

# BMJ Open Research priorities in health communication and participation: international survey of consumers and other stakeholders

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## ABSTRACT

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

**Setting** International.

**Participants** We included anyone with an interest in health communication and participation. Up to 151 participants (18–80 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 4 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 focused 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 (eg, lack of holistic, patient-centred, culturally safe care) and building health professionals'

## 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.

communication skills. Solutions should be devised in partnership with consumers, and focus on the needs of vulnerable groups.

## 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.<sup>1–3</sup> 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,<sup>3,4</sup> patient experience-led improvement,<sup>5</sup> health literacy<sup>6,7</sup> and the codesign of health services, policy and research.<sup>8,9</sup> In this study, we define these concepts collectively, as



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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.<sup>10 11</sup> Aside from obvious ethical imperatives, poor communication and inadequate patient participation in their health impacts on healthcare quality and safety.<sup>12 13</sup> 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.<sup>12 14</sup> Conversely, considerable evidence supports 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.<sup>15</sup> 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,<sup>16</sup> and self-monitoring interventions can improve medication adherence and clinical outcomes and reduce mortality in some people.<sup>17</sup>

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.<sup>1 18</sup> Often termed ‘stakeholders’, this includes consumers (patients and their families or carers, those receiving services and the public),<sup>18</sup> and health professionals, managers, policymakers, research funders and researchers.<sup>19</sup> Research priority setting with stakeholders is thought to both align research with the needs of those who it affects,<sup>20</sup> and reduce research waste.<sup>21</sup> Increasingly, priority-setting methods are being applied not just for primary research, but to identify the most important questions for systematic reviews.<sup>22</sup> While existing research priority setting methods and frameworks (eg, Viergever *et al*)<sup>23</sup> can be used for prioritising systematic reviews,<sup>24</sup> the final selection of priority systematic review topics may also be informed by their appropriateness and feasibility for systematic review teams.<sup>25</sup>

Within the area of health communication and participation, overarching research priorities of consumers and other stakeholders are unknown, with the exception of medication adherence<sup>26</sup> and patient safety in primary care.<sup>27</sup> Research priority setting partnerships are typically conducted for specific health conditions or clinical settings.<sup>20 28</sup> 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 were a top priority in asthma,<sup>29</sup> dementia,<sup>30</sup> palliative care,<sup>31</sup> preterm birth<sup>32</sup> and type 1 diabetes.<sup>33</sup> Given potential solutions to these problems are complex<sup>34</sup> and common across conditions,<sup>35</sup> an in-depth exploration of research priorities in this area

across health conditions and contexts has the potential to add valuable information to healthcare policymaking.

### Study aim

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

### METHODS

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

We worked in partnership with consumers and other stakeholders to plan and undertake all project stages.<sup>38</sup> Our approach was informed by the principles of coproduction, that is, recognising expertise, building on strengths, enabling shared control and mutually beneficial and supported relationships.<sup>39 40</sup> We reported activities and data against the relevant sections of a 32-item research priority setting appraisal checklist.<sup>41</sup>

### Context of the priority setting partnership

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

### Project steering group

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

We held three face-to-face steering group meetings (some joined by teleconference), with ad hoc input over email.

### Scope of the priority setting

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

### Participants and recruitment

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

In May 2015 we undertook purposive and snowball sampling,<sup>53</sup> promoting the survey by email and in newsletters. Approximately 1000 individuals and organisations were identified from the networks of the project team and steering group, and internet searches (for international patient groups, in particular), and were invited to forward the survey link to their networks or members. Those who received the email included consumer groups, Australian government health departments and health networks, medical and nursing colleges, national health organisations and advocacy groups, researchers and CCG authors and other contributors. Additional efforts, in the form of phone calls and facilitated introductions, were made to Australian organisations working with or representing Indigenous people and people from diverse cultural and linguistic backgrounds. We sent weekly email reminders while the survey was open.

### Collecting research priorities

We invited people to share their 'ideas for future research topics in the area of health communication and participation' via an online survey (see online supplementary file

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

We used an online survey as it allowed international participation and is recommended in the James Lind Alliance process.<sup>37</sup> 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,<sup>34 35</sup> 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 (ie, participants, settings and interventions).<sup>55</sup> 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<sup>17</sup> or interventions for providers to promote a patient-centred approach in clinical consultations.<sup>56</sup> We avoided technical research terms (eg, 'systematic reviews', 'Cochrane reviews', 'interventions') given consumers are often unfamiliar with these terms.<sup>57 58</sup>

We piloted the survey with six people, including consumers (n=4), a health professional (n=1) and a policymaker (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.<sup>59</sup> Taxonomies classify 'multifaceted, complex phenomena according to a set of common conceptual domains and dimensions'<sup>59</sup> (p 1761), and are well suited to grouping similar interventions in health communication and participation.<sup>60 61</sup> We used both conceptual (key health communication and participation concept domains and their essential dimensions) and participant

characteristic (identifying characteristics of stakeholders) codes.<sup>59</sup> Two researchers independently coded data, with a third to resolve disagreements (AJS, JSN, DL). Data were coded iteratively, and we compared interpretations and agreed on a set of codes, then topics and themes.<sup>62 63</sup>

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

We grouped similar conceptual problem codes together to form priority research topics,<sup>59</sup> which were then aggregated into groups labelled with simple descriptive themes using straightforward health systems language,<sup>64</sup> the aim being to adhere closely to the elements specified by respondents.<sup>65</sup> 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 often used in priority setting in clinical, condition-specific areas.<sup>37</sup> We retained the terminology used by participants to devise the topics, meaning synonymous terms were included (eg, some themes refer to ‘consumers’ and others to ‘patients’).

