Stakeholder priorities for research in health communication and participation

FINDINGS FROM THE COCHRANE CONSUMERS AND COMMUNICATION PRIORITY SETTING PROJECT

LA TROBE UNIVERSITY

CENTRE FOR HEALTH COMMUNICATION AND PARTICIPATION

Cochrane
Consumers and
Communication

ABOUT US

The Cochrane Consumers and Communication Group is based in the Centre for Health Communication and Participation at La Trobe University in Melbourne, Australia.

We are part of the international organisation, Cochrane. Cochrane is an independent, not-for-profit organisation dedicated to producing up-to-date, accurate information about the effects of health care for everyone to access.

ABOUT COCHRANE REVIEWS

Cochrane Reviews are high quality reviews of the research in health care and health policy. They are published in the Cochrane Library at www.cochranelibrary.com.

Cochrane Reviews are used internationally by health policy makers, health professionals, and others to plan and deliver best practice in health care. They are also used by many consumers, to inform their own health care decisions.

DEFINING HEALTH COMMUNICATION AND PARTICIPATION

Our Cochrane Reviews summarise the evidence about improving health communication and participation. In this project, we asked people to share their priorities for research in health communication and participation.

We define this 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.'

DEFINING CONSUMERS AND STAKEHOLDERS

We use the term 'consumer' to include patients and potential patients, their family members and carers, organisations representing consumers' views and the public. We use the term 'stakeholder' to include consumers, and others with an interest in this area, such as health policy makers, health professionals, researchers and research funders. In some places in this report, we use the words used by the people who took part. For example, sometimes 'patients' is used instead of 'consumers'.

Stakeholder priorities for research in health communication and participation

BACKGROUND

In March 2015, we started a wide-ranging consultation process. We wanted to choose 5 new topics for our Cochrane Reviews, and to make sure they would be as useful as possible to the people who need to use, or might be affected by our research: health policy makers, health professionals, researchers, consumers and carers, and the wider community. So we asked representatives from all these areas to share their priorities. This report describes what we learnt, and the priority Cochrane Review topics we decided as a result.

During the process, the people we consulted said the co-design approach we used, partnering with consumers and other stakeholders, could be useful for many different people and organisations. We have written this report in the hope that it will assist others to work together and co-design research and policy priorities. We also hope it will be useful to people who might be able to address, or advocate for the priority research topics identified, and of interest to the people who took part.

Aims and methods

AIMS

The aims of the project were to identify stakeholder priorities for research in health communication and participation, broadly, and to use this list to identify 5 priority topics for Cochrane Reviews in this area.

METHODS

Step 1: Online survey

WHAT WE DID:
We invited anyone with an interest in health communication and participation to tell us their ideas for new research topics in this area. We used an online survey and asked the following 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?

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

WHO TOOK PART:
- 151 people (mostly Australians) aged between 18 and 80 years
- A mix of stakeholders; with 30% consumers or carers, about 50% health professionals or health service staff, about 30% researchers, and 7% policy makers (some people wore multiple 'hats')

THE OUTPUT:
- People suggested 191 priorities for research in health communication and participation
- We grouped similar ideas together and came up with **22 initial research priorities**

Step 2: Workshop

WHAT WE DID:
On 10 September 2015 we held a workshop in Melbourne. In a series of small and large group discussions, we asked people to:

- Review the 22 initial research priorities generated in the online survey
- Generate and rank the high priority ideas by individual voting
- Explore and refine the high priority ideas in small groups

WHO TOOK PART:
- 28 people including consumers and carers, health professionals, health service managers, policy makers and researchers
- Half the participants were consumer or carer representatives, and we included people from metropolitan and regional areas and people from indigenous and non-English speaking backgrounds

THE OUTPUT:
- This resulted in the **top 12 research priorities**
- And a whole lot of ideas we could take on board as part of the priority Cochrane Reviews

