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

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TITLE

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

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Community Participation, Patient Preference, Communication; Patient-Centered Care, Quality of Health Care

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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.

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.

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

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17 The methods were informed by guidance from the James Lind Alliance,[30] and Cochrane Priority
18 Setting Methods Group.[31, 32] In this first stage, we conducted an online survey.
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22 We worked in partnership with stakeholders to plan and undertake all project stages.[33] Our
23 approach was informed by the principles of co-production (i.e. stakeholders are active agents with
24 respected expertise, blurred roles between researchers and stakeholders, with mutually-beneficial
25 and reciprocal relationships).[34, 35] We reported activities and data against the relevant sections of
26 a 32-item research priority setting appraisal checklist.[36, 37] The study was approved by the La
27 Trobe University Science Health and Engineering College Human Ethics Sub-Committee (S15-52).
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31 **Context of the priority setting partnership**

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

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51 We convened a 14-member steering group at project commencement.[30] The group included
52 people representing: the Australian Commission for Safety and Quality in Health Care; the National
53 Health and Medical Research Council, Safer Care Victoria; Victorian health services (with people in
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3 clinical and managerial positions); health consumer organisations; health consumer representatives;
4 and Cochrane Australia. Two researchers with priority-setting expertise also joined the group.
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6 Steering group input was sought to define project scope; advise on participant selection and
7 recruitment; refine identified priorities at key points; and plan and assist with dissemination. We
8 held three face-to-face steering group meetings (some joined by teleconference), with ad hoc input
9 over email.
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12 13 14 **Scope of the priorities being set**

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17 The steering group recommended the project scope reflect the scope of CCC reviews (i.e.
18 ‘interventions that affect the way people interact with healthcare professionals, services and
19 researchers’).[39] Making sense of research in this area is challenging; interventions are complex[27]
20 with innumerable related and inconsistently-defined concepts,[40, 41] and international variations
21 in terminology and meaning.[42, 43] To aid clarity in survey promotion, we used the term ‘health
22 communication and participation research’, defined as ‘activities that help patients, consumers and
23 carers to be knowledgeable about their health and to participate in their health in different ways.
24 This includes being able to express their views and beliefs, make informed choices, and to access
25 high quality health information and health services’.[44] We provided examples clarifying that this
26 included broader participation in health services, policy and research. We sought international
27 priorities that could be answered in, or scoped to inform, intervention reviews, given Cochrane’s
28 global reach and predominant focus on intervention effectiveness.
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37 **Participants and recruitment**

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40 We sought wide participation in the survey internationally; inviting people aged 18 years and over
41 who identified as ‘patients, consumers, carers, and their advocates, health professionals, policy
42 makers, researchers, funders, and anyone with an interest in the area’. English-language proficiency
43 was implied given the survey was only available in English.
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49 In May 2015 we promoted the survey by email and in newsletters. Participants could request to
50 complete the survey by post or phone. Organisations and individuals who received the email
51 included consumer groups, government health departments and health networks, medical and
52 nursing colleges, national health organisations and advocacy groups, researchers and CCC authors
53 and other contributors. Additional efforts, in the form of phone calls and facilitated introductions,
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3 were made to organisations working with or representing Indigenous people and people from
4 diverse cultural and linguistic backgrounds. We sent weekly reminders over three weeks.
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7 **Collecting the priorities**

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10 We invited people to share their 'ideas for future research topics in the area of health
11 communication and participation' via an online survey (see Supplementary File S1) using
12 SurveyMonkey[45]. We advised that their ideas would inform topic selection of 'reviews of the latest
13 evidence'. We used the following set of questions: (1) What is the health communication and
14 participation problem you would like to see addressed?, (2) In your experience, is this a problem for
15 particular groups of people?, (3) Is there a particular setting or group of health professionals this is
16 relevant to?, and (4) Do you have any particular solutions you would like to see tested? If so, please
17 describe. Participants could submit up to four research ideas.
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25 The aforementioned survey questions were devised in response to the complexity and breadth of
26 project scope, and in consideration of the diversity of respondents' familiarity with the topic and
27 terminology. We opened with the 'problem' question to (1) provide participants a conceptual
28 'anchor' to enter the survey, (2) generate a description of the context or rationale to inform a
29 potential review;[27, 28] and (3) allow participants to describe what they would like to see research
30 address, without needing to be familiar with the wide range of potential interventions to solve the
31 problem. Subsequent questions allowed participants to share information relevant to generating
32 systematic review questions (i.e. participants, settings and interventions).[46] We took this approach
33 because systematic reviews in communication and participation in health are frequently framed to
34 capture a range of interventions which share a common goal addressing a known issue or problem,
35 for example, interventions to improve safe and effective medicines use by consumers[47] or
36 interventions for providers to promote a patient-centred approach in clinical consultations.[48] We
37 avoided technical research terms (e.g. 'systematic reviews', 'Cochrane reviews', 'interventions')
38 given consumers are often unfamiliar with these terms.[49, 50]
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48 We piloted the survey with four consumers, one health professional and one policy maker. After
49 completing the survey, they participated in a telephone interview, describing the experience and
50 suggesting improvements. The survey structure was endorsed by these participants, and we made
51 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

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 (\pm 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 \pm SD, range)	49 \pm 13 (18 – 80)
Female	117 (79)
Stakeholder perspective²	
Person <i>without</i> a health condition	32 (21)
Person <i>with</i> 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)

¹The 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

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

³Included 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.

⁴Belgium, 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).

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

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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3 Priority theme 2: Health professional level issues
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6 Within health professional level issues, the five priority topics centred on individual health
7 professional-patient communication issues. For example, stakeholders suggested some health
8 professionals don't understand or ask about patients about preferences and priorities, nor do they
9 always know how to gauge how much their patients understand. Other suggested that health
10 professionals do not provide enough information, or decision-making support.
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15 Priority theme 3: Consumer and carer issues in their own care
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18 Stakeholders identified six priority topics related to issues for consumers and carers in their own
19 care. These focussed predominantly on issues related to a lack of understanding or awareness on
20 the part of consumers and carers about their health, treatment options, rights and available
21 services, affecting their ability to participate in their own care.
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26 Priority themes 4 to 6: Broader consumer and carer involvement in services; accessibility of high
27 quality health information access; and ageing and end-of-life care
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31 Stakeholders identified two priority topics in theme 4; that researchers and health services do not
32 properly involve consumers and carers in (1) research, or (2) service planning and design. The final
33 two themes each included only one priority topic, that publically available health information can be
34 contradictory, hard to understand, and hard to find and assess (theme 5) and that there is
35 insufficient support and understanding about older people's needs and end of life decisions (theme
36 6).
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42 **Populations affected (across priority themes and topics)**
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45 Participants stated that certain people or groups were more likely to be affected for each idea or
46 problem, but acknowledged that everyone can experience poor communication and participation in
47 health. Those identified as more vulnerable were people: from diverse cultural and linguistic
48 backgrounds, with limited English, with caring responsibilities, with limited education and/or limited
49 literacy and numeracy, from low socioeconomic areas, with mental illness, older people, with
50 dementia and cognitive issues, with chronic illness or multi-morbidity, from rural and regional areas,
51 from Indigenous backgrounds, and with disability.
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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).

