L., et al., *How does communication heal? Pathways linking clinician–patient communication to health outcomes.* Patient Education and Counseling, 2009. **74**(3): p. 295-301.

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

14. Coulter, A. and E. J, *Patient-focussed interventions: A review of the evidence*. 2006, The Health Foundation: London, United Kingdom.

15. Stacey, D., et al., *Decision aids for people facing health treatment or screening decisions.* Cochrane Database of Systematic Reviews, 2017(4).

16. Posadzki, P., et al., *Automated telephone communication systems for preventive healthcare and management of long-term conditions.* Cochrane Database of Systematic Reviews, 2016(12).

17. Ryan, R., et al., *Interventions to improve safe and effective medicines use by consumers: an overview of systematic reviews.* Cochrane Database of Systematic Reviews, 2014. **4**.

18. National Health and Medical Research Council and Consumers Health Forum of Australia, *Statement on consumer and community involvement in health and medical research*, Commonwealth of Australia, Editor. 2016.

19. Concannon, T.W., et al., *A New Taxonomy for Stakeholder Engagement in Patient-Centered Outcomes Research.* Journal of General Internal Medicine, 2012. **27**(8): p. 985-991.

20. Crowe, S., et al., *Patients', clinicians' and the research communities' priorities for treatment research: there is an important mismatch.* Research Involvement and Engagement, 2015. **1**(1): p. 1-10.

21. Chalmers, I., et al., *How to increase value and reduce waste when research priorities are set.* The Lancet, 2014. **383**(9912): p. 156-165.

22. Nasser, M., et al., *Ensuring relevance for Cochrane reviews: evaluating processes and methods for prioritizing topics for Cochrane reviews.* Journal of Clinical Epidemiology, 2013. **66**(5): p. 474-482.

23. Viergever, R.F., et al., *A checklist for health research priority setting: nine common themes of good practice.* Health Research Policy and Systems, 2010. **8**.

24. Nasser, M., et al., *Evidence in agenda setting: new directions for the Cochrane Collaboration.* Journal of Clinical Epidemiology, 2013. **66**(5): p. 469-471.

25. Akl, E.A., et al., *The SPARK Tool to prioritise questions for systematic reviews in health policy and systems research: development and initial validation.* Health Res Policy Syst, 2017. **15**(1): p. 77.

26. McMullen, C.K., et al., *Patient-centered priorities for improving medication management and adherence.* Patient Education and Counseling, 2015.

27. NIHR Greater Manchester Primary Care Patient Safety Translational Research Centre *Patient Safety in Primary Care Research PSP*. 2017 13 June 1017]; Available from: http://research.bmh.manchester.ac.uk/PatientSafetyPSP/Top10/.

For peer review only

28. Domecq, J.P., et al., *Patient engagement in research: a systematic review.* BMC health services research, 2014. **14**.

29. Elwyn, G., et al., *Identifying and prioritizing uncertainties: patient and clinician engagement in the identification of research questions.* Journal of Evaluation in Clinical Practice, 2010. **16**(3): p. 627-631.

30. Kelly, S., et al., *Dementia priority setting partnership with the James Lind Alliance: using patient and public involvement and the evidence base to inform the research agenda.* Age and Ageing, 2015. **44**(6): p. 985-993.

31. Smith, R., S. Best, and B. Noble, *Identifying palliative and end-of-life care research priorities: a UK approach to consult end users.* European Journal of Palliative Care, 2015. **22**: p. 114-117.

32. Petit-Zeman, S. and S. Uhm, *Identifying research priorities in preterm birth.* Infant, 2012. **8**.

33. Gadsby, R., et al., *Setting research priorities for Type 1 diabetes.* Diabetic Medicine, 2012. **29**(10): p. 1321-1326.

34. Craig, P., et al., *Developing and evaluating complex interventions: the new Medical Research Council guidance.* BMJ, 2008. **337**.

35. Hill, S., Lowe, D, Ryan, R, *Interventions for communication and participation; their purpose and practice*, in *The Knowledgeable Patient* S. Hill, Editor. 2011, Wiley-Blackwell: London, UK.

36. Synnot, A., *Stakeholder priorities for research in health communication and participation: Findings from the Cochrane Consumers and Communication priority setting project*. 2016, Centre for Health Communication and Participation, La Trobe University: Melbourne.

37. The James Lind Alliance, *The James Lind Alliance Guidebook (version 6)*. 2016, National Institutes for Health Research.

38. IAP2 Australasia, *Quality Assurance Standard For Community and Stakeholder Engagement*. 2015, International Association for Public Participation Australasia (IAP2): Wollongong, Australia.

39. Ocloo, J. and R. Matthews, *From tokenism to empowerment: progressing patient and public involvement in healthcare improvement.* BMJ Qual Saf, 2016. **25**(8): p. 626-32.

40. Heaton, J., J. Day, and N. Britten, *Collaborative research and the co-production of knowledge for practice: an illustrative case study.* Implementation Science, 2016. **11**(1): p. 20.

41. Tong, A., et al., *Research priority setting in organ transplantation: a systematic review.* Transplant International, 2017. **30**: p. 327–343

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

42. Cochrane, *Strategy to 2020.* 2016, Cochrane: London, UK. p. www. community.cochrane.org/organizational-info/resources/strategy-2020.

43. Australian Commission on Safety and Quality in Health Care. *Australian Commission on Safety and Quality in Health Care,*. 2018 15 January 2018]; Available from: https://www.safetyandquality.gov.au/.

44. National Health and Medical Research Council. *National Health and Medical Research Council*. 2018 15 January 2018]; Available from: https://www.nhmrc.gov.au/.

45. State Government of Victoria. *Safer Care Victoria*. 2018 15 January 2018]; Available from: https://www2.health.vic.gov.au/hospitals-and-health-services/safer-care-victoria.

46. The Cochrane Collaboration. *Cochrane Australia*. 2018; Available from: http://australia.cochrane.org/.

47. Cochrane Consumers and Communication. *Scope of our work*. 2017 24 July 2017]; Available from: http://cccrg.cochrane.org/scope-our-work.

48. Kitson, A., et al., *What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing.* Journal of Advanced Nursing, 2013. **69**(1): p. 4-15.

49. Kaufman, J., et al., *Face to face interventions for informing or educating parents about early childhood vaccination.* Cochrane Database of Systematic Reviews, 2013(5).

50. IAPO, *What is Patient-Centred Healthcare? A Review of Definitions and Principles*. 2007, International Alliance of Patients' Organization: London, United Kingdom.

51. Boote, J., R. Telford, and C. Cooper, *Consumer involvement in health research: a review and research agenda.* Health Policy, 2002. **61**(2): p. 213-236.

52. Ryan, R.E. and S.J. Hill, *Improving the experiences and health of people with multimorbidity: exploratory research with policymakers and information providers on comorbid arthritis.* Australian Journal of Primary Health, 2014. **20**(2): p. 188-196.

53. Quinn Patton, M., *Chapter 5. Designing Qualitative Studies*, in *Qualitative Research and Evaluation Methods: Integrating Theory and Practice (4th Edition)*. 2015, SAGE Publications: Thousand Oaks, California.

54. SurveyMonkey Inc, *SurveyMonkey*. San Mateo, California, USA.

55. O'Connor, D., S. Green, and J.P. Higgins, *Chapter 5: Defining the review question and developing criteria for including studies*, in *Cochrane Handbook for Systematic Reviews of Interventions Version 5.1.0 [updated March 2011]*, J. Higgins and S. Green, Editors. 2011, The Cochrane Collaboration, Available from www.handbook.cochrane.org.

For peer review only

56. Dwamena, F., et al., *Interventions for providers to promote a patient-centred approach in clinical consultations.* Cochrane Database of Systematic Reviews, 2012. **12**.

57. Synnot, A.J., et al., *The evolution of Cochrane evidence summaries in health communication and participation: seeking and responding to stakeholder feedback.* Evidence & policy, 2017. **Fast track online**.

58. Glenton, C., et al., *Presenting the results of Cochrane Systematic Reviews to a consumer audience: a qualitative study.* Med Decis Making, 2010. **30**(5): p. 566-77.

59. Bradley, E.H., L.A. Curry, and K.J. Devers, *Qualitative data analysis for health services research: developing taxonomy, themes, and theory.* Health Serv Res, 2007. **42**(4): p. 1758-72.

60. Lowe, D., et al., *Development of a taxonomy of interventions to organise the evidence on consumers' medicines use.* Patient Education and Counseling, 2011. **85**(2): p. e101-e107.

61. Willis, N., et al., *"Communicate to vaccinate": the development of a taxonomy of communication interventions to improve routine childhood vaccination.* BMC international health and human rights, 2013. **13**: p. 23.

62. Braun, V. and V. Clarke, *Successful qualitative research: a practical guide for beginners*. 2013, London, UK: Sage Publications.

63. Liamputtong, P., *Rigour and Ethics in Qualitative Research*, in *Qualitative research methods (4th ed)*. 2013, Oxford University Press: South Melbourne, Australia.

64. Lohr, K. and D. Steinwachs, *Health Services Research: An Evolving Definition of the Field.* Health Services Research, 2002. **37**: p. 15-17.

65. Thomas, J. and A. Harden, *Methods for the thematic synthesis of qualitative research in systematic reviews.* BMC Med Res Methodol, 2008. **8**: p. 45.

66. Cross, A., R. Elliott, and J. George, *Interventions for improving medication-taking ability and adherence in older adults prescribed multiple medications (Protocol).* Cochrane Database of Systematic Reviews, 2016. **10**: p. Art. No.: CD012419

67. Australian Commission on Safety and Quality in Health Care, *National Consensus Statement: essential elements for safe and high ‑quality end-of-life care.* 2015, ACSQHC: Sydney.

68. AHRQ, *National Healthcare Quality and Disparities Report and 5th Anniversary Update on the National Quality Strategy*. 2016, Agency for Healthcare Research and Quality: Rockville, MD.

69. Australian Commission on Safety and Quality in Health Care, *Australian Safety and Quality Framework for Health Care*, C. ACSQHC, Editor. 2010.

For peer review only

70. Harter, M., T. van der Weijden, and G. Elwyn, *Policy and practice developments in the implementation of shared decision making: an international perspective.* Z Evid Fortbild Qual Gesundhwes, 2011. **105**(4): p. 229-33.

71. Bastiaens, H., et al., *Older people's preferences for involvement in their own care: A qualitative study in primary health care in 11 European countries.* Patient Education and Counseling, 2007. **68**(1): p. 33-42.

72. Partridge, J.C., et al., *International comparison of care for very low birth weight infants: parents' perceptions of counseling and decision-making.* Pediatrics, 2005. **116**(2): p. e263-71.

73. Nasser, M., et al., *An equity lens can ensure an equity-oriented approach to agenda setting and priority setting of Cochrane Reviews.* J Clin Epidemiol, 2013. **66**(5): p. 511-21.

74. Oliver, S., et al., *Health promotion, inequalities and young people's health: a systematic review of research*. 2008, EPPI-Centre, Social Science Research Unit, Institute of Education, University of London: London.

75. Evans, T. and H. Brown, *Road traffic crashes: operationalizing equity in the context of health sector reform.* Injury Control and Safety Promotion, 2003. **10**(1-2): p. 11-12.

76. Australian Bureau of Statistics, *Reflecting a Nation: Stories from the 2011 Census, 2012–2013 , cat. no. 2071.0, http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/2071.0main+features902012-2013.* 2012.

77. Australian Bureau of Statistics, *Australian Social Trends, Data cube - Population, Table 1: Population, National Summary, 1998–2011, Excel spreadsheet, cat. no. 4102.0*. 2016.