Step 3: Evidence mapping against Cochrane topic list
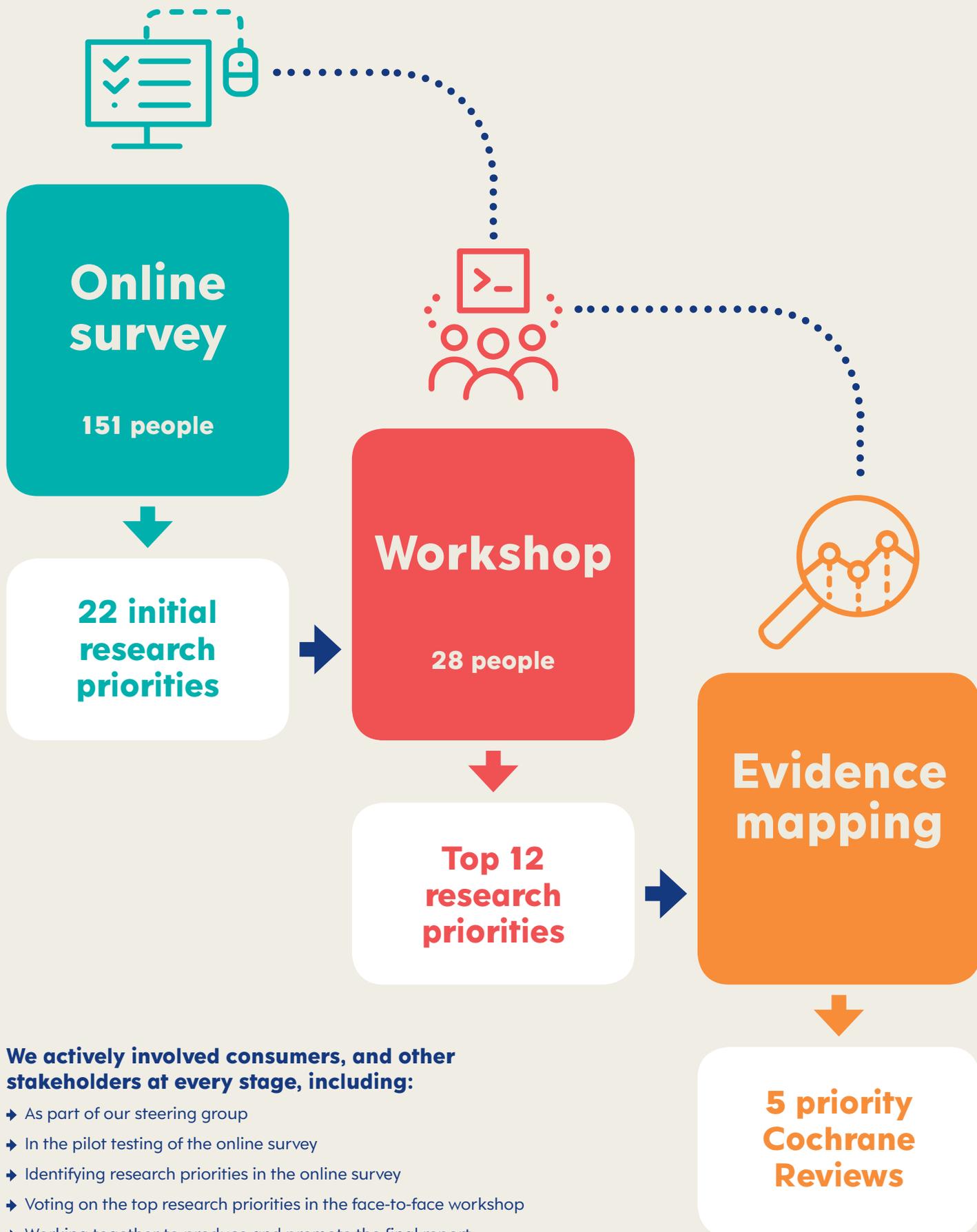
WHAT WE DID:
- Took the top 12 research priorities, and the other ideas and themes that emerged from the online survey and the workshop, and read them all very carefully
- Compared this against our list of planned and published Cochrane Reviews
- We then selected 5 Cochrane Review topics that closely aligned with one or more of the priorities identified by stakeholders

WHO TOOK PART:
- This work was undertaken by staff at Cochrane Consumers and Communication, with input from the project steering group

THE OUTPUT:
- **5 priority Cochrane Reviews** to be commenced immediately
- An additional set of possible topics for further investigation and planning before starting as Cochrane Reviews