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

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3 professionals and others. Notable amongst the myriad suggestions is the degree to which
4 stakeholders want evidence about interventions which address structural and cultural barriers to
5 communication and participation within health services (e.g., addressing the lack of holistic, patient-
6 centred and culturally safe care) or building health professionals' communication skills and practices.
7 Stakeholders also want to identify solutions to consumers' and carers' lack of understanding and
8 awareness about their health, or know about treatment options or their rights. Importantly,
9 respondents suggested consumers and carers work in partnership with researchers and health
10 services to devise these solutions. The priorities identified cut across acute and community health
11 settings, with relevance for policy and research, and across population groups and health conditions.
12 The most frequently suggested interventions focussed on training and cultural change activities for
13 health services and health professionals. Stakeholders emphasised that poor communication and
14 participation can affect everyone, but disproportionately affect people from diverse cultural and
15 linguistic backgrounds (relevant to the dominant culture and language of any country), carers,
16 people with low education/literacy levels, and people with mental illness, among others.
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26 We conducted what we believe is the first research priority setting partnership with stakeholders
27 (nearly 50% of whom identified as consumers, carers or consumer representatives) across
28 communication and participation in health. We have not only identified a broad range of issues to
29 inform future systematic reviews, but our list could be scoped by others, or subsequently prioritised
30 in local contexts or health conditions, to inform a strategic research agenda. In doing so, we make
31 three contributions to priority setting research methods; (1) demonstrating feasibility of priority
32 setting with stakeholders in a complex area; (2) offering a novel approach to framing priority-setting
33 survey questions and; (3) detailing a research-based approach to analysing and categorising
34 suggested priorities, a step which lacks clear guidance.[30, 60]
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42 There is considerable resonance between the research priorities we identified and policy priorities
43 for improving the quality and safety of health services and systems in Australia,[1] the United
44 Kingdom,[2] the United States[61] and globally.[4] For example, Australia has strategic goals and
45 standards around partnering with consumers in their own care and in health service governance and
46 evaluation.[1, 62] Similarly, the WHO's Framework on Integrated, People-Centred Health Services
47 outlines strategic goals that include people being empowered and engaged, and improved
48 coordination between and within health services.[4] For this reason, our steering group suggested
49 this broadly scoped priority list could be used by health decision makers, and consumer
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3 representatives or organisations, to support strategic policy or implementation activities, or
4 advocacy efforts, respectively.
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8 There are also synergies between our priorities and those in three aligned priority-setting activities
9 in medication adherence, [19] patient safety in primary care[20] and palliative and end of life
10 care[24]. All three identified research priorities addressing the information and support needs of
11 patients and families, plus health professional training in patient-centred care,[19] improved
12 communication and coordination between services,[24] and addressing the needs of vulnerable
13 groups.[24] Given the exponential growth of prioritisation activities,[21] there is an opportunity to
14 build up an international picture of communication and participation priorities, in which the
15 differences and similarities could be analysed.
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22 One potential criticism of our approach is a lack of inclusiveness;[63] over 90% of participants were
23 from Australia or other high-income, English-speaking countries and we lacked representative
24 numbers of Australians from diverse cultural and linguistic backgrounds,[64] Indigenous people,[65]
25 and people without a university degree [66]. This is important given consumers' perceptions of
26 health communication can differ based on such characteristics.[67] Our steering group encouraged
27 recruitment of these groups using face-to-face methods but despite our efforts we were limited by
28 time and resource constraints. A counter to this point, however, is the resonance between our
29 research priorities and international policy priorities, and that stakeholders singled out these
30 population groups, and others, as deserving particular focus in future systematic reviews.
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38 We acknowledge limitations related to online survey wording. First, participants may have been
39 influenced by some of the examples we provided. Of note is that 'training for health professionals'
40 used as an example response for, 'Do you have any particular solutions to this problem that you
41 would like to see tested?' and this was the most commonly received response. Second, we asked
42 participants to nominate all stakeholder perspectives that applied to them, rather than their 'main'
43 perspective, meaning our three stakeholder categories may not reflect how participants would
44 describe themselves.
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51 Decisions about undertaking new research should be informed by the needs of potential users of
52 this research, but also by what is already known[18]. Given this, research priority setting activities
53 will typically refine and prioritise the initial, 'interim' priorities and undertake an assessment of the
54 existing evidence, to determine which priorities are true 'research uncertainties'. [30] We
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3 subsequently convened a full-day workshop with stakeholders and undertook an evidence mapping
4 exercise to complete these steps,[29] which will be reported separately. Additionally, to inform
5 systematic reviews, the priorities must be ultimately be framed as searchable and answerable
6 questions,[46] which most of our priorities are not. While interpretive analytic approaches[57]
7 facilitate such a transformation of the data, we felt that given the potential for misinterpretation,
8 subsequent scoping of answerable research questions should be done in partnership with
9 stakeholders.
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14 15 **CONCLUSIONS**

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

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55 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.

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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?

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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)

For peer review only

About you

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

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

- Person without a health condition
- Person with a health condition
- Carer/family member of someone with a health condition
- Consumer/patient advocate, representative or volunteer
- Health professional
- Health service manager or staff
- Policy maker
- Researcher
- Research funder

Other (please specify)

21. How old are you? (optional)

* 22. What gender are you?

- Female
- Male
- Other
- Prefer not to say

* 23. In what country do you live?

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

What country do you live in?

About you (continued)

These questions are for Australians only.

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

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

- Yes
- No
- Prefer not to say

* 25. What is your highest level of education?

- Primary school
- Secondary school
- Occupational certificate or diploma
- University bachelor's degree
- University post-graduate degree
- Prefer not to say

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

- Yes
- No
- Prefer not to say

27. What is your postcode?

- Prefer not to say

My postcode is...

Table S1. Participant characteristics (by broad stakeholder group)

Characteristics	Broad stakeholder group		
	Consumer/ carer ¹ n (%)	Professional ² n (%)	Both ³ n (%)
Age (years; mean \pm SD, range)	53 \pm 14 (18 to 80)	44 \pm 11 (24 to 65)	53 \pm 11 (25 to 67)
Female	39 (81)	59 (79)	19 (76)
Stakeholder perspective⁴			
Person <i>without</i> a health condition	8 (17)	19 (25)	5 (20)
Person <i>with</i> 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)

¹Included 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.

²Included 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.

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

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

⁵Included 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.

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

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

Table S2. Additional demographic characteristics for Australian participants only

Characteristic	TOTAL (N = 110, %) ¹
Age (mean \pm SD, range)	48.7 \pm 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)

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

²Area 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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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/ carer¹ (n =)	Professional² (n =)	Both³ (n =)	NR⁴ (n =)
Theme 1: Health service-level issues				
Breakdowns in communication and coordination of care between and within health services are common <i>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!</i> (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 <i>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</i> (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>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</i> (Consumer/carer)	8	5	0	0
Cultural safety is not well-embedded in health services	4	4	2	0

	Consumer/ carer ¹ (n =)	Professional ² (n =)	Both ³ (n =)	NR ⁴ (n =)
<i>Health professionals are not always able to take into consideration language and cultural needs of patients (Consumer/carer)</i>				
<i>Cultural safety is not embedded well in health services and as a result our Aboriginal population struggles even further to access services required (Professional)</i>				
Informed consent for treatment and research does not always happen	0	5	1	0
<i>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)</i>				
Not enough time is given to allow good communication between health professionals and patients	0	5	1	0
<i>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)</i>				
Theme 2: Health professional-level issues				
Some health professionals don't understand or ask patients about their preferences and priorities	5	4	5	0
<i>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)</i>				
Some health professionals don't provide enough information to patients (some don't think it's a priority)	8	3	4	0
<i>Doctors do not explain why they prescribe treatments and interventions, nor ask about patient preferences regarding treatment and outcomes (Consumer/carer)</i>				

	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 <i>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)</i>	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) <i>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)</i>	3	3	0	1
Health professionals don't always know how to gauge how much their patients understand <i>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)</i>	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 <i>Improve patient understanding of their medical care (particularly for patients [who are] non-native English speakers) (Consumer/carer)</i>	4	5	0	1
Consumers and carers don't always know about all the options or services that exist	1	8	0	0