78. Australian Bureau of Statistics, *Estimates of Aboriginal and Torres Strait Islander Australians, June 2011, cat. no. 3238.0.55.001, viewed 1 May 2017, http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3238.0.55.001June%202011?OpenDocument*. 2013.

79. Australian Bureau of Statistics, *Education and Work, Australia, May 2016, 'Table 29 Highest non-school qualification: Bachelor Degree level or above, By age and sex, 1982 to 2016', data cube: Excel spreadsheet, cat. no. 6277.0, viewed 1 May 2016, http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/6227.0Main+Features1May%202016?OpenDocument*. 2016.

80. DeVoe, J.E., L.S. Wallace, and G.E. Fryer, *Measuring patients' perceptions of communication with healthcare providers: Do differences in demographic and socioeconomic characteristics matter?* Health Expectations, 2009. **12**: p. 70-80.

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

For peer review only

81. Jung, H.P., et al., *Patient characteristics as predictors of primary health care preferences: a systematic literature analysis.* Health Expect, 2003. **6**(2): p. 160-81.

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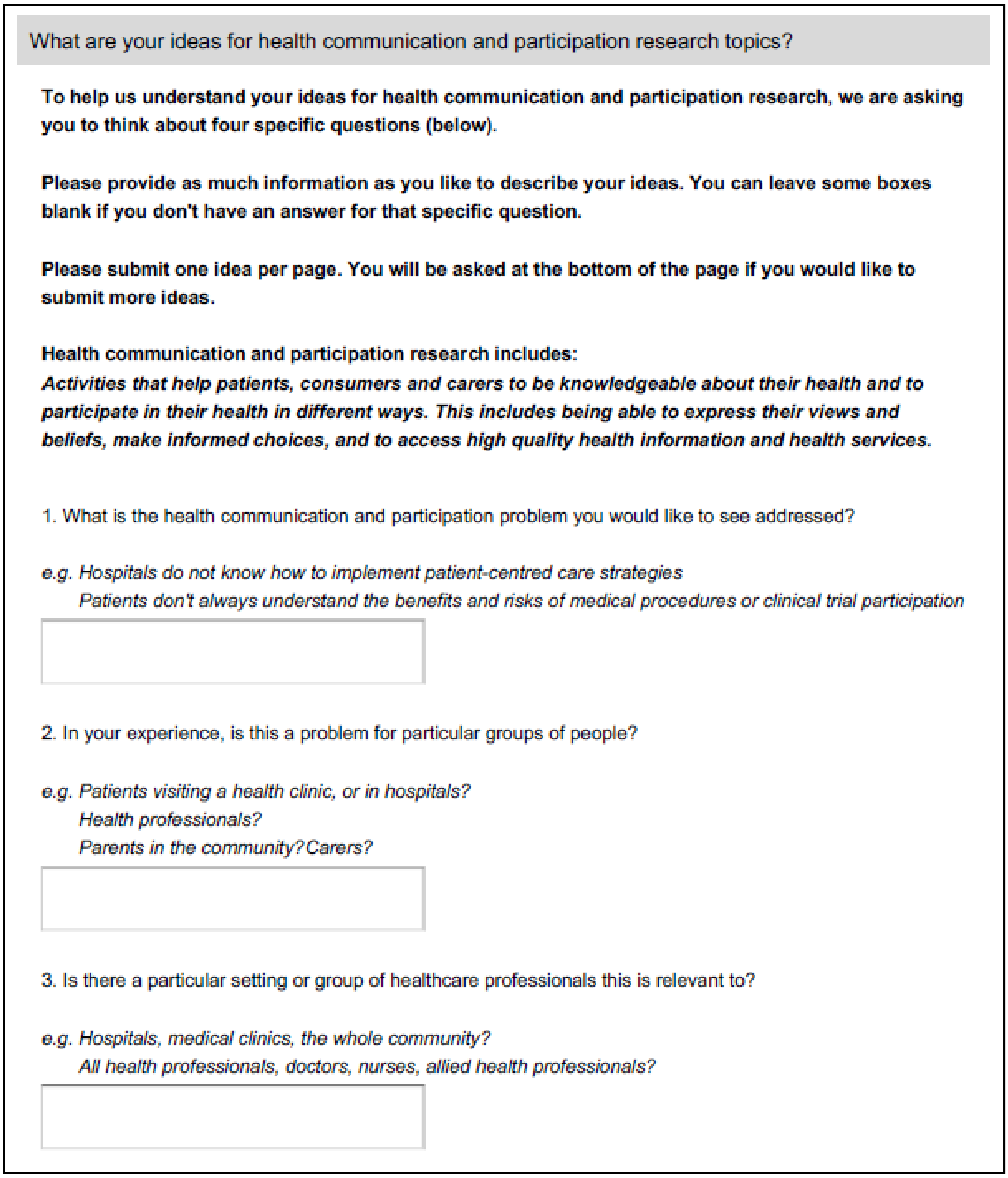
SUPPLEMENTARY FILE

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?

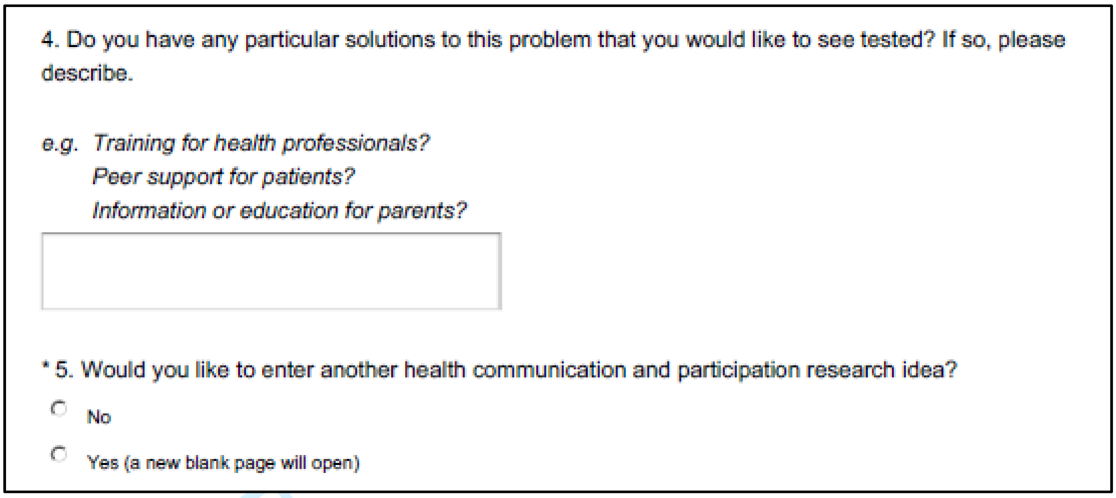
e.g. Hospitals do not know how to implement patient-centred care strategies
Patients don't always understand the benefits and risks of medical procedures or clinical trial participation

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)

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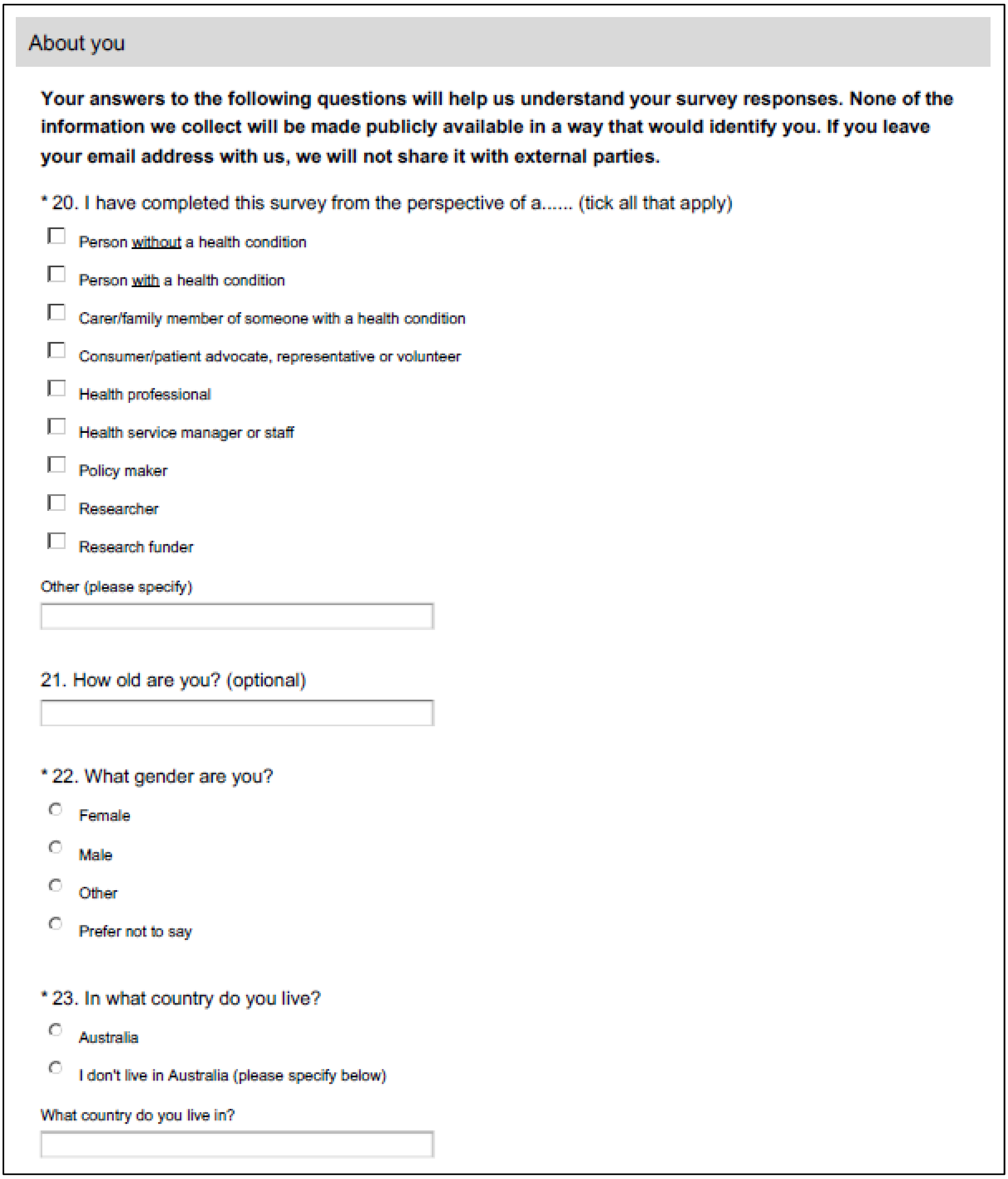


About you

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)