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

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

### Patient and public involvement

As described in more detail in the Methods section, we involved patients and the public (in this paper termed

**Table 1** Participant characteristics (n=151)

Characteristic	Total* n (%)
Age (years; mean±SD, range)	49±13 (18–80)
Female	117 (79)
<b>Stakeholder perspective†</b>	
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)
Policymaker	10 (7)
Researcher	43 (29)
Research funder	1 (1)
Other‡	11 (7)
No response provided	3 (2)
<b>Country</b>	
Australia	110 (74)
UK	13 (9)
Canada	7 (5)
USA	6 (4)
All other§	12 (8)

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

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

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

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

‘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 coauthors on this paper. In addition, we included the perspectives of a larger number of consumers as study participants. We created our final report<sup>36</sup> 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%), UK (n=13, 9%), Canada (n=7, 5%), the USA (n=6, 4%), and 12 other countries (8%; denominator 148 given

demographic data absent for three participants). The mean age ( $\pm$ SD) was 49 $\pm$ 13 years (range 18–80 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%).

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, policymakers 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 online supplementary table S1). Additional demographic details that were only asked of Australian participants are presented in online supplementary 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 1 of 21 research priority topics, and then into one of six overarching priority themes (see [table 2](#)).

### 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.<sup>66 67</sup> 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 between concepts in health communication and participation.

The most commonly cited priority topics, that is, the health communication and participation problems that stakeholders most wanted research to address include: insufficient consumer involvement in research (19 responses); 'official' health information that is contradictory and hard to understand (18 responses); communication and coordination breakdowns in health services

(15 responses); health information provision being a low priority for health professionals (15 responses); insufficient eliciting of patient preferences (14 responses); health services that poorly understand or implement patient-centred care (14 responses); lack of holistic care impacting quality and safety (13 responses); and inadequate involvement of consumers in service design (11 responses).

Below is a description of the priority themes and topics for all stakeholders, followed by priority populations and potential interventions. See online supplementary 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 (eg, language considerations or cultural needs) within health services and that the safety and quality of healthcare can be comprised by not treating patients holistically.

#### *Priority theme 2: health professional-level issues*

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

#### *Priority theme 3: consumer and carer issues in their own care*

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

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

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

### Populations affected (across priority themes and topics)

Participants stated that certain people or groups were more likely to be affected for each health communication

**Table 2** Priority topics, grouped by descriptive themes for scoping future Cochrane Reviews of interventions in health communication and participation

	Number of responses (n)
<b>Theme 1: health service-level issues</b>	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 (eg, 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
<b>Theme 2: health professional-level issues</b>	50
Some health professionals do not understand or ask patients about their preferences and priorities.	14
Some health professionals do not provide enough information to patients (some do not think it is a priority).	15
Health professionals do not always provide enough support for patient decision-making.	10
There are often two-way barriers to adequate communication and participation (eg, disability of individual plus discomfort of health professional).	7
Health professionals do not always know how to gauge how much their patients understand.	4
<b>Theme 3: consumers and carer issues in their own care</b>	37
Patients do not always understand their health problems, treatment options or their rights.	10
Consumers and carers do not always know about all the options or services that exist.	9
Consumers and carers are not always able to participate actively in their care.	5
The general public does not 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
<b>Theme 4: issues for broader consumer and carer involvement</b>	30
Health researchers do not adequately involve patients in research, nor share their findings.	19
Health services do not properly involve consumers and carers in health service planning and design.	11
<b>Theme 5: accessibility of high-quality health information</b>	18
'Official' health information can be contradictory and hard to understand, both written and online. Consumers and professionals do not know how to find and assess good quality information online.	18
<b>Theme 6: ageing and end-of-life care</b>	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

and participation research priority, but acknowledged that everyone can experience poor health communication and participation. Those identified as more vulnerable included (described in order of the frequency with which they were mentioned):

- ▶ People from diverse cultural and linguistic backgrounds.
- ▶ Those with limited English.
- ▶ People with caring responsibilities.
- ▶ Those with limited education and/or limited literacy and numeracy.
- ▶ People from low socioeconomic areas.
- ▶ People with mental illness.
- ▶ Older people.

- ▶ People with dementia and cognitive issues.
- ▶ Those with chronic illness or multimorbidity.
- ▶ People from rural and regional areas.
- ▶ Indigenous people.
- ▶ 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

### 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.

(see [box 1](#); interventions are described in order of the frequency with which they were mentioned).

## 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 among 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 (eg, 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 focused on training and cultural change activities for health services and health professionals. Stakeholders emphasised that poor communication and participation can affect everyone, but disproportionately affects 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 one of the the first research priority setting partnership with stakeholders

### 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.
  - 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 focused 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 in low/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 (ie, asthma and intensive care).

(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.

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,<sup>1</sup> the UK,<sup>2</sup> the USA<sup>68</sup> and globally.<sup>4</sup> For example, Australia has strategic goals and standards for partnering with consumers in their own care and in health service governance and evaluation.<sup>1 69</sup> 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.<sup>4</sup> 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,<sup>26</sup> patient safety in primary care<sup>27</sup>

and palliative and end-of-life care.<sup>31</sup> All three identified research priorities addressing the information and support needs of patients and families, plus health professional training in patient-centred care,<sup>26</sup> improved communication and coordination between services,<sup>31</sup> and addressing the needs of vulnerable groups.<sup>31</sup> Given the exponential growth of prioritisation activities,<sup>28</sup> there is an opportunity to build up an international picture of communication and participation priorities, in which the differences and similarities could be analysed (see [box 2](#)).

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

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

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

a consumer and a professional, when if asked, they may have described themselves as predominantly a consumer or a professional.

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

## CONCLUSIONS

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

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