	Consumer/ carer ¹ (n =)	Professional ² (n =)	Both ³ (n =)	NR ⁴ (n =)
<i>[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)</i>				
Consumers and carers aren't always able to participate actively in their care <i>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)</i>	1	2	2	0
The general public doesn't always have enough health literacy to navigate the health system and make health decisions <i>Health literacy. Many people do not have the skills/education or language skills to negotiate healthcare (and other) systems (Professional)</i>	2	2	1	0
Patients often experience information overload and are unable to retain the important information <i>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)</i>	3	1	0	0
Consumers and carers have difficulty understanding key medication information <i>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)</i>	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 <i>Researchers don't know how (or why they should) involve patients and carers in designing and reporting their research (Consumer/carer)</i>	5	9	3	2
Health services don't properly involve consumers and carers in health service planning and design <i>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)</i>	4	7	0	0
Theme 5: Accessibility of high quality health information				

<p>'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</p> <p><i>Standardised national leaflets about conditions provided by different sources (charities, NHS trusts, condition specific support groups), the information can vary wildly (Consumer/carer)</i></p>	3	11	4	0
<p>Theme 6: Ageing and end of life care</p>				
<p>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</p> <p><i>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)</i></p>	5	2	0	1

¹Included 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.

²Included 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.

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

⁴Three 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

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SDC Materials and Methods: Appraisal framework

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

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

BMJ Open

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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KEY WORDS

Research Priorities; Cochrane; Consumers; Stakeholders; Shared Decision-Making; Patient Preference, Communication; Patient-Centered Care, Quality Healthcare

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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.

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.

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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3 final selection of priority systematic review topics may also be informed by their appropriateness
4 and feasibility for systematic review teams.[25]
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8 Within the area of health communication and participation, overarching research priorities of
9 consumers and other stakeholders are unknown, with the exception of medication adherence[26]
10 and patient safety in primary care.[27] Research priority setting partnerships are typically conducted
11 for specific health conditions or clinical settings [20, 28]. However, it is notable that concepts like
12 doctor-patient communication, information and education, consumers as partners, and self-
13 management, are frequently identified as research priorities. For example, one or more of these
14 topics was a top priority in asthma,[29] dementia,[30] palliative care,[31] pre-term birth,[32] and
15 type 1 diabetes.[33] Given potential solutions to these problems are complex[34] and common
16 across conditions,[35] an in-depth exploration of research priorities in this area across health
17 conditions and contexts has the potential to add valuable information to healthcare policy making.
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24 25 **Study aim**

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28 In March 2015, we commenced a research priority setting project with the aim of identifying future
29 Cochrane Intervention Review topics in health communication and participation.[36] In this paper,
30 we report the first stage of the project, in which we used an international survey to identify priority
31 topics.
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35 36 **METHODS**

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39 The methods were informed by guidance from the James Lind Alliance,[37] and Cochrane Priority
40 Setting Methods Group.[22, 24] In this first stage, we conducted an online survey.
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44 We worked in partnership with consumers and other stakeholders to plan and undertake all project
45 stages.[38] Our approach was informed by the principles of co-production, i.e. recognising expertise,
46 building on strengths, enabling shared control and mutually beneficial and supported relationships
47 .[39, 40] We reported activities and data against the relevant sections of a 32-item research priority
48 setting appraisal checklist.[41] The study was approved by the La Trobe University Science Health
49 and Engineering College Human Ethics Sub-Committee.
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54 55 **Context of the priority setting partnership**

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

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

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42 The steering group recommended the project scope reflect the scope of CCC reviews (i.e.
43 'interventions that affect the way people interact with healthcare professionals, services and
44 researchers').[47] Making sense of research in this area is challenging; interventions are complex[34]
45 with innumerable related and inconsistently-defined concepts,[48, 49] and international variations
46 in terminology and meaning.[50, 51] To aid clarity in survey promotion, we used the term 'health
47 communication and participation research', defined as 'activities that help patients, consumers and
48 carers to be knowledgeable about their health and to participate in their health in different ways.
49 This includes being able to express their views and beliefs, make informed choices, and to access
50 high quality health information and health services'.[52] We provided examples to participants
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3 clarifying that this included broader participation in health services, policy and research. We sought
4 international priorities that could be scoped to inform intervention reviews, given Cochrane's global
5 reach and predominant focus on intervention effectiveness.
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8 9 **Participants and recruitment**

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11 We sought international participation in the online survey; inviting people aged 18 years and over
12 who identified as 'patients, consumers, carers, and their advocates, health professionals, policy
13 makers, researchers, funders, and persons interested in health communication and participation'.
14 English-language proficiency was implied given the survey was only available in English. Participants
15 were provided with the option to complete the survey by post or phone.
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19 In May 2015 we undertook purposive and snowball sampling,[53] promoting the survey by email and
20 in newsletters. Approximately 1,000 individuals and organisations were identified from the networks
21 of the project team and steering group, and internet searches (for international patient groups, in
22 particular), and were invited to forward the survey link to their networks or members. Those who
23 received the email included consumer groups, Australian government health departments and
24 health networks, medical and nursing colleges, national health organisations and advocacy groups,
25 researchers and CCC authors and other contributors. Additional efforts, in the form of phone calls
26 and facilitated introductions, were made to Australian organisations working with or representing
27 Indigenous people and people from diverse cultural and linguistic backgrounds. We sent weekly
28 email reminders while the survey was open.
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39 **Collecting research priorities**

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41 We invited people to share their 'ideas for future research topics in the area of health
42 communication and participation' via an online survey (see Supplementary File S1) that was open for
43 four weeks, using SurveyMonkey.[54] We advised that their ideas would inform topic selection of
44 'reviews of the latest evidence'. We used the following set of questions: (1) What is the health
45 communication and participation problem you would like to see addressed?, (2) In your experience,
46 is this a problem for particular groups of people?, (3) Is there a particular setting or group of health
47 professionals this is relevant to?, and (4) Do you have any particular solutions you would like to see
48 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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3 iteratively, and we compared interpretations and agreed on a set of codes, then topics and
4 themes.[62, 63]
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8 First, we downloaded data into Microsoft Excel and edited extraneous language to focus on key
9 concepts.[61] For each participant, we coded their data against three conceptual codes: the problem
10 they wanted addressed; who the problem affects (the 'participants' in the commonly used
11 systematic review question-formation structure of Participants, Interventions, Comparisons and
12 Outcomes (PICO)); and potential solutions to be tested in research (the 'interventions' in PICO).
13 Given participants were asked to submit their research ideas using four related questions per idea,
14 their answers to these four questions were treated as a single unit (or research idea) in the analysis.
15 At this stage, research ideas that were agreed to be out of scope for future reviews were excluded,
16 while those that contained one of more distinct conceptual problem code were split into two.
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23 We grouped similar conceptual problem codes together to form priority research topics,[59] which
24 were then aggregated into groups labelled with simple descriptive themes using straightforward
25 health systems language,[64], the aim being to adhere closely to the elements specified by
26 respondents.[65] We developed and applied this method of categorising topics because the analysis
27 commenced with the contextual problem (Q1, which was mandatory) and because this aids
28 identification of potential interventions to address this problem or meet this goal but in a non-
29 prescriptive way. This is in contrast to the more commonly used frame of "what is the effect of
30 intervention X for people with Y on outcomes Z" which is used in clinical, condition-specific
31 areas.[37] We retained the terminology used by participants to devise the topics, meaning
32 synonymous terms were included (e.g. some themes refer to 'consumers' and others to 'patients').
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41 For the participant characteristics code, we collapsed the 10 stakeholder groups into three mutually
42 exclusive groups; 'consumer or carer', 'healthcare professionals, policy makers and researchers' and
43 'both' (see Supplementary file, table S1 for definitions) to allow narrative comparison of
44 demographic characteristics and research priorities between stakeholders. We used Microsoft Excel
45 to analyse the descriptive data.
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50 We listed the priority topics, grouped by descriptive themes, and included the number of responses
51 coded to each topic. We elected not to present specific interventions and populations suggested for
52 each theme given the considerable overlap in interventions and populations suggested across topics
53 and the sometimes small number of responses per theme.
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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 (\pm 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 \pm SD, range)	49 \pm 13 (18 – 80)
Female	117 (79)
Stakeholder perspective²	
Person <i>without</i> a health condition	32 (21)
Person <i>with</i> 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)

¹The 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.