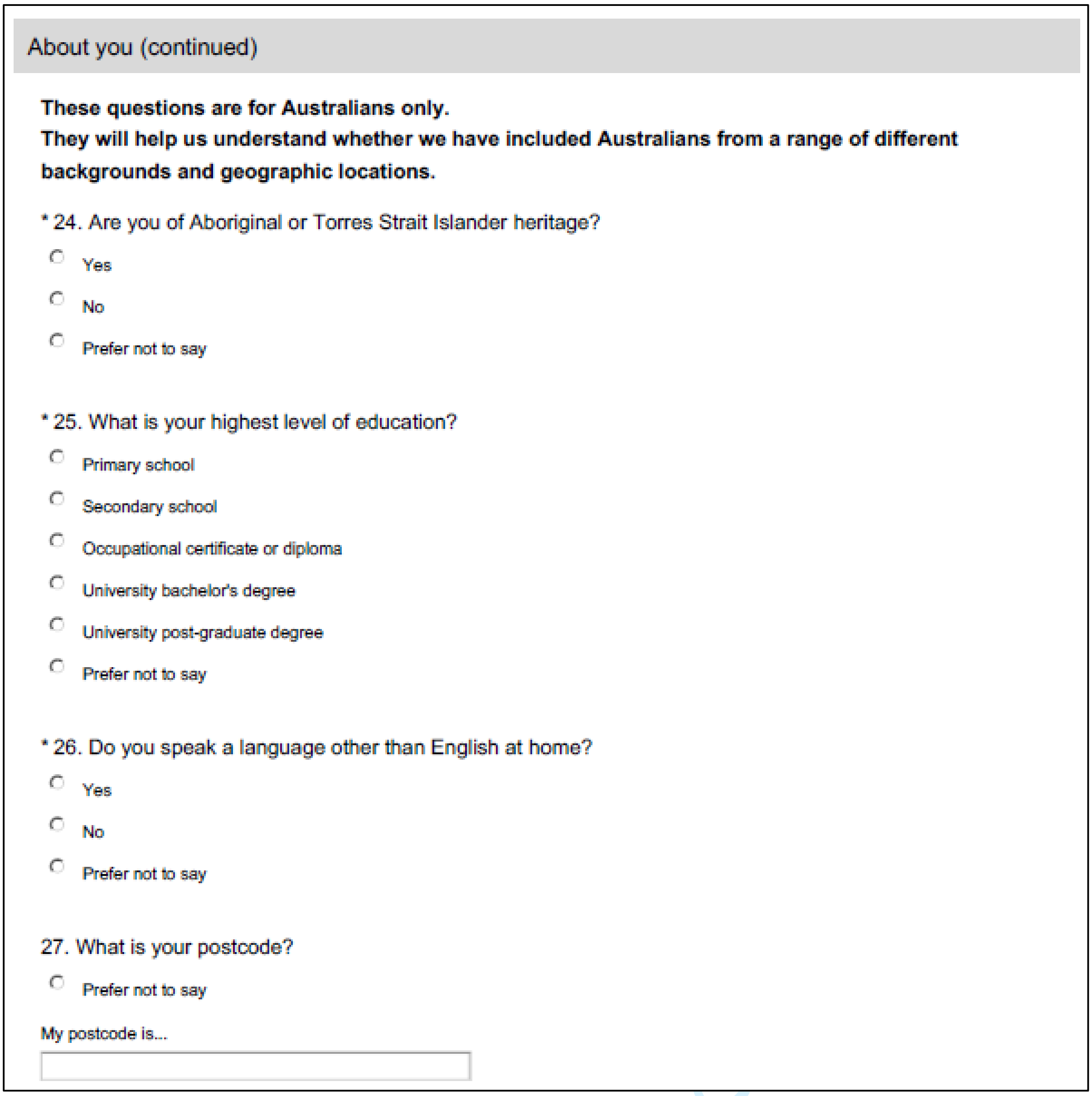
* 22. What gender are you?

- ○ 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...

only

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

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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.

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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

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	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

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	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

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	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				

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	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				

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‘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

Tong, A., Sautenet, B., Chapman, J. R., Harper, C., MacDonald, P., Shackel, N., Crowe, S., Hanson, C., Hill, S., Synnot, A. and Craig, J. C. (2017), Research priority setting in organ transplantation: a systematic review. Transpl Int, 30: 327–343. doi:10.1111/tri.12924

Available in Supplementary Material at: http://onlinelibrary.wiley.com/doi/10.1111/tri.12924/abstract

SDC Materials and Methods: Appraisal framework

ID	Item	Descriptor and/or examples	Page no.
A.	**Context and scope**		
1	Define geographical scope	*Global, regional, national, institutional, health service*	6
2	Define health area or focus	*Disease or condition specific, healthcare delivery*	7
3	Define end-users of research	*General population, patients*	7
4	Define the target audience	*Policy makers, funders, researchers, industry*	7
5	Identify the research focus	*Public health, health services, clinical, basic science; primary research, systematic reviews, guidelines*	6
6	Identify the type of research question	*Etiology, diagnosis, prevention, treatment, prognosis, health services, psychosocial, education, QOL, economic evaluation*	7
7	Define the time frame	*Short term or long term priorities*	NR
B.	**Governance and team**		
8	Describe selection of the project leader/s and team	*Steering Committee, working group, coordinators*	6-7
9	Describe the characteristics of the project leader/team members	*Stakeholder group, organisations represented, characteristics*	6-7
10	Training or experience in research priority setting	*Involvement of JLA advisor*	7
C.	**Inclusion of stakeholders/participants**		
11	Define the inclusion criteria for stakeholder groups involved in the PSP	*Stakeholder group*	7
12	State the strategy or method for identifying and engaging stakeholders	*Partnerships, social media, recruitment through hospitals*	7
13	Indicate the number of participants and/or organisations involved	*Individuals, organisations*	10
14	Describe the characteristics of stakeholders	*Name of stakeholder group e.g. clinicians, patients, policy makers*	10-11
15	Reimbursement for participation	*Cash, vouchers, certificates, acknowledgement*	NR
D.	**Identification and collection of research topics/questions**		
16	Describe methods for collecting all research topics or questions	*Technical data (burden of disease, incidence), systematic reviews, reviews of guidelines/other documents, surveys, interviews, focus groups, meetings, workshops*	8
17	Describe methods for collating and/or categorising topics or questions	*Taxonomy, framework, used to organised and aggregate topics or questions*	9
18	Describe methods or reason for initial removal or topics or questions	*Beyond scope, lack of clarity and ill-defined, duplicative, number of submissions*	9 & 11
19	Describe methods for refining research questions/topics	*Reviewed by Steering Committee*	9
20	Cross check to identify if research questions have been answered	*Systematic reviews, consultation with experts*	N/A (see footnote)

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21	Describe number of research questions/topics	*Report number of research questions at each stage of the process*	11
E.	**Prioritisation of research topics/questions**		
22	Describe methods for prioritising or achieving consensus on priority research areas, topics, or questions	*Consensus methods: Delphi, nominal group technique, workshops; define thresholds: ranking scores, proportions, votes (interim and final stage)*	N/A (see footnote)
23	Provide reasons for excluding research topics/questions	*Thresholds for ranking scores, proportions, votes (interim and final stage)*	N/A (see footnote)
F.	**Output**		
24	Define specificity of research priorities	*Area, topic, questions, PICO*	N/A (see footnote)
G.	**Evaluation and feedback**		
25	Describe how the research priorities exercise was evaluated	*Conduct a survey, interviews, debriefing session*	N/A (see footnote)
26	Describe how priorities were made accessible for review by stakeholders	*Circulate or upload a draft report*	N/A (see footnote)
27	State how feedback was integrated	*Describe changes made based on feedback*	N/A (see footnote)
28	Outline the strategy or action plans for implementing priorities	*Liaise with key partners*	N/A (see footnote)
29	Describe how impact will be measured	*Improved stakeholder understanding, shifted priorities, reallocation of resources, improved quality of decision-making, stakeholder acceptance and satisfaction*	N/A (see footnote)
30	State sources of funding	*Name of funders*	18
31	Outline the budget and/or cost	*Report project expenses*	N/A (see footnote)
32	Provide declaration of conflict of interest	*Statement of conflict of interest collected and reported*	18

Footnote: Given we report only the first stage of the priority setting project, several of the later items are not applicable as they were undertaken in the subsequent project stage.

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BMJ Open

Research priorities in health communication and participation: International survey of consumers and other stakeholders

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Manuscripts

TITLE

Research priorities in health communication and participation: International survey of consumers and other stakeholders

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ABSTRACT

OBJECTIVE: To identify research priorities of consumers and other stakeholders to inform Cochrane Reviews in 'health communication and participation' (including such concepts as patient experience, shared decision making and health literacy).

SETTING: International

PARTICIPANTS: We included anyone with an interest in health communication and participation. 151 participants (18 to 80 years; 117 female) across 12 countries took part, including 48 consumers (patients, carers, consumer representatives) and 75 professionals (health professionals, policymakers, researchers) (plus 25 people who identified as both).

DESIGN: Survey

METHODS: We invited people to submit their research ideas via an online survey open for four weeks. Using inductive thematic analysis, we generated priority research topics, then classified these into broader themes.

RESULTS: Participants submitted 200 research ideas, which we grouped into 21 priority topics. Key research priorities included: insufficient consumer involvement in research (19 responses), 'official' health information is contradictory and hard to understand (18 responses), communication/coordination breakdowns in health services (15 responses), health information provision a low priority for health professionals (15 responses), insufficient eliciting of patient preferences (14 responses), health services poorly understand/implement patient-centred care (14 responses), lack of holistic care impacting healthcare quality and safety (13 responses), and inadequate consumer involvement in service design (11 responses). These priorities encompassed acute and community health settings, with implications for policy and research. Priority populations of interest included people from diverse cultural and linguistic backgrounds, carers, and people with low educational attainment, or mental illness. Most frequently suggested interventions focussed on training and cultural change activities for health services and health professionals.

CONCLUSIONS: Consumers and other stakeholders want research addressing structural and cultural challenges in health services (e.g. lack of holistic, patient-centred, culturally safe care) and building health professionals' communication skills. Solutions should be devised in partnership with consumers, and focus on the needs of vulnerable groups.

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STRENGTHS AND LIMITATIONS OF THIS STUDY

- We partnered with stakeholders (nearly 50% of whom identified as consumers, carers or consumer representatives) and used a systematic process, to identify 21 international priority research topics in communication and participation in health.
- We have demonstrated the feasibility of priority setting with stakeholders in a complex healthcare area, and detail a research-based approach to analysing and categorising participant responses.
- Over 90% of stakeholders were from Australia or other high-income, English-speaking countries, limiting generalisability beyond high-income settings.
- The use of online-only methods may have resulted in inequitable participation, with less participation of people from vulnerable groups.
- Some of the examples we provided in the survey may have influenced the responses of participants.

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INTRODUCTION

People have the right to be actively involved in their healthcare, and should be provided with high quality, culturally appropriate and timely information, support and services, allowing them to be knowledgeable about, and to participate in their health in different ways.[1-3] Recognised as critical aspects of a well-functioning health system, health funders and deliverers are increasingly seeking to measure and apply concepts such as shared decision making and person-centred care,[3, 4] patient experience-led improvement,[5] health literacy,[6, 7] and the co-design of health services, policy and research.[8, 9] In this study we define these concepts collectively, as experiences of, or activities to improve, 'health communication and participation'.

Despite considerable efforts, people's experiences of health communication and participation are often less than optimal.[10, 11] Aside from obvious ethical imperatives, poor communication and inadequate patient participation in their health impacts upon healthcare quality and safety.[12, 13] For example, poor patient experience and low health literacy are associated with poorer health outcomes, adverse events, increased hospital length of stay and readmissions, reduced adherence to treatment and lower use of preventive services.[12, 14] Conversely, considerable international evidence now supports the use of numerous interventions to improve health communication and participation. For example, people exposed to decision aids feel better informed, better able to understand risks and are more active in the decision-making process.[15] The use of automated telephone communication systems in a wide variety of clinical contexts and settings can improve clinical outcomes and increase healthcare uptake, such as immunisation and appointment attendance,[16] and self-monitoring interventions can improve medication adherence, clinical outcomes and reduce mortality in some people.[17]

In this context, efforts to identify solutions to complex problems in both healthcare and research are increasingly being undertaken in partnership with the people and groups affected by the issues.[1, 18] Often termed 'stakeholders', this includes not only consumers (patients and their families or carers, those receiving services and the public)[18], but health professionals, managers, policy makers, research funders and researchers.[19] Research priority setting with stakeholders is thought to both align research with the needs of those who it affects,[20] and reduce research waste.[21] Increasingly, priority-setting methods are being applied not just for primary research, but to identify the most important questions for systematic reviews.[22] While existing research priority setting methods and frameworks (e.g. Viergever)[23] can be used for prioritising systematic reviews,[24] the

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final selection of priority systematic review topics may also be informed by their appropriateness and feasibility for systematic review teams.[25]

Within the area of health communication and participation, overarching research priorities of consumers and other stakeholders are unknown, with the exception of medication adherence[26] and patient safety in primary care.[27] Research priority setting partnerships are typically conducted for specific health conditions or clinical settings [20, 28]. However, it is notable that concepts like doctor-patient communication, information and education, consumers as partners, and self-management, are frequently identified as research priorities. For example, one or more of these topics was a top priority in asthma,[29] dementia,[30] palliative care,[31] pre-term birth,[32] and type 1 diabetes.[33] Given potential solutions to these problems are complex[34] and common across conditions,[35] an in-depth exploration of research priorities in this area across health conditions and contexts has the potential to add valuable information to healthcare policy making.