Online survey

151 people

↓

22 initial research priorities

→

Workshop

28 people

↓

Top 12 research priorities

→

Evidence mapping

↓

5 priority Cochrane Reviews

We actively involved consumers, and other stakeholders at every stage, including:

➜ As part of our steering group

➜ In the pilot testing of the online survey

➜ Identifying research priorities in the online survey

➜ Voting on the top research priorities in the face-to-face workshop

➜ Working together to produce and promote the final report

➜ And now, working together as the 5 priority Cochrane Reviews get underway

Initial 22 research priorities in health communication and participation

Health service issues

→ The quality and safety of patient care can be compromised by health services (particularly hospitals) not treating patients holistically

→ Breakdowns in communication and care coordination between/within health services are common

→ 'Patient-centred care' is poorly understood and implemented by health services/professionals

→ Transitions between health services are a particularly vulnerable time for poor communication

→ Cultural safety is not well-embedded in health services

→ Truly informed consent for treatment and research does not always happen

→ Not enough time is given to allow good communication between health professionals and patients

Health professional issues

→ Some health professionals don't understand or ask patients about preferences and priorities

→ Some health professionals don't provide enough information to patients (some don't think it's a priority)

→ There are often two-way barriers to adequate communication and participation (e.g. disability of individual plus discomfort of health professional)

→ Health professionals don't always provide enough support for patient decision-making

→ Health professionals don't always know how to gauge how much their patients understand

Consumer and carer involvement issues (broadly)

→ Health services don't properly involve consumers/carers in health service planning/design

→ Health researchers don't adequately involve patients in research, nor share their findings

Individual consumer and carer issues (for their own care)

→ Consumers and carers don't always know about all the options or services that exist

→ Consumers and carers aren't always able to participate actively in their care

→ The public don't always have enough health literacy to navigate health system and make informed health decisions

→ Patients don't always understand their health problems, treatment options or their rights

→ Patients often experience information overload and are unable to retain all information

→ Consumers and carers have particular issues understanding key medication information

Publicly available information

→ 'Official' health information can be contradictory and hard to understand, both written and online. Consumers and professionals don't know how to find and assess quality information online

Ageing and end of life care

→ 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

'Doctors, clinicians and health professionals are not speaking in a voice that can be understood, especially by marginalised groups. [Research should focus on] communication training for health professionals.'
ONLINE SURVEY PARTICIPANT

'Patients and their relatives are often unprepared for the possibility of death, and health professionals frequently perform poorly in managing communication around this issue. [Research should focus on] mandatory training for all doctors and enhanced communication for relatives.'
ONLINE SURVEY PARTICIPANT

'Health care providers continue to discount the role played by the patient as primary driver of their own care, they do not ask, do not listen and then wonder why the patient doesn't follow their good advice. [Research should focus on] more integrated training for health professionals across the learning years.'
ONLINE SURVEY PARTICIPANT

Top 12 research priorities for health communication and participation research

Health service issues

→ The quality and safety of patient care can be compromised by health services (particularly hospitals) not treating patients holistically

→ Breakdowns in communication and care coordination between/within health services are common

→ 'Patient-centred care' is poorly understood and implemented by health services/professionals

→ Transitions between health services are a particularly vulnerable communication time

Health professional issues

→ Some health professionals don't understand or ask patients about preferences and priorities

→ Some health professionals don't provide enough information to patients (some don't think it's a priority)

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Consumer and carer involvement issues (broadly)

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Individual consumer and carer issues (in their own care)