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

³Included 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.

⁴Belgium, 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

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.

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3 The most commonly cited priority topics, i.e. the health communication and participation problems
4 that stakeholders most wanted research to address include: insufficient consumer involvement in
5 research (19 responses); 'official' health information that is contradictory and hard to understand
6 (18 responses); communication and coordination breakdowns in health services (15 responses);,
7 health information provision being a low priority for health professionals (15 responses); insufficient
8 eliciting of patient preferences (14 responses); health services that poorly understand or implement
9 patient-centred care (14 responses); lack of holistic care impacting quality and safety (13 responses);
10 and inadequate involvement of consumers in service design (11 responses).
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17 Below is a description of the priority themes and topics for all stakeholders, followed by priority
18 populations and potential interventions. See Supplementary file, table S3 for the number of
19 responses to each of the priority topics broken down by main stakeholder group, with example
20 quotes.
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23 24 25 Priority theme 1: Health service level issues 26

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28 The theme on health service level issues contained six topics. The most frequently cited topics were
29 breakdowns in communication and coordination between and within health services, poor
30 understanding and/or embedding of 'patient-centred care' and cultural safety (e.g. language
31 considerations or cultural needs) within health services and that the safety and quality of healthcare
32 can be comprised by not treating patients holistically.
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36 37 38 Priority theme 2: Health professional level issues 39

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41 Within health professional level issues, the five priority topics centred on individual health
42 professional-patient communication issues. For example, stakeholders suggested some health
43 professionals don't understand or ask about patients about preferences and priorities, nor do they
44 always know how to gauge how much their patients understand. Other suggested that health
45 professionals do not provide enough information, or decision-making support.
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50 51 52 Priority theme 3: Consumer and carer issues in their own care 53

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55 Stakeholders identified six priority topics related to issues for consumers and carers in their own
56 care. These focussed predominantly on issues related to a lack of understanding or awareness on
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3 the part of consumers and carers about: their health; treatment options; rights; and available
4 services, affecting their ability to participate in their own care.
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8 Priority themes 4 to 6: Broader consumer and carer involvement in services; accessibility of high
9 quality health information access; and ageing and end-of-life care
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12 Stakeholders identified two priority topics in theme 4; that researchers and health services do not
13 properly involve consumers and carers in (1) research, or (2) service planning and design. The final
14 two themes each included only one priority topic, that publically available health information can be
15 contradictory, hard to understand, and hard to find and assess (theme 5) and that there is
16 insufficient support and understanding about older people's needs and end of life decisions (theme
17 6).
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23 **Populations affected (across priority themes and topics)**

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

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42 Participants suggested a range of interventions that could be researched to address the problems
43 identified. Potential interventions included communication skills training for health professionals,
44 training and cultural change activities for hospital and health professionals about involving
45 consumers and carers in health services, and personally controlled electronic health records (see Box
46 1; interventions are described in order of the frequency with which they were mentioned).
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51 **Box 1. Suggested interventions to address health communication and participation priority themes** 52 **and topics** 53 54 55 56 57 58 59 60

- 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

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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3 There is considerable consistency between the research priorities we identified and policy priorities
4 for improving the quality and safety of health services and systems in Australia,[1] the United
5 Kingdom,[2] the United States[68] and globally.[4] For example, Australia has strategic goals and
6 standards for partnering with consumers in their own care and in health service governance and
7 evaluation.[1, 69] Similarly, the WHO's Framework on Integrated, People-Centred Health Services
8 outlines strategic goals that include people being empowered and engaged, and improved
9 coordination between and within health services.[4] For this reason, our steering group suggested
10 this broadly scoped priority list could be used by health decision makers, and consumer
11 representatives or organisations, to support strategic policy or implementation activities, or
12 advocacy efforts, respectively.
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20 There are also synergies between our priorities and those in three aligned priority-setting activities
21 in medication adherence,[26] patient safety in primary care[27] and palliative and end of life
22 care.[31] All three identified research priorities addressing the information and support needs of
23 patients and families, plus health professional training in patient-centred care,[26] improved
24 communication and coordination between services,[31] and addressing the needs of vulnerable
25 groups.[31] Given the exponential growth of prioritisation activities,[28] there is an opportunity to
26 build up an international picture of communication and participation priorities, in which the
27 differences and similarities could be analysed (see Box 2).
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34 We acknowledge as a limitation that over 90% of participants were from Australia or other high-
35 income, English-speaking countries. This is unsurprising given the project team and steering group
36 were predominantly based in Australia, and the survey was only available in English. While there is
37 variation in health communication and participation practices internationally,[70] studies show there
38 can be considerable inter-country similarities[71] and differences[72] in patient preferences for
39 involvement in their healthcare. As such, our results may be more applicable to higher income
40 countries.
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47 A second limitation relates to potential inequity in our priority-setting approach.[73]
48 Reflecting the PROGRESS-PLUS equity checklist (place of residence, race/ethnicity, occupation,
49 gender, religion, education, socioeconomic status, social capital, age, sexual orientation, and
50 disability)[74, 75] there was a low proportion of Australians from diverse cultural and linguistic
51 backgrounds,[76], regional and rural areas,[77] Indigenous people,[78] and people without a
52 university degree,[79] in our study. This is important given consumers' perceptions of health
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3 communication can differ based on such characteristics.[80] We also included more women than
4 men. Given gender (relative to other demographic factors, like religion, ethnicity and age) is not a
5 major predictor of healthcare preferences[81] we believe our results are broadly applicable across
6 genders. While we made targeted efforts to recruit people from cultural and linguistically diverse
7 backgrounds, and Indigenous people, we could only achieve what was feasible within the resources
8 available. We note, however, that stakeholders themselves were equity-focussed, as they
9 recommended these vulnerable population groups, and others, as deserving particular focus in
10 future systematic reviews.
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17 Finally, we acknowledge limitations related to online survey wording. First, participants may have
18 been influenced by some of the examples we provided. Of note is that 'training for health
19 professionals' used as an example response for, 'Do you have any particular solutions to this
20 problem that you would like to see tested?' and this was the most commonly received response.
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22 Second, we asked participants to nominate all stakeholder perspectives that applied to them, rather
23 than their 'main' perspective, meaning our three stakeholder categories may not reflect how
24 participants would describe themselves.
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30 Decisions regarding new research should be informed by the needs of potential users of this
31 research, but also by the existing evidence.[21] Given this, research priority setting activities will
32 typically refine and prioritise the initial, 'interim' priorities and undertake an assessment of the
33 existing evidence, to determine which priorities are true 'research uncertainties'.[37] We
34 subsequently convened a full-day workshop with stakeholders and undertook an evidence mapping
35 exercise to complete these steps,[36] which will be reported separately. Additionally, to inform
36 systematic reviews, the priorities must be ultimately be framed as searchable and answerable
37 questions,[55] which most of our priorities are not. While interpretive analytic approaches[65]
38 facilitate such a transformation of the data, we felt that given the potential for misinterpretation,
39 subsequent scoping of answerable research questions should be done in partnership with
40 stakeholders.
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48 **CONCLUSIONS**