Study aim

In March 2015, we commenced a research priority setting project with the aim of identifying future Cochrane Intervention Review topics in health communication and participation.[36] In this paper, we report the first stage of the project, in which we used an international survey to identify priority topics.

METHODS

The methods were informed by guidance from the James Lind Alliance,[37] and Cochrane Priority Setting Methods Group.[22, 24] In this first stage, we conducted an online survey.

We worked in partnership with consumers and other stakeholders to plan and undertake all project stages.[38] Our approach was informed by the principles of co-production, i.e. recognising expertise, building on strengths, enabling shared control and mutually beneficial and supported relationships .[39, 40] We reported activities and data against the relevant sections of a 32-item research priority setting appraisal checklist.[41] The study was approved by the La Trobe University Science Health and Engineering College Human Ethics Sub-Committee.

Context of the priority setting partnership

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The project was initiated by researchers at the Centre for Health Communication and Participation ('the Centre'), La Trobe University, Australia. At this Centre, the Cochrane Consumers and Communication (CCC) Group coordinates the preparation and publication of Cochrane Reviews of interventions that affect the way people interact with healthcare professionals, services and researchers.[35] Conducted as part of a suite of stakeholder engagement activities, the project also coincided with new strategic directions within Cochrane, in which the organisation committed to engage with consumers and other stakeholders to identify their most relevant and important questions, and prioritising Cochrane Review topics accordingly .[42] (p.11).

Project steering group

We convened an 11-member steering group at project commencement.[37] The group was based in Australia and included people representing: the Australian Commission on Safety and Quality in Health Care (n = 1);[43] the National Health and Medical Research Council (n = 1);[44] Safer Care Victoria (n = 1);[45] Victorian health services (with people in clinical (n = 1) and managerial (n = 1) positions); health consumer organisations (n = 1); health consumer representatives (n = 2); and Cochrane Australia (n = 1).[46] Two researchers (one of whom was based in the UK) with priority-setting expertise also joined the group. Steering group input defined project scope; advised on participant selection and recruitment; refined identified priorities at key points; and planned and assisted with dissemination. We held three face-to-face steering group meetings (some joined by teleconference), with ad hoc input over email.

Scope of the priority setting

The steering group recommended the project scope reflect the scope of CCC reviews (i.e. 'interventions that affect the way people interact with healthcare professionals, services and researchers').[47] Making sense of research in this area is challenging; interventions are complex[34] with innumerable related and inconsistently-defined concepts,[48, 49] and international variations in terminology and meaning.[50, 51] To aid clarity in survey promotion, we used the term 'health communication and participation research', defined as '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'.[52] We provided examples to participants

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clarifying that this included broader participation in health services, policy and research. We sought international priorities that could be scoped to inform intervention reviews, given Cochrane's global reach and predominant focus on intervention effectiveness.

Participants and recruitment

We sought international participation in the online survey; inviting people aged 18 years and over who identified as 'patients, consumers, carers, and their advocates, health professionals, policy makers, researchers, funders, and persons interested in health communication and participation'. English-language proficiency was implied given the survey was only available in English. Participants were provided with the option to complete the survey by post or phone.

In May 2015 we undertook purposive and snowball sampling,[53] promoting the survey by email and in newsletters. Approximately 1,000 individuals and organisations were identified from the networks of the project team and steering group, and internet searches (for international patient groups, in particular), and were invited to forward the survey link to their networks or members. Those who received the email included consumer groups, Australian government health departments and health networks, medical and nursing colleges, national health organisations and advocacy groups, researchers and CCC authors and other contributors. Additional efforts, in the form of phone calls and facilitated introductions, were made to Australian organisations working with or representing Indigenous people and people from diverse cultural and linguistic backgrounds. We sent weekly email reminders while the survey was open.

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Collecting research priorities

We invited people to share their 'ideas for future research topics in the area of health communication and participation' via an online survey (see Supplementary File S1) that was open for four weeks, using SurveyMonkey.[54] We advised that their ideas would inform topic selection of 'reviews of the latest evidence'. We used the following set of questions: (1) What is the health communication and participation problem you would like to see addressed?, (2) In your experience, is this a problem for particular groups of people?, (3) Is there a particular setting or group of health professionals this is relevant to?, and (4) Do you have any particular solutions you would like to see tested? If so, please describe. The online system permitted up to four research priority submissions per participant. To facilitate clarity, context and meaning each question was followed by illustrative examples (see Supplementary File S1).

We used an online survey as it allowed international participation and is recommended by the James Lind Alliance process.[37] The online survey questions were devised in response to the complexity and breadth of project scope, and in consideration of the diversity of respondents' familiarity with the topic and terminology. We opened with the 'problem' question to (1) provide participants a conceptual 'anchor' to enter the survey, (2) generate a description of the context or rationale to inform a potential review,[34, 35] and (3) allow participants to describe what they would like to see research address, without needing to be familiar with the wide range of potential interventions to solve the problem. Subsequent questions allowed participants to share information relevant to generating systematic review questions (i.e. participants, settings and interventions).[55] We took this approach because systematic reviews in health communication and participation are frequently framed to capture a range of interventions which share a common goal addressing a known issue or problem, for example, interventions to improve safe and effective medicines use by consumers[17] or interventions for providers to promote a patient-centred approach in clinical consultations.[56] We avoided technical research terms (e.g. 'systematic reviews', 'Cochrane reviews', 'interventions') given consumers are often unfamiliar with these terms.[57, 58]

We piloted the survey with six people, including consumers (n = 4), a health professional (n = 1) and a policy maker (n = 1). After completing the survey, they participated in a telephone interview, describing the experience and suggesting improvements. The survey structure was endorsed by these participants, and we made minor wording and format changes.

Analysing and grouping research priorities

We conducted an inductive thematic analysis, using a taxonomy method for analysing qualitative health services research.[59] Taxonomies classify 'multifaceted, complex phenomena according to a set of common conceptual domains and dimensions'[59] (p.1761), and are well suited to grouping similar interventions in health communication and participation.[60, 61] We used both conceptual (key health communication and participation concept domains and their essential dimensions) and participant characteristic (identifying characteristics of stakeholders) codes.[59] Two researchers independently coded data, with a third to resolve disagreements (AS, JN, DL). Data was coded

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iteratively, and we compared interpretations and agreed on a set of codes, then topics and themes.[62, 63]

First, we downloaded data into Microsoft Excel and edited extraneous language to focus on key concepts.[61] For each participant, we coded their data against three conceptual codes: the problem they wanted addressed; who the problem affects (the 'participants' in the commonly used systematic review question-formation structure of Participants, Interventions, Comparisons and Outcomes (PICO)); and potential solutions to be tested in research (the 'interventions' in PICO). Given participants were asked to submit their research ideas using four related questions per idea, their answers to these four questions were treated as a single unit (or research idea) in the analysis. At this stage, research ideas that were agreed to be out of scope for future reviews were excluded, while those that contained one of more distinct conceptual problem code were split into two.

We grouped similar conceptual problem codes together to form priority research topics,[59] which were then aggregated into groups labelled with simple descriptive themes using straightforward health systems language,[64], the aim being to adhere closely to the elements specified by respondents.[65] We developed and applied this method of categorising topics because the analysis commenced with the contextual problem (Q1, which was mandatory) and because this aids identification of potential interventions to address this problem or meet this goal but in a non-prescriptive way. This is in contrast to the more commonly used frame of "what is the effect of intervention X for people with Y on outcomes Z" which is used in clinical, condition-specific areas.[37] We retained the terminology used by participants to devise the topics, meaning synonymous terms were included (e.g. some themes refer to 'consumers' and others to 'patients').

For the participant characteristics code, we collapsed the 10 stakeholder groups into three mutually exclusive groups: 'consumer or carer', 'healthcare professionals, policy makers and researchers' and 'both' (see Supplementary file, table S1 for definitions) to allow narrative comparison of demographic characteristics and research priorities between stakeholders. We used Microsoft Excel to analyse the descriptive data.

We listed the priority topics, grouped by descriptive themes, and included the number of responses coded to each topic. We elected not to present specific interventions and populations suggested for each theme given the considerable overlap in interventions and populations suggested across topics and the sometimes small number of responses per theme.

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Patient and public involvement

As described in more detail in the methods, we involved patients and the public (in this paper termed ‘consumers’) throughout the study. The three consumer representatives on our steering group contributed to study scope, design, recruitment, interpretation of results and dissemination. They are co-authors on this paper. In addition, we included the perspectives of a larger number of consumers as study participants. We created our final report[36] with consumer input, and shared this with study participants and with relevant groups and individuals in the sector, more broadly.

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RESULTS

Participant characteristics

In total, 151 participants from 12 countries took part (see Table 1). Participants were from Australia (n = 110, 74%), United Kingdom (n = 13, 9%), Canada (n = 7, 5%), the United States (n = 6, 4%), and 12 other countries (8%; denominator 148 given demographic data absent for three participants). The mean age (± SD) was 48.9 ± 12.8 years (range 18 to 80 years), and 117 (79%) were female. Nearly all (n = 148, 98%) completed the survey online. The stakeholder groups most commonly self-nominated were that of consumer/patient advocate, representative or volunteer (n = 57, 38%), then health professional (n = 55, 36%), person with a health condition (n = 51, 34%), carer or family member of someone with a health condition (n = 49, 33%), and researcher (n = 43, 29%).

Table 1. Participant characteristics (N=151)

Characteristic	**TOTAL**[1] n (%)
Age (years; mean ± SD, range)	49 ± 13 (18 – 80)
Female	117 (79)
Stakeholder perspective[2]	
Person *without* a health condition	32 (21)
Person *with* a health condition	51 (34)
Carer/family member of someone with a health condition	49 (33)
Consumer/patient advocate, representative or volunteer	57 (38)
Health professional	55 (36)
Health service manager or staff	19 (13)
Policy maker	10 (7)
Researcher	43 (29)
Research funder	1 (1)
Other[3]	11 (7)

No response provided	3 (2)
Country	
Australia	110 (74)
United Kingdom	13 (9)
Canada	7 (5)
United States	6 (4)
All other[4]	12 (8)

[1] The total number of participants was n = 151, but the denominator for most items was n = 148 given n = 3 participants did not provide any demographic information.

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

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

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

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Many participants self-nominated more than one stakeholder perspective. To facilitate a meaningful comparison, we grouped all stakeholders into one of three mutually exclusive groups: Consumers or carers (n = 48; 32%), Healthcare professionals, policy makers and researchers (n = 75; 51%), and a group where people identified as both (n = 25; 17%). In Table 1 we present the demographic characteristics for the 151 participants because there did not appear to be any meaningful differences between stakeholder groups (see Supplementary file, table S1). Additional demographic details that were only asked of Australian participants only are presented in Supplementary file, table S2.