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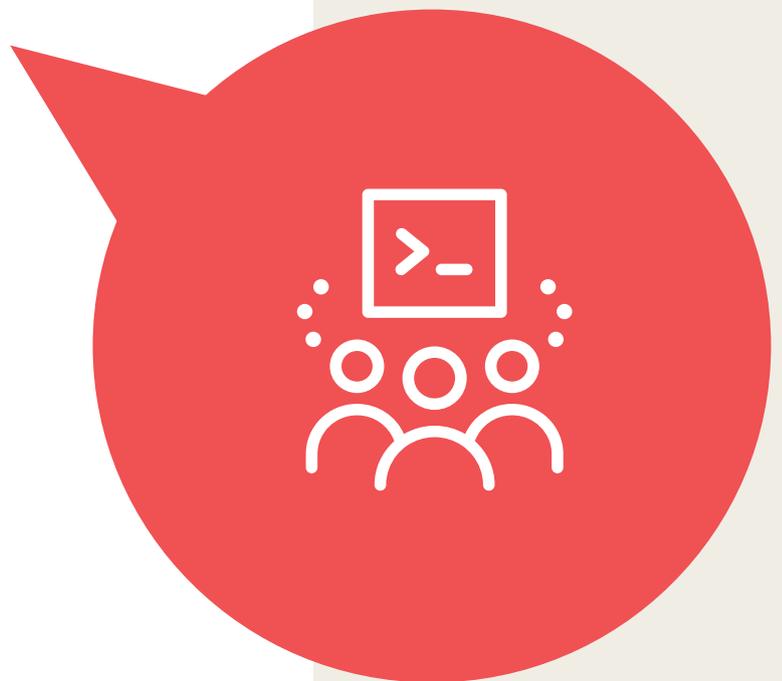
Ageing and end of life care

→ 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

'Hospitals, healthcare providers and pharmacists don't always communicate effectively with each other, regarding treatments, medications, referrals, etc. [This affects] all patients, but the elderly and people with mental health conditions are particularly vulnerable.'
ONLINE SURVEY PARTICIPANT

'Hospitals don't understand how to include patients and families as partners in patient safety. [Research should focus on] training for health professionals to respond positively to safety issues raised by consumers and carers.'
ONLINE SURVEY PARTICIPANT

Who do these health communication and participation issues affect?

Everyone! Stakeholders told us that most of these issues can affect everyone in the community to some degree, but there are certain groups of people that these issues affect more than others. Particular groups that were highlighted include:

- People from diverse cultural and linguistic backgrounds
- Carers
- People with limited education, or limited reading and writing skills
- People from low socioeconomic areas
- People with mental health issues
- Older people, including people with dementia or cognitive issues
- People with chronic or multiple illnesses
- People from rural and regional areas
- Aboriginal people
- People with a disability
- Prisoners
- Injecting drug users
- Sex workers
- Lesbian, gay, bisexual, transgender, queer and intersex people
- People with blood-borne viruses

What should we keep in mind when researching possible solutions to these problems?

Many people told us they wanted us to focus on research activities that are targeted at health professionals and health services (for example, improving organisational culture and governance).

Additionally, stakeholders were keen to see these research activities focus on activities to improve care for individuals, rather than activities targeted at the general population.

Finally, stakeholders wanted us to focus research activities that involve consumers as partners or advisors, for example in communication training or undergraduate teaching of health professionals.

'Cultural safety is not embedded well in health services and as a result our Aboriginal population struggles even further to access services required. [Research should focus on how to get] cultural safety training embedded into mandatory training schedules and accreditation standards.'

ONLINE SURVEY PARTICIPANT

Introducing our 5 priority topics for Cochrane Reviews

Improving communication about end of life care

COCHRANE REVIEW TITLE:
Interventions for communication about end of life care among health professionals and patients and their families or carers.

STATUS:
This will be a new Review. The team is currently preparing their plan for the Review (called a protocol).

AUTHOR TEAM:
Amanda Henderson (lead), University of the Sunshine Coast, with colleagues from La Trobe University, the University of New South Wales, the University of Queensland, Health Care Consumers Association of the ACT and Lady Cilento Children's Hospital.

The author team says:

*'Everyone dies. No matter who you are, where you live, or how it happens, there are two experiences that every living person has in common—they were born, and one day they will die.
So how is it that there is limited evidence for communication surrounding such a universal and indiscriminate challenge as end of life care?*

Our review seeks to find evidence of interventions to support communication strategies and approaches between healthcare professionals and patients/ families / carers for end of life care.'

Patient, family and carer involvement in patient safety

COCHRANE REVIEW TITLE:
Interventions to increase patient and family involvement in escalation of care for acute life threatening illness.

STATUS:
This will be a new Review. The team is currently preparing their plan for the Review (or protocol).

AUTHOR TEAM:
Nicola Mackintosh (lead) and colleagues from King's College London.

The author team says:

'Service users and families have a valuable role in recognising signs of acute illness and helping to secure timely and appropriate help from professionals. However this role is often difficult to undertake in practice; notions of 'expertise', 'involvement' and 'partnership' need to be examined in the context of people experiencing acute episodes of illness.