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51 Consumers and other stakeholders identified a broad mix of research priorities in health
52 communication and participation. Notable amongst the myriad of priorities is the degree to which
53 people want research addressing structural and cultural challenges in health services (e.g. lack of
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3 holistic, patient-centred, culturally safe care) and building health professionals' communication
4 skills. Solutions should be devised in partnership with consumers, with particular focus on the needs
5 of vulnerable groups.
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10
11
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31 32 **COMPETING INTERESTS STATEMENT**

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35 The authors have no competing interests to declare.
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38 39 **DATA SHARING STATEMENT**

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42 No additional unpublished data are available.
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45 46 **AUTHOR'S CONTRIBUTIONS**

47
48 AS led the study design, data collection, analysis and interpretation and manuscript preparation. As
49 steering group members, PB, LH, DK, DG, SM, NP, NB, NL, DV, SO, and KC contributed to study design
50 and interpretation, and commented on manuscript drafts. DL contributed to data analysis and
51 interpretation, and commented on manuscript drafts. JN contributed to study design, data analysis
52 and interpretation, and commented on manuscript drafts. MO contributed to study design, data
53 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.

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For peer review only

SUPPLEMENTARY FILE

S1. Online survey

What are your ideas for health communication and participation research?

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?

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

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7 *e.g. Training for health professionals?*

8 *Peer support for patients?*

9 *Information or education for parents?*

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

15 No

16 Yes (a new blank page will open)

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For peer review only

About you

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

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

- Person without a health condition
- Person with a health condition
- Carer/family member of someone with a health condition
- Consumer/patient advocate, representative or volunteer
- Health professional
- Health service manager or staff
- Policy maker
- Researcher
- Research funder

Other (please specify)

21. How old are you? (optional)

* 22. What gender are you?

- Female
- Male
- Other
- Prefer not to say

* 23. In what country do you live?

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

What country do you live in?

About you (continued)

These questions are for Australians only.

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

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

- Yes
- No
- Prefer not to say

* 25. What is your highest level of education?

- Primary school
- Secondary school
- Occupational certificate or diploma
- University bachelor's degree
- University post-graduate degree
- Prefer not to say

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

- Yes
- No
- Prefer not to say

27. What is your postcode?

- Prefer not to say

My postcode is...

Table S1. Participant characteristics (by broad stakeholder group)

Characteristics	Broad stakeholder group		
	Consumer/ carer ¹ n (%)	Professional ² n (%)	Both ³ n (%)
Age (years; mean \pm SD, range)	53 \pm 14 (18 to 80)	44 \pm 11 (24 to 65)	53 \pm 11 (25 to 67)
Female	39 (81)	59 (79)	19 (76)
Stakeholder perspective⁴			
Person <i>without</i> a health condition	8 (17)	19 (25)	5 (20)
Person <i>with</i> 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)

¹Included 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.

²Included 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.

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

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

⁵Included 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.

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

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

Table S2. Additional demographic characteristics for Australian participants only

Characteristic	TOTAL (N = 110, %) ¹
Age (mean ± SD, range)	48.7 ± 13.3 (18 to 80)
Gender (n = , % female)	88 (80)
Highest education level	
Primary school	0 (0)
Secondary school	2 (2)
Occupational certificate or diploma	12 (13)
University bachelor's degree	25 (27)
University post-graduate degree	64 (68)
Identify as Indigenous (yes,)	2 (2)
Non-English speaking background (yes,)	15 (15)
Area of residence²	
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)

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

²Area 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

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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 <i>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!</i> (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 <i>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</i> (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>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</i> (Consumer/carer)	8	5	0	0
Cultural safety is not well-embedded in health services	4	4	2	0

	Consumer/ carer ¹ (n =)	Professional ² (n =)	Both ³ (n =)	NR ⁴ (n =)
<i>Health professionals are not always able to take into consideration language and cultural needs of patients (Consumer/carer)</i>				
<i>Cultural safety is not embedded well in health services and as a result our Aboriginal population struggles even further to access services required (Professional)</i>				
Informed consent for treatment and research does not always happen	0	5	1	0
<i>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)</i>				
Not enough time is given to allow good communication between health professionals and patients	0	5	1	0
<i>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)</i>				
Theme 2: Health professional-level issues				
Some health professionals don't understand or ask patients about their preferences and priorities	5	4	5	0
<i>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)</i>				
Some health professionals don't provide enough information to patients (some don't think it's a priority)	8	3	4	0
<i>Doctors do not explain why they prescribe treatments and interventions, nor ask about patient preferences regarding treatment and outcomes (Consumer/carer)</i>				

	Consumer/ carer¹ (n =)	Professional² (n =)	Both³ (n =)	NR⁴ (n =)
Health professionals don't always provide enough support for patient decision-making <i>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)</i>	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) <i>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)</i>	3	3	0	1
Health professionals don't always know how to gauge how much their patients understand <i>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)</i>	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 <i>Improve patient understanding of their medical care (particularly for patients [who are] non-native English speakers) (Consumer/carer)</i>	4	5	0	1
Consumers and carers don't always know about all the options or services that exist	1	8	0	0

	Consumer/ carer ¹ (n =)	Professional ² (n =)	Both ³ (n =)	NR ⁴ (n =)
<i>[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/carers)</i>				
Consumers and carers aren't always able to participate actively in their care <i>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)</i>	1	2	2	0
The general public doesn't always have enough health literacy to navigate the health system and make health decisions <i>Health literacy. Many people do not have the skills/education or language skills to negotiate healthcare (and other) systems (Professional)</i>	2	2	1	0
Patients often experience information overload and are unable to retain the important information <i>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)</i>	3	1	0	0
Consumers and carers have difficulty understanding key medication information <i>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)</i>	0	2	2	0
Theme 4: Issues for broader consumer and carer involvement				

	Consumer/ carer¹ (n =)	Professional² (n =)	Both³ (n =)	NR⁴ (n =)
Health researchers don't adequately involve patients in research, nor share their findings <i>Researchers don't know how (or why they should) involve patients and carers in designing and reporting their research</i> (Consumer/carer)	5	9	3	2
Health services don't properly involve consumers and carers in health service planning and design <i>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</i> (Professional)	4	7	0	0
Theme 5: Accessibility of high quality health information				

<p>'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</p> <p><i>Standardised national leaflets about conditions provided by different sources (charities, NHS trusts, condition specific support groups), the information can vary wildly (Consumer/carer)</i></p>	3	11	4	0
<p>Theme 6: Ageing and end of life care</p>				
<p>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</p> <p><i>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)</i></p>	5	2	0	1

¹Included 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.

²Included 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.