Results of the coding process

Overall, 191 ideas for health communication and participation research were submitted. Ten were removed for being out of scope (n = 8) or lacking sufficient clarity (n = 2). Several remaining ideas were split, as they contained more than one distinct problem. As such, there were 200 research ideas that were coded and grouped into one of 21 research priority topics, and then into one of six overarching priority themes (see Table 2).

Table 2. Priority topics, grouped by descriptive themes for scoping future systematic reviews of interventions in health communication and participation

	Number of responses (n =)
Theme 1: Health service-level issues	64

Breakdowns in **communication and coordination** of care between and within health services are common	15
The term **patient-centred care is poorly understood** and implemented by health services and health professionals	14
The **quality and safety of patient care** can be compromised by health services (particularly hospitals) not treating patients **holistically**	13
Cultural safety (e.g. language considerations and cultural needs) is not well-embedded in health services	10
Informed consent for treatment and research does not always happen	6
N**ot enough time** is given to allow good communication between health professionals and patients	6
Theme 2: Health professional-level issues	50
Some health professionals **don't understand or ask patients** about their **preferences and priorities**	14
Some health professionals **don't provide enough information** to patients (some don't think it's a priority)	15
Health professionals don't always provide enough **support for patient decision making**	10
There are often two-way **barriers to adequate communication and participation** (e.g. disability of individual plus discomfort of health professional)	7
Health professionals don't always know how to **gauge how much their patients understand**	4
Theme 3: Consumers and carer issues in their own care	37
Patients don't always **understand their health problems, treatment options or their rights**	10
Consumers and carers don't always **know about all the options or services** that exist	9
Consumers and carers aren't always able to **participate actively** in their care	5
The general public doesn't always have enough **health literacy** to navigate the health system and make health decisions	5
Patients often experience **information overload** and are unable to retain the important information	4
Consumers and carers have difficulty **understanding key medication** information	4
Theme 4: Issues for broader consumer and carer involvement	30
Health researchers don't adequately **involve patients** in research, nor share their findings	19
Health services don't properly **involve consumers and carers** in **health service planning and design**	11
Theme 5: Accessibility of high quality health information	18
'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**	18
Theme 6: Ageing and end of life care	8
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	8

Priority themes and topics in health communication and participation

The priority themes were issues at (1) health service level, (2) health professional level; and (3) for consumers and carers in their own care; along with (4) broader consumer and carer involvement; (5) accessibility of high quality health information; and (6) ageing and end-of-life care (see Table 2). The latter topic is more specific than others but our coding was both pragmatic and reflective of respondents' answers, and it is a feature of many health systems that communication with older people or people who are dying are treated as separate issues and interventions designed accordingly.[66, 67] The 21 research priority topics are broadly scoped priority issues to be addressed in research, some of which are not mutually exclusive given the overlap in concepts in health communication and participation.

The most commonly cited priority topics, i.e. the health communication and participation problems that stakeholders most wanted research to address include: insufficient consumer involvement in research (19 responses); 'official' health information that is contradictory and hard to understand (18 responses); communication and coordination breakdowns in health services (15 responses); health information provision being a low priority for health professionals (15 responses); insufficient eliciting of patient preferences (14 responses); health services that poorly understand or implement patient-centred care (14 responses); lack of holistic care impacting quality and safety (13 responses); and inadequate involvement of consumers in service design (11 responses).

Below is a description of the priority themes and topics for all stakeholders, followed by priority populations and potential interventions. See Supplementary file, table S3 for the number of responses to each of the priority topics broken down by main stakeholder group, with example quotes.

Priority theme 1: Health service level issues

The theme on health service level issues contained six topics. The most frequently cited topics were breakdowns in communication and coordination between and within health services, poor understanding and/or embedding of 'patient-centred care' and cultural safety (e.g. language considerations or cultural needs) within health services and that the safety and quality of healthcare can be comprised by not treating patients holistically.

Priority theme 2: Health professional level issues

Within health professional level issues, the five priority topics centred on individual health professional-patient communication issues. For example, stakeholders suggested some health professionals don't understand or ask about patients about preferences and priorities, nor do they

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always know how to gauge how much their patients understand. Other suggested that health professionals do not provide enough information, or decision-making support.

Priority theme 3: Consumer and carer issues in their own care

Stakeholders identified six priority topics related to issues for consumers and carers in their own care. These focussed predominantly on issues related to a lack of understanding or awareness on the part of consumers and carers about: their health; treatment options; rights; and available services, affecting their ability to participate in their own care.

Priority themes 4 to 6: Broader consumer and carer involvement in services; accessibility of high quality health information access; and ageing and end-of-life care

Stakeholders identified two priority topics in theme 4; that researchers and health services do not properly involve consumers and carers in (1) research, or (2) service planning and design. The final two themes each included only one priority topic, that publically available health information can be contradictory, hard to understand, and hard to find and assess (theme 5) and that there is insufficient support and understanding about older people's needs and end of life decisions (theme 6).

Populations affected (across priority themes and topics)

Participants stated that certain people or groups were more likely to be affected for each health communication and participation research priority, but acknowledged that everyone can experience poor health communication and participation. Those identified as more vulnerable included:

- people from diverse cultural and linguistic backgrounds;
- those with limited English;
- people with caring responsibilities;
- those with limited education and/or limited literacy and numeracy;
- people from low socioeconomic areas;
- people with mental illness;
- older people;
- people with dementia and cognitive issues;
- those with chronic illness or multi-morbidity;

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- people from rural and regional areas;
- Indigenous people; and
- people with disability.

Possible interventions (across priority themes and topics)

Participants suggested a range of interventions that could be researched to address the problems identified. Potential interventions included communication skills training for health professionals, training and cultural change activities for hospital and health professionals about involving consumers and carers in health services, and personally controlled electronic health records (see Box 1; interventions are described in order of the frequency with which they were mentioned).

Box 1. Suggested interventions to address health communication and participation priority themes and topics

- Training for health professionals and health services personnel, in how to:
    - Better involve patients and carers in their individual care
    - Communicate with patients and carers, particularly people from diverse cultural and linguistic backgrounds
    - Involve consumers and carers in the health service more broadly
- Cultural change activities for hospitals and health professionals
- Electronic health records (accessible by patients and carers)
- Support for patients and family members to negotiate healthcare services, for example patient advocates in hospital or peer support workers
- Better information for general public, patients and family members, including written and online formats that are easy to read, standardised and present risks and harms
- Community education campaigns about when and how to access health services and understanding key health concepts
- Training for researchers and consumers in how to involve consumers in research and share research findings in understandable ways

DISCUSSION

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We identified 21 priority topics highlighting a wide range of potential systematic review questions in health communication and participation from an international survey of 151 consumers, health professionals and others. Notable amongst the myriad of suggestions is the degree to which stakeholders want evidence about interventions which address structural and cultural barriers to communication and participation within health services (e.g., addressing the lack of holistic, patient-centred and culturally safe care) or building health professionals' communication skills and practices. Stakeholders also want to identify solutions to consumers' and carers' lack of understanding and awareness about their health, treatment options and their rights. Importantly, respondents suggested consumers and carers work in partnership with researchers and health services to devise these solutions. The priorities identified encompassed acute and community health settings, with relevance for policy and research, and many population groups and health conditions. The most frequently suggested interventions focussed on training and cultural change activities for health services and health professionals. Stakeholders emphasised that poor communication and participation can affect everyone, but disproportionately affect people from diverse cultural and linguistic backgrounds (relevant to the dominant culture and language of any country), carers, people with low education/literacy levels, and people with mental illness, among others.

We conducted what we believe is the first research priority setting partnership with stakeholders (nearly 50% of whom identified as consumers, carers or consumer representatives) across health communication and participation. We have not only identified a broad range of issues to inform future systematic reviews, but our list could be scoped by others, or subsequently prioritised in local contexts or health conditions, to inform a strategic research agenda (see Box 2). In doing so, we make three contributions to priority setting research methods: (1) demonstrating feasibility of priority setting with stakeholders in a complex healthcare area, (2) offering a novel approach to framing priority-setting survey questions and, (3) detailing a research-based approach to analysing and categorising suggested priorities.

Box 2. Recommendations

Recommendations for health communication and participation researchers:

- Prioritise research into interventions that:
    - address structural and cultural barriers to health communication and participation within health services;
    - build health professionals communication skills and practices; and

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    - support consumers' and carers' to better understand their health, treatment options and rights.
- Explicitly consider priority populations of interest, including people from diverse cultural and linguistic backgrounds, carers, people with low educational attainment and those with mental illness.
- Work in partnership with consumers and carers to devise specific interventions to be tested in research, but consider interventions focussed on training and cultural change activities for health services and health professionals.

Recommendations for future priority-setting research in health communication and participation:

- Identify the health communication and participation research priorities of consumers and other stakeholders low and middle-income settings; and
- Compare the similarities and differences in health communication and participation research priorities generated in this study with those generated in priority setting exercises in condition- and context-specific topics (i.e. asthma and intensive care).

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There is considerable consistency between the research priorities we identified and policy priorities for improving the quality and safety of health services and systems in Australia,[1] the United Kingdom,[2] the United States[68] and globally.[4] For example, Australia has strategic goals and standards for partnering with consumers in their own care and in health service governance and evaluation.[1, 69] Similarly, the WHO's Framework on Integrated, People-Centred Health Services outlines strategic goals that include people being empowered and engaged, and improved coordination between and within health services.[4] For this reason, our steering group suggested this broadly scoped priority list could be used by health decision makers, and consumer representatives or organisations, to support strategic policy or implementation activities, or advocacy efforts, respectively.

There are also synergies between our priorities and those in three aligned priority-setting activities in medication adherence,[26] patient safety in primary care[27] and palliative and end of life care.[31] All three identified research priorities addressing the information and support needs of patients and families, plus health professional training in patient-centred care,[26] improved communication and coordination between services,[31] and addressing the needs of vulnerable groups.[31] Given the exponential growth of prioritisation activities,[28] there is an opportunity to build up an international picture of communication and participation priorities, in which the differences and similarities could be analysed (see Box 2).

We acknowledge as a limitation that over 90% of participants were from Australia or other high-income, English-speaking countries. This is unsurprising given the project team and steering group were predominantly based in Australia, and the survey was only available in English. While there is variation in health communication and participation practices internationally,[70] studies show there can be considerable inter-country similarities[71] and differences[72] in patient preferences for involvement in their healthcare. As such, our results may be more applicable to higher income countries.

A second limitation relates to potential inequity in our priority-setting approach.[73]
Reflecting the PROGRESS-PLUS equity checklist (place of residence, race/ethnicity, occupation, gender, religion, education, socioeconomic status, social capital, age, sexual orientation, and disability)[74, 75] there was a low proportion of Australians from diverse cultural and linguistic backgrounds,[76], regional and rural areas,[77] Indigenous people,[78] and people without a university degree,[77] in our study. This is important given consumers' perceptions of health communication can differ based on such characteristics.[79] Our self-selection study included considerably more women than men. Given gender (relative to other demographic factors, like religion, ethnicity and age) is not a major predictor of healthcare preferences[80] we suggest that our results are broadly applicable across genders. While we made targeted efforts to recruit people from cultural and linguistically diverse backgrounds, and Indigenous people, we could only achieve what was feasible within the resources available. We note, however, that stakeholders themselves were equity-focussed, as they recommended these vulnerable population groups, and others, as deserving particular focus in future systematic reviews.