Our review will focus not only on the evidence base for interventions designed to help service users and families contribute to their safety, but whether these interventions enable an appropriate response from health professionals, and the influence of context on outcomes.

We are delighted that our review has been identified by stakeholders as a priority as it supports our belief that this is an important topic for patients and families, policy makers, managers, health care professionals and health service researchers looking to improve care in this area.'

Improving future doctors' communication skills

COCHRANE REVIEW TITLE:
Interventions for improving medical students' communication skills in doctor-patient consultations

STATUS:
This will be a new Review. The team is currently finalising their review plan (or protocol).

AUTHOR TEAM:
Conor Gilligan (lead), the University of Newcastle, with colleagues from the University of Newcastle, Monash University, Deakin University, Australian Catholic University, Barts and The London School of Medicine and Dentistry, and University of Cambridge.

The author team says:

'We have a shared interest in teaching communication skills to medical students and in applying research evidence to the selection of teaching approaches. Educating medical students, future doctors, to use effective and person-centred communication is something that benefits the whole community, so we were thrilled that our review was recognised as a priority by those who ultimately benefit most from effective educational strategies. We hope the review is also valuable in contributing to the evidence for educators, to help guide decisions about effective teaching.'

Consumer engagement strategies

COCHRANE REVIEW TITLE:
Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material

STATUS:
This review is already available in the Cochrane Library, but it needs to be updated to include the latest studies. The author team has been reconfigured and the scope and methods may be revised.

AUTHOR TEAM:
Louise Wiles, University of South Australia and the South Australian Health and Medical Research Institute (SAHMRI) and Debra Kay, SAHMRI (Consumer Engagement) will undertake the work with Hilde Tinderholt Myrhaug from the Knowledge Center for Health Services, Norwegian Institute of Public Health (a member of the original team); Susan Hiller and Julie Luker from the University of South Australia; and Annie Synnot from La Trobe University.

The author team says:
'It is a privilege to be part of this priority review. We expect this work to provide an update on evidence-based information about efficacy of consumer engagement strategies. It will also test an approach to engage with stakeholders in framing, undertaking and disseminating the work. We anticipate the report to be of interest to people working in all areas of health care, service delivery, policy and research.'

Promoting patient-centred care

COCHRANE REVIEW TITLE:
Interventions to promote a patient-centred approach in clinical consultations

STATUS:
This review is already available in the Cochrane Library, but it needs to be updated to include the latest studies. A revised author team will undertake this update, and may revise the scope and methods.

AUTHOR TEAM:
We are currently finding a new lead author (likely based at La Trobe University) to join the existing team to undertake this update.

Bronwen Merner (Managing Editor, Cochrane Consumers and Communication) says:

'A diverse range of health policy, health professional and consumer organisations have used this Cochrane Review to inform their work. These organisations include the World Health Organization, the UK's National Institute for Health and Care Excellence, Planetree, the International Alliance of Patients' Organizations, the Picker Institute, the Sax institute, the Health Foundation and the Institute for Healthcare Improvement. Given the increasing focus on improving patient-centred care since the last update in 2012, we anticipate this review update will further contribute to the evidence base already informing health policy and practice.'

INVOLVING STAKEHOLDERS IN THE PRIORITY COCHRANE REVIEWS

All our priority Cochrane Reviews will actively involve consumers and other stakeholders (such as health professionals, medical students or policy makers) as co-authors, partners or advisers in the review process. They will be involved with planning, undertaking, interpreting and disseminating the Reviews.

What participants said about being involved

'I was pleased to be part of the consumer collaboration throughout the project. My involvement has been through the multiple stages of this project from the initial piloting of the online survey to the workshop and then providing feedback on the draft final report. During the piloting of the online survey I provided topics for possible Cochrane research and was pleased to see one of my suggested research priorities in the workshop. The research priorities generated in the project are very relevant to a lot of the policy work being done in Australia around quality and safety in health care.'

HEATHER WATSON, CONSUMER HEALTH REPRESENTATIVE

'On paper this seemed such an unenviable challenge – to distil the concerns and ideas of a diverse group of practitioners, advocates and patients into a priority list of 5 topics. And yet, with expertise and meticulous planning, this is what was achieved. The priority setting workshop generated many ideas and areas of concern for which evidence is either lacking or uncertain. As a Cochrane insider, I'm often talking to others about Cochrane's commitment to producing evidence that is useful to both practitioners and patients, so to be practically involved in such a process was very rewarding.'