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

⁴Three 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	<i>Global, regional, national, institutional, health service</i>	6
2	Define health area or focus	<i>Disease or condition specific, healthcare delivery</i>	7
3	Define end-users of research	<i>General population, patients</i>	7
4	Define the target audience	<i>Policy makers, funders, researchers, industry</i>	7
5	Identify the research focus	<i>Public health, health services, clinical, basic science; primary research, systematic reviews, guidelines</i>	6
6	Identify the type of research question	<i>Etiology, diagnosis, prevention, treatment, prognosis, health services, psychosocial, education, QOL, economic evaluation</i>	7
7	Define the time frame	<i>Short term or long term priorities</i>	NR
B. Governance and team			
8	Describe selection of the project leader/s and team	<i>Steering Committee, working group, coordinators</i>	6-7
9	Describe the characteristics of the project leader/team members	<i>Stakeholder group, organisations represented, characteristics</i>	6-7
10	Training or experience in research priority setting	<i>Involvement of JLA advisor</i>	7
C. Inclusion of stakeholders/participants			
11	Define the inclusion criteria for stakeholder groups involved in the PSP	<i>Stakeholder group</i>	7
12	State the strategy or method for identifying and engaging stakeholders	<i>Partnerships, social media, recruitment through hospitals</i>	7
13	Indicate the number of participants and/or organisations involved	<i>Individuals, organisations</i>	10
14	Describe the characteristics of stakeholders	<i>Name of stakeholder group e.g. clinicians, patients, policy makers</i>	10-11
15	Reimbursement for participation	<i>Cash, vouchers, certificates, acknowledgement</i>	NR
D. Identification and collection of research topics/questions			
16	Describe methods for collecting all research topics or questions	<i>Technical data (burden of disease, incidence), systematic reviews, reviews of guidelines/other documents, surveys, interviews, focus groups, meetings, workshops</i>	8
17	Describe methods for collating and/or categorising topics or questions	<i>Taxonomy, framework, used to organised and aggregate topics or questions</i>	9
18	Describe methods or reason for initial removal or topics or questions	<i>Beyond scope, lack of clarity and ill-defined, duplicative, number of submissions</i>	9 & 11
19	Describe methods for refining research questions/topics	<i>Reviewed by Steering Committee</i>	9
20	Cross check to identify if research questions have been answered	<i>Systematic reviews, consultation with experts</i>	N/A (see footnote)

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

BMJ Open

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TITLE

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

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KEY WORDS

Research Priorities; Cochrane; Consumers; Stakeholders; Shared Decision Making; Patient Preference, Communication; Patient-Centered Care, Quality Healthcare

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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.

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.

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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3 final selection of priority systematic review topics may also be informed by their appropriateness
4 and feasibility for systematic review teams.[25]
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8 Within the area of health communication and participation, overarching research priorities of
9 consumers and other stakeholders are unknown, with the exception of medication adherence[26]
10 and patient safety in primary care.[27] Research priority setting partnerships are typically conducted
11 for specific health conditions or clinical settings [20, 28]. However, it is notable that concepts like
12 doctor-patient communication, information and education, consumers as partners, and self-
13 management, are frequently identified as research priorities. For example, one or more of these
14 topics was a top priority in asthma,[29] dementia,[30] palliative care,[31] pre-term birth,[32] and
15 type 1 diabetes.[33] Given potential solutions to these problems are complex[34] and common
16 across conditions,[35] an in-depth exploration of research priorities in this area across health
17 conditions and contexts has the potential to add valuable information to healthcare policy making.
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24 25 **Study aim**

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28 In March 2015, we commenced a research priority setting project with the aim of identifying future
29 Cochrane Intervention Review topics in health communication and participation.[36] In this paper,
30 we report the first stage of the project, in which we used an international survey to identify priority
31 topics.
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35 36 **METHODS**

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39 The methods were informed by guidance from the James Lind Alliance,[37] and Cochrane Priority
40 Setting Methods Group.[22, 24] In this first stage, we conducted an online survey.
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44 We worked in partnership with consumers and other stakeholders to plan and undertake all project
45 stages.[38] Our approach was informed by the principles of co-production, i.e. recognising expertise,
46 building on strengths, enabling shared control and mutually beneficial and supported relationships
47 .[39, 40] We reported activities and data against the relevant sections of a 32-item research priority
48 setting appraisal checklist.[41] The study was approved by the La Trobe University Science Health
49 and Engineering College Human Ethics Sub-Committee.
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54 55 **Context of the priority setting partnership**

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

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

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42 The steering group recommended the project scope reflect the scope of CCC reviews (i.e.
43 'interventions that affect the way people interact with healthcare professionals, services and
44 researchers').[47] Making sense of research in this area is challenging; interventions are complex[34]
45 with innumerable related and inconsistently-defined concepts,[48, 49] and international variations
46 in terminology and meaning.[50, 51] To aid clarity in survey promotion, we used the term 'health
47 communication and participation research', defined as 'activities that help patients, consumers and
48 carers to be knowledgeable about their health and to participate in their health in different ways.
49 This includes being able to express their views and beliefs, make informed choices, and to access
50 high quality health information and health services'.[52] We provided examples to participants
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3 clarifying that this included broader participation in health services, policy and research. We sought
4 international priorities that could be scoped to inform intervention reviews, given Cochrane's global
5 reach and predominant focus on intervention effectiveness.
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8 9 **Participants and recruitment**

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11 We sought international participation in the online survey; inviting people aged 18 years and over
12 who identified as 'patients, consumers, carers, and their advocates, health professionals, policy
13 makers, researchers, funders, and persons interested in health communication and participation'.
14 English-language proficiency was implied given the survey was only available in English. Participants
15 were provided with the option to complete the survey by post or phone.
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19 In May 2015 we undertook purposive and snowball sampling,[53] promoting the survey by email and
20 in newsletters. Approximately 1,000 individuals and organisations were identified from the networks
21 of the project team and steering group, and internet searches (for international patient groups, in
22 particular), and were invited to forward the survey link to their networks or members. Those who
23 received the email included consumer groups, Australian government health departments and
24 health networks, medical and nursing colleges, national health organisations and advocacy groups,
25 researchers and CCC authors and other contributors. Additional efforts, in the form of phone calls
26 and facilitated introductions, were made to Australian organisations working with or representing
27 Indigenous people and people from diverse cultural and linguistic backgrounds. We sent weekly
28 email reminders while the survey was open.
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39 **Collecting research priorities**

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41 We invited people to share their 'ideas for future research topics in the area of health
42 communication and participation' via an online survey (see Supplementary File S1) that was open for
43 four weeks, using SurveyMonkey.[54] We advised that their ideas would inform topic selection of
44 'reviews of the latest evidence'. We used the following set of questions: (1) What is the health
45 communication and participation problem you would like to see addressed?, (2) In your experience,
46 is this a problem for particular groups of people?, (3) Is there a particular setting or group of health
47 professionals this is relevant to?, and (4) Do you have any particular solutions you would like to see
48 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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3 iteratively, and we compared interpretations and agreed on a set of codes, then topics and
4 themes.[62, 63]
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8 First, we downloaded data into Microsoft Excel and edited extraneous language to focus on key
9 concepts.[61] For each participant, we coded their data against three conceptual codes: the problem
10 they wanted addressed; who the problem affects (the 'participants' in the commonly used
11 systematic review question-formation structure of Participants, Interventions, Comparisons and
12 Outcomes (PICO)); and potential solutions to be tested in research (the 'interventions' in PICO).
13 Given participants were asked to submit their research ideas using four related questions per idea,
14 their answers to these four questions were treated as a single unit (or research idea) in the analysis.
15 At this stage, research ideas that were agreed to be out of scope for future reviews were excluded,
16 while those that contained one of more distinct conceptual problem code were split into two.
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23 We grouped similar conceptual problem codes together to form priority research topics,[59] which
24 were then aggregated into groups labelled with simple descriptive themes using straightforward
25 health systems language,[64], the aim being to adhere closely to the elements specified by
26 respondents.[65] We developed and applied this method of categorising topics because the analysis
27 commenced with the contextual problem (Q1, which was mandatory) and because this aids
28 identification of potential interventions to address this problem or meet this goal but in a non-
29 prescriptive way. This is in contrast to the more commonly used frame of "what is the effect of
30 intervention X for people with Y on outcomes Z" which is used in clinical, condition-specific
31 areas.[37] We retained the terminology used by participants to devise the topics, meaning
32 synonymous terms were included (e.g. some themes refer to 'consumers' and others to 'patients').
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40 For the participant characteristics code, we collapsed the 10 stakeholder groups into three mutually
41 exclusive groups: 'consumer or carer', 'healthcare professionals, policy makers and researchers' and
42 'both' (see Supplementary file, table S1 for definitions) to allow narrative comparison of
43 demographic characteristics and research priorities between stakeholders. We used Microsoft Excel
44 to analyse the descriptive data.
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50 We listed the priority topics, grouped by descriptive themes, and included the number of responses
51 coded to each topic. We elected not to present specific interventions and populations suggested for
52 each theme given the considerable overlap in interventions and populations suggested across topics
53 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.