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Finally, we acknowledge limitations related to online survey wording. First, participants may have been influenced by some of the examples we provided. Of note is that 'training for health professionals' used as an example response for, 'Do you have any particular solutions to this problem that you would like to see tested?' and this was the most commonly received response. Second, we asked participants to nominate all stakeholder perspectives that applied to them (e.g. person with a health condition, health professional etc.), rather than nominating their 'primary' perspective for the purposes of the online survey. For the participants who ticked multiple perspectives, we may have classified them into the category of both a consumer and a professional, when if asked, they may have described themselves as predominantly a consumer or a professional.

Decisions regarding new research should be informed by the needs of potential users of this research, but also by the existing evidence.[21] Given this, research priority setting activities will typically refine and prioritise the initial, 'interim' priorities and undertake an assessment of the existing evidence, to determine which priorities are true 'research uncertainties'.[37] We subsequently convened a full-day workshop with stakeholders and undertook an evidence mapping exercise to complete these steps,[36] which will be reported separately. Additionally, to inform systematic reviews, the priorities must be ultimately be framed as searchable and answerable questions,[55] which most of our priorities are not. While interpretive analytic approaches[65] facilitate such a transformation of the data, we decided that given the potential for misinterpretation, subsequent scoping of answerable research questions should be undertaken in partnership with stakeholders.

CONCLUSIONS

Consumers and other stakeholders identified a broad mix of research priorities in health communication and participation. Notable amongst the myriad of priorities is the degree to which people want research addressing structural and cultural challenges in health services (e.g. lack of holistic, patient-centred, culturally safe care) and building health professionals' communication skills. Solutions should be devised in partnership with consumers, with particular focus on the needs of vulnerable groups.

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COMPETING INTERESTS STATEMENT

The authors have no competing interests to declare.

DATA SHARING STATEMENT

No additional unpublished data are available.

AUTHOR'S CONTRIBUTIONS

AS led the study design, data collection, analysis and interpretation and manuscript preparation. As steering group members, PB, LH, DK, DG, SM, NP, NB, NL, DV, SO, and KC contributed to study design and interpretation, and commented on manuscript drafts. DL contributed to data analysis and interpretation, and commented on manuscript drafts. JN contributed to study design, data analysis and interpretation, and commented on manuscript drafts. MO contributed to study design, data collection and commented on manuscript drafts. AT contributed to data interpretation and critically revised the manuscript for important content. SH contributed to study design, analysis and interpretation, and critically revised the manuscript for important content. All authors approved the final version of the manuscript.

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REFERENCES

1. Australian Commission on Safety and Quality in Health Care, *National Safety and Quality Health Service Standards (September 2012).* 2012, ACSQHC: Sydney.
2. National Institute for Health and Care Excellence, *Patient experience in adult NHS services: improving the experience of care for people using adult NHS services. NICE guideline (CG138)*. February 2012.
3. Institute of Medicine (US) Committee on Quality of Health Care in America, *Chapter 2. Improving the 21st-century Health Care System*, in *Crossing the Quality Chasm: A New Health System for the 21st Century*. 2001, National Academies Press (US): Washington (DC).
4. World Health Organization, *Framework on integrated, people-centred health services, A69/39*, S.-N.W.H. Assembly, Editor. 2016.
5. Raleigh, V., et al., *Patients' experience of using hospital services: An analysis of trends in inpatient surveys in NHS acute trusts in England, 2005–13*. 2015, The Kin's Fund and Picker Institute Europe: London, United Kingdom.
6. Australian Commission on Safety and Quality in Health Care (ACSQHC), *National Statement on Health Literacy*. n.d., ACSQHC: Sydney.
7. Brega, A., et al., *AHRQ Health Literacy Universal Precautions Toolkit, Second Edition*. 2015, Agency for Healthcare Research and Quality: Rockville, MD.
8. Boyd, H., S. McKernon, and A. Old, *Health Service Co-design: working with patients to improve healthcare services.* 2010, Waitemata District Health Board: Auckland, New Zealanad.
9. Health Canada and the Public Health Agency of Canada, *Guidelines on Public Engagement*. 2016, Health Canada: Ottawa.
10. Harrison, R., M. Walton, and E. Manias, *Patients' experiences in Australian hospitals: an Evidence Check rapid review brokered by the Sax Institute (www.saxinstitute.org.au) for the Australian Commission on Safety and Quality in Health Care*. 2015.
11. Care Quality Commission. *Better care in my hands: A review of how people are involved in their care*. 2016. London.
12. Doyle, C., L. Lennox, and D. Bell, *A systematic review of evidence on the links between patient experience and clinical safety and effectiveness.* BMJ Open, 2013. **3**(1).
13. Street Jr, R.L., et al., *How does communication heal? Pathways linking clinician–patient communication to health outcomes.* Patient Education and Counseling, 2009. **74**(3): p. 295-301.
14. Coulter, A. and E. J, *Patient-focussed interventions: A review of the evidence*. 2006, The Health Foundation: London, United Kingdom.
15. Stacey, D., et al., *Decision aids for people facing health treatment or screening decisions.* Cochrane Database of Systematic Reviews, 2017(4).
16. Posadzki, P., et al., *Automated telephone communication systems for preventive healthcare and management of long-term conditions.* Cochrane Database of Systematic Reviews, 2016(12).
17. Ryan, R., et al., *Interventions to improve safe and effective medicines use by consumers: an overview of systematic reviews.* Cochrane Database of Systematic Reviews, 2014. **4**.
18. National Health and Medical Research Council and Consumers Health Forum of Australia, *Statement on consumer and community involvement in health and medical research*, Commonwealth of Australia, Editor. 2016.
19. Concannon, T.W., et al., *A New Taxonomy for Stakeholder Engagement in Patient-Centered Outcomes Research.* Journal of General Internal Medicine, 2012. **27**(8): p. 985-991.

For peer review only

20. Crowe, S., et al., *Patients', clinicians' and the research communities' priorities for treatment research: there is an important mismatch.* Research Involvement and Engagement, 2015. **1**(1): p. 1-10.
21. Chalmers, I., et al., *How to increase value and reduce waste when research priorities are set.* The Lancet, 2014. **383**(9912): p. 156-165.
22. Nasser, M., et al., *Ensuring relevance for Cochrane reviews: evaluating processes and methods for prioritizing topics for Cochrane reviews.* Journal of Clinical Epidemiology, 2013. **66**(5): p. 474-482.
23. Viergever, R.F., et al., *A checklist for health research priority setting: nine common themes of good practice.* Health Research Policy and Systems, 2010. **8**.
24. Nasser, M., et al., *Evidence in agenda setting: new directions for the Cochrane Collaboration.* Journal of Clinical Epidemiology, 2013. **66**(5): p. 469-471.
25. Akl, E.A., et al., *The SPARK Tool to prioritise questions for systematic reviews in health policy and systems research: development and initial validation.* Health Res Policy Syst, 2017. **15**(1): p. 77.
26. McMullen, C.K., et al., *Patient-centered priorities for improving medication management and adherence.* Patient Education and Counseling, 2015.
27. NIHR Greater Manchester Primary Care Patient Safety Translational Research Centre *Patient Safety in Primary Care Research PSP*. 2017 13 June 1017]; Available from: http://research.bmh.manchester.ac.uk/PatientSafetyPSP/Top10/.
28. Domecq, J.P., et al., *Patient engagement in research: a systematic review.* BMC health services research, 2014. **14**.
29. Elwyn, G., et al., *Identifying and prioritizing uncertainties: patient and clinician engagement in the identification of research questions.* Journal of Evaluation in Clinical Practice, 2010. **16**(3): p. 627-631.
30. Kelly, S., et al., *Dementia priority setting partnership with the James Lind Alliance: using patient and public involvement and the evidence base to inform the research agenda.* Age and Ageing, 2015. **44**(6): p. 985-993.
31. Smith, R., S. Best, and B. Noble, *Identifying palliative and end-of-life care research priorities: a UK approach to consult end users.* European Journal of Palliative Care, 2015. **22**: p. 114-117.
32. Petit-Zeman, S. and S. Uhm, *Identifying research priorities in preterm birth.* Infant, 2012. **8**.
33. Gadsby, R., et al., *Setting research priorities for Type 1 diabetes.* Diabetic Medicine, 2012. **29**(10): p. 1321-1326.
34. Craig, P., et al., *Developing and evaluating complex interventions: the new Medical Research Council guidance.* BMJ, 2008. **337**.
35. Hill, S., Lowe, D, Ryan, R, *Interventions for communication and participation; their purpose and practice*, in *The Knowledgeable Patient* S. Hill, Editor. 2011, Wiley-Blackwell: London, UK.
36. Synnot, A., *Stakeholder priorities for research in health communication and participation: Findings from the Cochrane Consumers and Communication priority setting project*. 2016, Centre for Health Communication and Participation, La Trobe University: Melbourne.
37. The James Lind Alliance, *The James Lind Alliance Guidebook (version 6)*. 2016, National Institutes for Health Research.
38. IAP2 Australasia, *Quality Assurance Standard For Community and Stakeholder Engagement*. 2015, International Association for Public Participation Australasia (IAP2): Wollongong, Australia.
39. Ocloo, J. and R. Matthews, *From tokenism to empowerment: progressing patient and public involvement in healthcare improvement.* BMJ Qual Saf, 2016. **25**(8): p. 626-32.
40. Heaton, J., J. Day, and N. Britten, *Collaborative research and the co-production of knowledge for practice: an illustrative case study.* Implementation Science, 2016. **11**(1): p. 20.

For peer review only

41. Tong, A., et al., *Research priority setting in organ transplantation: a systematic review.* Transplant International, 2017. **30**: p. 327–343
42. Cochrane, *Strategy to 2020.* 2016, Cochrane: London, UK. p. www. community.cochrane.org/organizational-info/resources/strategy-2020.
43. Australian Commission on Safety and Quality in Health Care. *Australian Commission on Safety and Quality in Health Care,*. 2018 15 January 2018]; Available from: https://www.safetyandquality.gov.au/.
44. National Health and Medical Research Council. *National Health and Medical Research Council*. 2018 15 January 2018]; Available from: https://www.nhmrc.gov.au/.
45. State Government of Victoria. *Safer Care Victoria*. 2018 15 January 2018]; Available from: https://www2.health.vic.gov.au/hospitals-and-health-services/safer-care-victoria.
46. The Cochrane Collaboration. *Cochrane Australia*. 2018; Available from: http://australia.cochrane.org/.
47. Cochrane Consumers and Communication. *Scope of our work*. 2017 24 July 2017]; Available from: http://cccrg.cochrane.org/scope-our-work.
48. Kitson, A., et al., *What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing.* Journal of Advanced Nursing, 2013. **69**(1): p. 4-15.
49. Kaufman, J., et al., *Face to face interventions for informing or educating parents about early childhood vaccination.* Cochrane Database of Systematic Reviews, 2013(5).
50. IAPO, *What is Patient-Centred Healthcare? A Review of Definitions and Principles*. 2007, International Alliance of Patients' Organization: London, United Kingdom.
51. Boote, J., R. Telford, and C. Cooper, *Consumer involvement in health research: a review and research agenda.* Health Policy, 2002. **61**(2): p. 213-236.
52. Ryan, R.E. and S.J. Hill, *Improving the experiences and health of people with multimorbidity: exploratory research with policymakers and information providers on comorbid arthritis.* Australian Journal of Primary Health, 2014. **20**(2): p. 188-196.
53. Quinn Patton, M., *Chapter 5. Designing Qualitative Studies*, in *Qualitative Research and Evaluation Methods: Integrating Theory and Practice (4th Edition)*. 2015, SAGE Publications: Thousand Oaks, California.
54. SurveyMonkey Inc, *SurveyMonkey*. San Mateo, California, USA.
55. O'Connor, D., S. Green, and J.P. Higgins, *Chapter 5: Defining the review question and developing criteria for including studies*, in *Cochrane Handbook for Systematic Reviews of Interventions Version 5.1.0 [updated March 2011]*, J. Higgins and S. Green, Editors. 2011, The Cochrane Collaboration, Available from www.handbook.cochrane.org.
56. Dwamena, F., et al., *Interventions for providers to promote a patient-centred approach in clinical consultations.* Cochrane Database of Systematic Reviews, 2012. **12**.
57. Synnot, A.J., et al., *The evolution of Cochrane evidence summaries in health communication and participation: seeking and responding to stakeholder feedback.* Evidence & policy, 2017. **Fast track online**.
58. Glenton, C., et al., *Presenting the results of Cochrane Systematic Reviews to a consumer audience: a qualitative study.* Med Decis Making, 2010. **30**(5): p. 566-77.
59. Bradley, E.H., L.A. Curry, and K.J. Devers, *Qualitative data analysis for health services research: developing taxonomy, themes, and theory.* Health Serv Res, 2007. **42**(4): p. 1758-72.
60. Lowe, D., et al., *Development of a taxonomy of interventions to organise the evidence on consumers' medicines use.* Patient Education and Counseling, 2011. **85**(2): p. e101-e107.
61. Willis, N., et al., *"Communicate to vaccinate": the development of a taxonomy of communication interventions to improve routine childhood vaccination.* BMC international health and human rights, 2013. **13**: p. 23.