STEVE MCDONALD, COCHRANE AUSTRALIA

"This has informed my role as a consumer representative. I'll be able to contribute more perspective which could add some insight to health practice at [my community health centre] to better cater for health consumers.'

WORKSHOP PARTICIPANT FEEDBACK

"Thank you so much for all your help to allow me to participate in the workshop. It was one of the best experiences of my life, I felt 'heard' and I hope I was able to help in some way.'

WORKSHOP PARTICIPANT FEEDBACK

'I participated in the Priority Setting Committee as a health consumer representative. I appreciated the respectful and rigorous way in which consumer perspectives were sought and incorporated in this project.'

DEBRA KAY, CONSUMER HEALTH REPRESENTATIVE

'Would love to hear about further opportunities to be involved. These sessions help to support communication across services – policy makers, government, health professionals and consumers – Great!'

WORKSHOP PARTICIPANT FEEDBACK

Broader impact on policy, practice and research

'This report will raise awareness that further work is needed to ensure that health providers and professionals understand the value of health communication and participation, and how it on health outcomes. Consumer participation has been identified as an essential aspect of care. For example, the National Safety and Quality Health Service Standards, including Standard 2 'Partnering with Consumers', are gaining momentum and are part of healthcare accreditation.'

NORA REFAHI, CONSUMER

'Consumers bring valuable experience that can enrich the best research minds to be responsive and relevant to the needs of people affected, placing them at the centre of research. Involving consumers with clinical experts, researchers and policy makers in setting research priorities will ensure research has the greatest impact.'

SUSAN HANSON, CANCER AUSTRALIA

'Researchers, policy makers, service administrators, regulators, clinicians and others employed in the health sector are increasingly acknowledging the ethical and practical imperative to engage consumers and the community in the co-production of health and health research. The priorities identified in this project will engage and inform communities seeking to enhance consumer engagement and better health and wellbeing for all.'

DEBRA KAY, CONSUMER HEALTH REPRESENTATIVE

'Our community and members are keen to become more involved in shaping the way our health service runs, but sometimes struggle to engage with the hospital that provides services to most of our members. Being involved in this project has not only given me more ideas about how we can partner better with the hospital, but hopefully this report, and the reviews that flow on from it, will also provide evidence that we can take to our health service about the value and necessity of consumer participation.'

LOUISA WALSH, PRESIDENT, HEART AND LUNG TRANSPLANT TRUST VICTORIA

Consumer and carer representatives can help shape health policy and practice by being involved in health service committees, consumer bodies, forums, or partnering in research projects. Sharing the findings of this project with consumers and carers is a good way to introduce Cochrane to a new audience."

HEATHER WATSON, CONSUMER HEALTH REPRESENTATIVE

What's next?

Top 5 priority Cochrane Reviews

All 5 priority Cochrane Reviews are now underway (or very soon to be underway). Cochrane Reviews can take quite some time to complete, but we hope the first Reviews will be published and actively promoted towards the end of 2017.

We will be providing updates about our priority review progress (see Stay in Touch).

Next round of priority Cochrane Review topics

We will continue to scope and refine the other suggested research priorities to identify another round of priority Cochrane Reviews in 2017.

Stay in touch

To stay in touch with our priority Cochrane Review progress, and our other work, follow us on Twitter (@CochraneCCRG), visit our website (cccrg.cochrane.org) or sign up for our newsletter (cccrg.cochrane.org/newsletters).

You can also contact us directly at Cochrane-review@latrobe.edu.au.

'This was an even more valuable experience than I expected. Participants in all stages and roles gave us the benefit of their knowledge and experience and five important priorities have emerged. But we learned much more. We are committed to acting on the priorities but the guidance we received will also influence our advice to future Cochrane authors and our commitment to broad communication of the research.'

SOPHIE HILL, HEAD, CENTRE FOR HEALTH COMMUNICATION AND PARTICIPATION, AND COORDINATING EDITOR, COCHRANE CONSUMERS AND COMMUNICATION

Acknowledgements

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