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 (\pm 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 \pm SD, range)	49 \pm 13 (18 – 80)
Female	117 (79)
Stakeholder perspective ²	
Person <i>without</i> a health condition	32 (21)
Person <i>with</i> 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)

¹The 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.

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

³Included 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.

⁴Belgium, 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
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

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3 latter topic is more specific than others but our coding was both pragmatic and reflective of
4 respondents' answers, and it is a feature of many health systems that communication with older
5 people or people who are dying are treated as separate issues and interventions designed
6 accordingly.[66, 67] The 21 research priority topics are broadly scoped priority issues to be
7 addressed in research, some of which are not mutually exclusive given the overlap in concepts in
8 health communication and participation.
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14 The most commonly cited priority topics, i.e. the health communication and participation problems
15 that stakeholders most wanted research to address include: insufficient consumer involvement in
16 research (19 responses); 'official' health information that is contradictory and hard to understand
17 (18 responses); communication and coordination breakdowns in health services (15 responses);
18 health information provision being a low priority for health professionals (15 responses); insufficient
19 eliciting of patient preferences (14 responses); health services that poorly understand or implement
20 patient-centred care (14 responses); lack of holistic care impacting quality and safety (13 responses);
21 and inadequate involvement of consumers in service design (11 responses).
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28 Below is a description of the priority themes and topics for all stakeholders, followed by priority
29 populations and potential interventions. See Supplementary file, table S3 for the number of
30 responses to each of the priority topics broken down by main stakeholder group, with example
31 quotes.
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36 Priority theme 1: Health service level issues 37

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39 The theme on health service level issues contained six topics. The most frequently cited topics were
40 breakdowns in communication and coordination between and within health services, poor
41 understanding and/or embedding of 'patient-centred care' and cultural safety (e.g. language
42 considerations or cultural needs) within health services and that the safety and quality of healthcare
43 can be comprised by not treating patients holistically.
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48 Priority theme 2: Health professional level issues 49

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51 Within health professional level issues, the five priority topics centred on individual health
52 professional-patient communication issues. For example, stakeholders suggested some health
53 professionals don't understand or ask about patients about preferences and priorities, nor do they
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3 always know how to gauge how much their patients understand. Other suggested that health
4 professionals do not provide enough information, or decision-making support.
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8 Priority theme 3: Consumer and carer issues in their own care
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11 Stakeholders identified six priority topics related to issues for consumers and carers in their own
12 care. These focussed predominantly on issues related to a lack of understanding or awareness on
13 the part of consumers and carers about: their health; treatment options; rights; and available
14 services, affecting their ability to participate in their own care.
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18 Priority themes 4 to 6: Broader consumer and carer involvement in services; accessibility of high
19 quality health information access; and ageing and end-of-life care
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23 Stakeholders identified two priority topics in theme 4; that researchers and health services do not
24 properly involve consumers and carers in (1) research, or (2) service planning and design. The final
25 two themes each included only one priority topic, that publically available health information can be
26 contradictory, hard to understand, and hard to find and assess (theme 5) and that there is
27 insufficient support and understanding about older people's needs and end of life decisions (theme
28 6).
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34 **Populations affected (across priority themes and topics)** 35

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37 Participants stated that certain people or groups were more likely to be affected for each health
38 communication and participation research priority, but acknowledged that everyone can experience
39 poor health communication and participation. Those identified as more vulnerable included:
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- 42 • people from diverse cultural and linguistic backgrounds;
- 43 • those with limited English;
- 44 • people with caring responsibilities;
- 45 • those with limited education and/or limited literacy and numeracy;
- 46 • people from low socioeconomic areas;
- 47 • people with mental illness;
- 48 • older people;
- 49 • people with dementia and cognitive issues;
- 50 • 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

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

- 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).

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

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3 build up an international picture of communication and participation priorities, in which the
4 differences and similarities could be analysed (see Box 2).
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7 We acknowledge as a limitation that over 90% of participants were from Australia or other high-
8 income, English-speaking countries. This is unsurprising given the project team and steering group
9 were predominantly based in Australia, and the survey was only available in English. While there is
10 variation in health communication and participation practices internationally,[70] studies show there
11 can be considerable inter-country similarities[71] and differences[72] in patient preferences for
12 involvement in their healthcare. As such, our results may be more applicable to higher income
13 countries.
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20 A second limitation relates to potential inequity in our priority-setting approach.[73]
21 Reflecting the PROGRESS-PLUS equity checklist (place of residence, race/ethnicity, occupation,
22 gender, religion, education, socioeconomic status, social capital, age, sexual orientation, and
23 disability)[74, 75] there was a low proportion of Australians from diverse cultural and linguistic
24 backgrounds,[76], regional and rural areas,[77] Indigenous people,[78] and people without a
25 university degree,[77] in our study. This is important given consumers' perceptions of health
26 communication can differ based on such characteristics.[79] Our self-selection study included
27 considerably more women than men. Given gender (relative to other demographic factors, like
28 religion, ethnicity and age) is not a major predictor of healthcare preferences[80] we suggest that
29 our results are broadly applicable across genders. While we made targeted efforts to recruit people
30 from cultural and linguistically diverse backgrounds, and Indigenous people, we could only achieve
31 what was feasible within the resources available. We note, however, that stakeholders themselves
32 were equity-focussed, as they recommended these vulnerable population groups, and others, as
33 deserving particular focus in future systematic reviews.
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44 Finally, we acknowledge limitations related to online survey wording. First, participants may have
45 been influenced by some of the examples we provided. Of note is that 'training for health
46 professionals' used as an example response for, 'Do you have any particular solutions to this
47 problem that you would like to see tested?' and this was the most commonly received response.
48 Second, we asked participants to nominate all stakeholder perspectives that applied to them (e.g.
49 person with a health condition, health professional etc.), rather than nominating their 'primary'
50 perspective for the purposes of the online survey. For the participants who ticked multiple
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3 perspectives, we may have classified them into the category of both a consumer and a professional,
4 when if asked, they may have described themselves as predominantly a consumer or a professional.
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8 Decisions regarding new research should be informed by the needs of potential users of this
9 research, but also by the existing evidence.[21] Given this, research priority setting activities will
10 typically refine and prioritise the initial, 'interim' priorities and undertake an assessment of the
11 existing evidence, to determine which priorities are true 'research uncertainties'. [37] We
12 subsequently convened a full-day workshop with stakeholders and undertook an evidence mapping
13 exercise to complete these steps,[36] which will be reported separately. Additionally, to inform
14 systematic reviews, the priorities must be ultimately be framed as searchable and answerable
15 questions,[55] which most of our priorities are not. While interpretive analytic approaches[65]
16 facilitate such a transformation of the data, we decided that given the potential for
17 misinterpretation, subsequent scoping of answerable research questions should be undertaken in
18 partnership with stakeholders.
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25 26 **CONCLUSIONS**

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

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14 The authors have no competing interests to declare.
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16 **DATA SHARING STATEMENT**

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20 No additional unpublished data are available.
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23 **AUTHOR'S CONTRIBUTIONS**

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26 AS led the study design, data collection, analysis and interpretation and manuscript preparation. As
27 steering group members, PB, LH, DK, DG, SM, NP, NB, NL, DV, SO, and KC contributed to study design
28 and interpretation, and commented on manuscript drafts. DL contributed to data analysis and
29 interpretation, and commented on manuscript drafts. JN contributed to study design, data analysis
30 and interpretation, and commented on manuscript drafts. MO contributed to study design, data
31 collection and commented on manuscript drafts. AT contributed to data interpretation and critically
32 revised the manuscript for important content. SH contributed to study design, analysis and
33 interpretation, and critically revised the manuscript for important content. All authors approved the
34 final version of the manuscript.
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For peer review only

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SUPPLEMENTARY FILE

S1. Online survey

What are your ideas for health communication and participation research?