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62. Braun, V. and V. Clarke, *Successful qualitative research: a practical guide for beginners*. 2013, London, UK: Sage Publications.

63. Liamputtong, P., *Rigour and Ethics in Qualitative Research*, in *Qualitative research methods (4th ed)*. 2013, Oxford University Press: South Melbourne, Australia.

64. Lohr, K. and D. Steinwachs, *Health Services Research: An Evolving Definition of the Field.* Health Services Research, 2002. **37**: p. 15-17.

65. Thomas, J. and A. Harden, *Methods for the thematic synthesis of qualitative research in systematic reviews.* BMC Med Res Methodol, 2008. **8**: p. 45.

66. Cross, A., R. Elliott, and J. George, *Interventions for improving medication-taking ability and adherence in older adults prescribed multiple medications (Protocol).* Cochrane Database of Systematic Reviews, 2016. **10**: p. Art. No.: CD012419

67. Australian Commission on Safety and Quality in Health Care, *National Consensus Statement: essential elements for safe and high*quality end-of-life care.* 2015, ACSQHC: Sydney.

68. AHRQ, *National Healthcare Quality and Disparities Report and 5th Anniversary Update on the National Quality Strategy*. 2016, Agency for Healthcare Research and Quality: Rockville, MD.

69. Australian Commission on Safety and Quality in Health Care, *Australian Safety and Quality Framework for Health Care*, C. ACSQHC, Editor. 2010.

70. Harter, M., T. van der Weijden, and G. Elwyn, *Policy and practice developments in the implementation of shared decision making: an international perspective.* Z Evid Fortbild Qual Gesundhwes, 2011. **105**(4): p. 229-33.

71. Bastiaens, H., et al., *Older people's preferences for involvement in their own care: A qualitative study in primary health care in 11 European countries.* Patient Education and Counseling, 2007. **68**(1): p. 33-42.

72. Partridge, J.C., et al., *International comparison of care for very low birth weight infants: parents' perceptions of counseling and decision-making.* Pediatrics, 2005. **116**(2): p. e263-71.

73. Nasser, M., et al., *An equity lens can ensure an equity-oriented approach to agenda setting and priority setting of Cochrane Reviews.* J Clin Epidemiol, 2013. **66**(5): p. 511-21.

74. Oliver, S., et al., *Health promotion, inequalities and young people's health: a systematic review of research*. 2008, EPPI-Centre, Social Science Research Unit, Institute of Education, University of London: London.

75. Evans, T. and H. Brown, *Road traffic crashes: operationalizing equity in the context of health sector reform.* Injury Control and Safety Promotion, 2003. **10**(1-2): p. 11-12.

76. Australian Bureau of Statistics, *Reflecting a Nation: Stories from the 2011 Census, 2012–2013 , cat. no. 2071.0,* *http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/2071.0main+features902012-2013.* 2012.

77. Australian Bureau of Statistics, *Education and Work, Australia, May 2016, 'Table 29 Highest non-school qualification: Bachelor Degree level or above, By age and sex, 1982 to 2016', data cube: Excel spreadsheet, cat. no. 6277.0, viewed 1 May 2016,* *http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/6227.0Main+Features1May%202016?OpenDocument.* 2016.

78. Australian Bureau of Statistics, *Estimates of Aboriginal and Torres Strait Islander Australians, June 2011, cat. no. 3238.0.55.001, viewed 1 May 2017,* *http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3238.0.55.001June%202011?OpenDocument*. 2013.

79. DeVoe, J.E., L.S. Wallace, and G.E. Fryer, *Measuring patients' perceptions of communication with healthcare providers: Do differences in demographic and socioeconomic characteristics matter?* Health Expectations, 2009. **12**: p. 70-80.

80. Jung, H.P., et al., *Patient characteristics as predictors of primary health care preferences: a systematic literature analysis.* Health Expect, 2003. **6**(2): p. 160-81.

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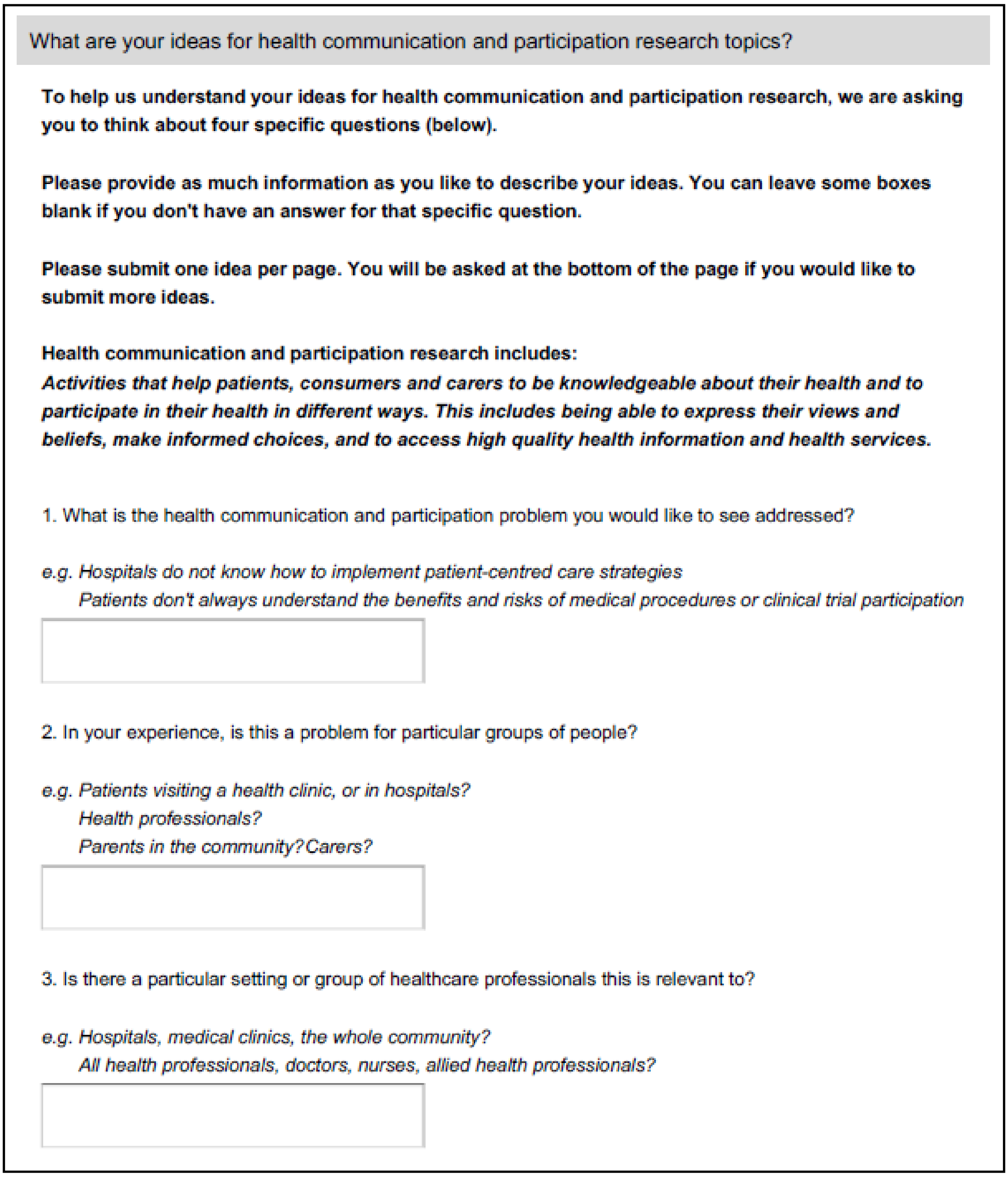
SUPPLEMENTARY FILE

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?

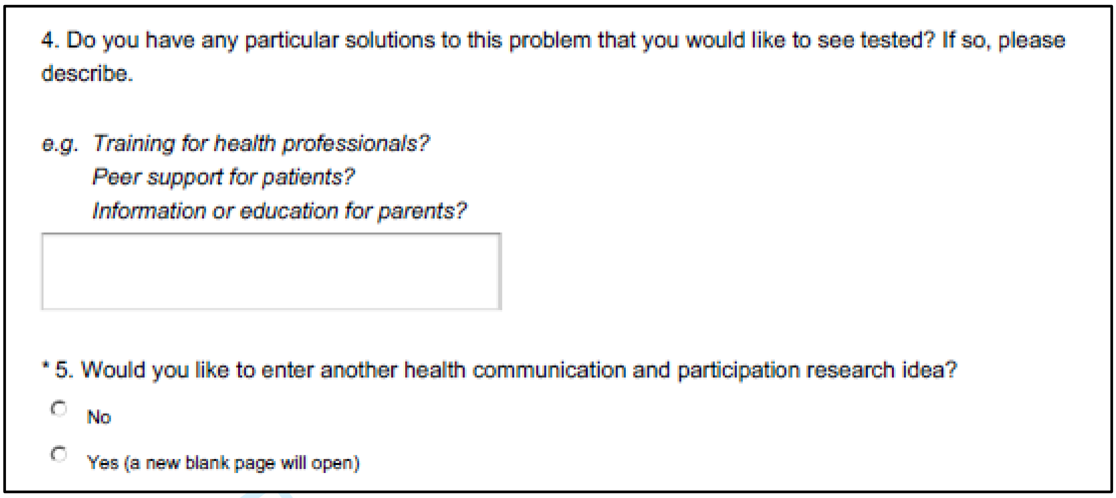
e.g. Hospitals do not know how to implement patient-centred care strategies
Patients don't always understand the benefits and risks of medical procedures or clinical trial participation

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)