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?

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

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7 *e.g. Training for health professionals?*

8 *Peer support for patients?*

9 *Information or education for parents?*

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

15 No

16 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...

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 \pm SD, range)	53 \pm 14 (18 to 80)	44 \pm 11 (24 to 65)	53 \pm 11 (25 to 67)
Female	39 (81)	59 (79)	19 (76)
Stakeholder perspective⁴			
Person <i>without</i> a health condition	8 (17)	19 (25)	5 (20)
Person <i>with</i> 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)

¹Included 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.

²Included 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.

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

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

⁵Included 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.

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

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

Table S2. Additional demographic characteristics for Australian participants only

Characteristic	TOTAL (N = 110, %) ¹
Age (mean ± SD, range)	48.7 ± 13.3 (18 to 80)
Gender (n = , % female)	88 (80)
Highest education level	
Primary school	0 (0)
Secondary school	2 (2)
Occupational certificate or diploma	12 (13)
University bachelor's degree	25 (27)
University post-graduate degree	64 (68)
Identify as Indigenous (yes,)	2 (2)
Non-English speaking background (yes,)	15 (15)
Area of residence²	
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)

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

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

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

References

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

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

	Consumer/ carer ¹ (n =)	Professional ² (n =)	Both ³ (n =)	NR ⁴ (n =)
Theme 1: Health service-level issues				
<p>Breakdowns in communication and coordination of care between and within health services are common</p> <p><i>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!</i> (Person who identified as both consumer/carer and professional)</p>	4	9	2	0
<p>The term patient-centred care is poorly understood and implemented by health services and health professionals</p> <p><i>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</i> (Person who identified as both consumer/carer and professional)</p>	4	4	5	1
<p>The quality and safety of patient care can be compromised by health services (particularly hospitals) not treating patients holistically</p> <p><i>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 this impacting on patient recovery</i> (Consumer/carer)</p>	8	5	0	0
<p>Cultural safety is not well-embedded in health services</p>	4	4	2	0

	Consumer/ carer ¹ (n =)	Professional ² (n =)	Both ³ (n =)	NR ⁴ (n =)
<i>Health professionals are not always able to take into consideration language and cultural needs of patients (Consumer/carers)</i>				
<i>Cultural safety is not embedded well in health services and as a result our Aboriginal population struggles even further to access services required (Professional)</i>				
Informed consent for treatment and research does not always happen	0	5	1	0
<i>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)</i>				
Not enough time is given to allow good communication between health professionals and patients	0	5	1	0
<i>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)</i>				
Theme 2: Health professional-level issues				
Some health professionals don't understand or ask patients about their preferences and priorities	5	4	5	0
<i>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/carers)</i>				
Some health professionals don't provide enough information to patients (some don't think it's a priority)	8	3	4	0
<i>Doctors do not explain why they prescribe treatments and interventions, nor ask about patient preferences regarding treatment and outcomes (Consumer/carers)</i>				

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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	3	5	2	0
<i>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)</i>				
There are often two-way barriers to adequate communication and participation (e.g. disability of individual plus discomfort of health professional)	3	3	0	1
<i>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)</i>				
Health professionals don't always know how to gauge how much their patients understand	1	2	1	0
<i>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)</i>				
Theme 3: Consumers and carer issues in their own care				
Patients don't always understand their health problems, treatment options or their rights	4	5	0	1
<i>Improve patient understanding of their medical care (particularly for patients [who are] non-native English speakers) (Consumer/carer)</i>				
Consumers and carers don't always know about all the options or services that exist	1	8	0	0

	Consumer/ carer ¹ (n =)	Professional ² (n =)	Both ³ (n =)	NR ⁴ (n =)
<i>[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/carers)</i>				
Consumers and carers aren't always able to participate actively in their care <i>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)</i>	1	2	2	0
The general public doesn't always have enough health literacy to navigate the health system and make health decisions <i>Health literacy. Many people do not have the skills/education or language skills to negotiate healthcare (and other) systems (Professional)</i>	2	2	1	0
Patients often experience information overload and are unable to retain the important information <i>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)</i>	3	1	0	0
Consumers and carers have difficulty understanding key medication information <i>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)</i>	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 <i>Researchers don't know how (or why they should) involve patients and carers in designing and reporting their research (Consumer/carer)</i>	5	9	3	2
Health services don't properly involve consumers and carers in health service planning and design <i>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)</i>	4	7	0	0
Theme 5: Accessibility of high quality health information				

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<p>‘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</p> <p><i>Standardised national leaflets about conditions provided by different sources (charities, NHS trusts, condition specific support groups), the information can vary wildly (Consumer/carer)</i></p>	3	11	4	0
<p>Theme 6: Ageing and end of life care</p>				
<p>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</p> <p><i>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)</i></p>	5	2	0	1

¹Included 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.

²Included 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.

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

⁴Three 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	<i>Global, regional, national, institutional, health service</i>	6
2	Define health area or focus	<i>Disease or condition specific, healthcare delivery</i>	7
3	Define end-users of research	<i>General population, patients</i>	7
4	Define the target audience	<i>Policy makers, funders, researchers, industry</i>	7
5	Identify the research focus	<i>Public health, health services, clinical, basic science; primary research, systematic reviews, guidelines</i>	6
6	Identify the type of research question	<i>Etiology, diagnosis, prevention, treatment, prognosis, health services, psychosocial, education, QOL, economic evaluation</i>	7
7	Define the time frame	<i>Short term or long term priorities</i>	NR
B. Governance and team			
8	Describe selection of the project leader/s and team	<i>Steering Committee, working group, coordinators</i>	6-7
9	Describe the characteristics of the project leader/team members	<i>Stakeholder group, organisations represented, characteristics</i>	6-7
10	Training or experience in research priority setting	<i>Involvement of JLA advisor</i>	7
C. Inclusion of stakeholders/participants			
11	Define the inclusion criteria for stakeholder groups involved in the PSP	<i>Stakeholder group</i>	7
12	State the strategy or method for identifying and engaging stakeholders	<i>Partnerships, social media, recruitment through hospitals</i>	7
13	Indicate the number of participants and/or organisations involved	<i>Individuals, organisations</i>	10
14	Describe the characteristics of stakeholders	<i>Name of stakeholder group e.g. clinicians, patients, policy makers</i>	10-11
15	Reimbursement for participation	<i>Cash, vouchers, certificates, acknowledgement</i>	NR
D. Identification and collection of research topics/questions			
16	Describe methods for collecting all research topics or questions	<i>Technical data (burden of disease, incidence), systematic reviews, reviews of guidelines/other documents, surveys, interviews, focus groups, meetings, workshops</i>	8
17	Describe methods for collating and/or categorising topics or questions	<i>Taxonomy, framework, used to organised and aggregate topics or questions</i>	9
18	Describe methods or reason for initial removal or topics or questions	<i>Beyond scope, lack of clarity and ill-defined, duplicative, number of submissions</i>	9 & 11
19	Describe methods for refining research questions/topics	<i>Reviewed by Steering Committee</i>	9
20	Cross check to identify if research questions have been answered	<i>Systematic reviews, consultation with experts</i>	N/A (see footnote)

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