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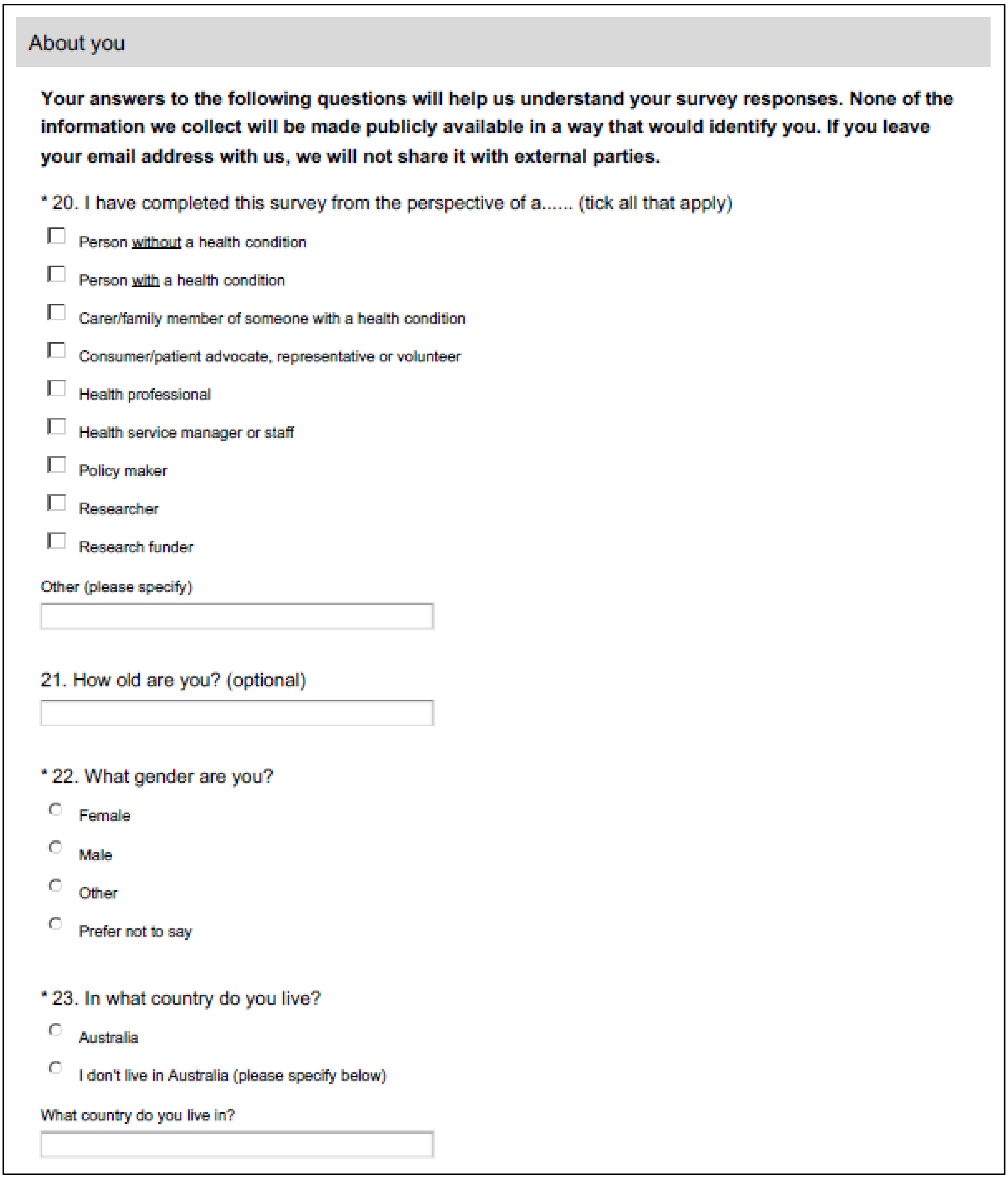


About you

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

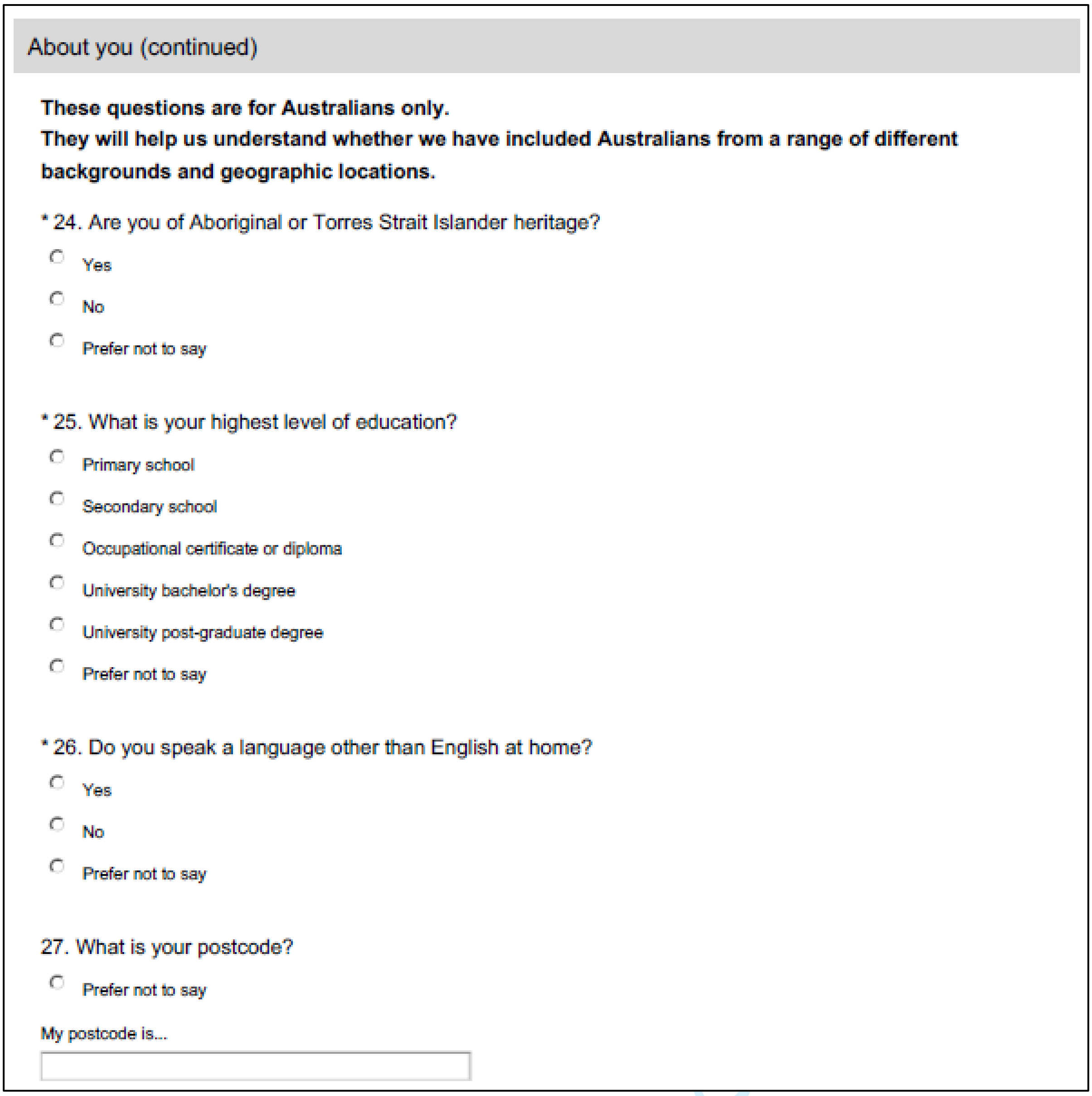
○ Prefer not to say

* 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...

only

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

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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.

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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

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	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

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	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

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	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				

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	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				

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‘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

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[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

Tong, A., Sautenet, B., Chapman, J. R., Harper, C., MacDonald, P., Shackel, N., Crowe, S., Hanson, C., Hill, S., Synnot, A. and Craig, J. C. (2017), Research priority setting in organ transplantation: a systematic review. Transpl Int, 30: 327–343. doi:10.1111/tri.12924

Available in Supplementary Material at: http://onlinelibrary.wiley.com/doi/10.1111/tri.12924/abstract

SDC Materials and Methods: Appraisal framework

ID	Item	Descriptor and/or examples	Page no.
A.	**Context and scope**		
1	Define geographical scope	*Global, regional, national, institutional, health service*	6
2	Define health area or focus	*Disease or condition specific, healthcare delivery*	7
3	Define end-users of research	*General population, patients*	7
4	Define the target audience	*Policy makers, funders, researchers, industry*	7
5	Identify the research focus	*Public health, health services, clinical, basic science; primary research, systematic reviews, guidelines*	6
6	Identify the type of research question	*Etiology, diagnosis, prevention, treatment, prognosis, health services, psychosocial, education, QOL, economic evaluation*	7
7	Define the time frame	*Short term or long term priorities*	NR
B.	**Governance and team**		
8	Describe selection of the project leader/s and team	*Steering Committee, working group, coordinators*	6-7
9	Describe the characteristics of the project leader/team members	*Stakeholder group, organisations represented, characteristics*	6-7
10	Training or experience in research priority setting	*Involvement of JLA advisor*	7
C.	**Inclusion of stakeholders/participants**		
11	Define the inclusion criteria for stakeholder groups involved in the PSP	*Stakeholder group*	7
12	State the strategy or method for identifying and engaging stakeholders	*Partnerships, social media, recruitment through hospitals*	7
13	Indicate the number of participants and/or organisations involved	*Individuals, organisations*	10
14	Describe the characteristics of stakeholders	*Name of stakeholder group e.g. clinicians, patients, policy makers*	10-11
15	Reimbursement for participation	*Cash, vouchers, certificates, acknowledgement*	NR
D.	**Identification and collection of research topics/questions**		
16	Describe methods for collecting all research topics or questions	*Technical data (burden of disease, incidence), systematic reviews, reviews of guidelines/other documents, surveys, interviews, focus groups, meetings, workshops*	8
17	Describe methods for collating and/or categorising topics or questions	*Taxonomy, framework, used to organised and aggregate topics or questions*	9
18	Describe methods or reason for initial removal or topics or questions	*Beyond scope, lack of clarity and ill-defined, duplicative, number of submissions*	9 & 11
19	Describe methods for refining research questions/topics	*Reviewed by Steering Committee*	9
20	Cross check to identify if research questions have been answered	*Systematic reviews, consultation with experts*	N/A (see footnote)

21	Describe number of research questions/topics	*Report number of research questions at each stage of the process*	11
E.	**Prioritisation of research topics/questions**		
22	Describe methods for prioritising or achieving consensus on priority research areas, topics, or questions	*Consensus methods: Delphi, nominal group technique, workshops; define thresholds: ranking scores, proportions, votes (interim and final stage)*	N/A (see footnote)
23	Provide reasons for excluding research topics/questions	*Thresholds for ranking scores, proportions, votes (interim and final stage)*	N/A (see footnote)
F.	**Output**		
24	Define specificity of research priorities	*Area, topic, questions, PICO*	N/A (see footnote)
G.	**Evaluation and feedback**		
25	Describe how the research priorities exercise was evaluated	*Conduct a survey, interviews, debriefing session*	N/A (see footnote)
26	Describe how priorities were made accessible for review by stakeholders	*Circulate or upload a draft report*	N/A (see footnote)
27	State how feedback was integrated	*Describe changes made based on feedback*	N/A (see footnote)
28	Outline the strategy or action plans for implementing priorities	*Liaise with key partners*	N/A (see footnote)
29	Describe how impact will be measured	*Improved stakeholder understanding, shifted priorities, reallocation of resources, improved quality of decision-making, stakeholder acceptance and satisfaction*	N/A (see footnote)
30	State sources of funding	*Name of funders*	18
31	Outline the budget and/or cost	*Report project expenses*	N/A (see footnote)
32	Provide declaration of conflict of interest	*Statement of conflict of interest collected and reported*	18

Footnote: Given we report only the first stage of the priority setting project, several of the later items are not applicable as they were undertaken in the subsequent project stage.

For peer review only