



CENTRE FOR HEALTH COMMUNICATION AND PARTICIPATION

Year in Review 2015

The Centre for Health Communication and Participation is located in the School of Psychology and Public Health at La Trobe University, Melbourne, Australia. The Centre investigates the best ways to increase the participation of consumers in health care through effective communication.

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ABOUT OUR CENTRE

Our mission is to improve the health of consumers by supporting their participation in health care through effective communication with health care providers. Consumers include patients, and potential patients, their family members and carers, organisations representing consumers' views and the public.

We partner with consumers, health professionals and policymakers to promote health care decision-making that is informed by high quality research as well as consumers' views and experiences. We investigate different approaches that seek to foster informed and active health care consumers. Examples of these approaches include cultural competence education for health professionals, peer support for carers, using decision aids to help consumers weigh the benefits and harms of different medical treatments and finding out the best ways to assist consumers to take their medications as prescribed. Our work shows many of these strategies do improve consumers' health and experiences.

Our researchers bring a strong and diverse track record to the field of health communication and participation. We also run a substantial program for Higher Degree research students in the emerging public health field of Consumer Participation.

In all our work we seek to build the evidence base for effective communication and participation. We actively promote our work and engage with many different groups of people to ensure recognition of the issues and uptake of our research. We provide education and training in conventional and innovative ways.

In this Year in Review for 2015 we present our activities and outputs for the year and preview our strategic directions for 2016.

The Centre runs two major research programs:

1

Cochrane Consumers and Communication

We provide the editorial base for Cochrane Consumers and Communication, which is part of the international organisation, Cochrane. As such, our role involves publishing high-quality reviews of the evidence about interventions or approaches which affect the way consumers interact with each other, or with health care professionals, health services and health researchers. We recently engaged in widespread consultation to ensure our future review topics are relevant for consumers, health professionals and policymakers (see *Setting priorities for Cochrane reviews on consumer and communication topics*).

2

Innovative research projects focusing on health communication and participation

We collaborate with consumer organisations, health professionals, health care services, governments and universities in Australia and internationally to conduct leading research into priority health communication and participation topics.

High-profile health care issues we investigate include:

- Improving communication about childhood vaccination (see page 15 *Communicate to Vaccinate*)
- Improving communication about use of medicines
- Understanding the specific communication and participation needs of people with multiple health problems
- Understanding how consumers participate to prevent medical mistakes
- Implementing the best ways to share evidence with or transfer knowledge to policy makers, health professionals and consumers.

HEAD OF CENTRE'S REPORT

2015 was a productive year by any measure. I would like to thank and acknowledge our funders, our Cochrane authors, editors and referees, staff and advisory groups, students, consumers, consumer organisations, health services, government, and the University for helping us achieve our mission.

Our mission is to improve the health of consumers by supporting their participation in health care through effective communication with health care providers. Our two main programs drive us forward to achieve this by building the evidence base and researching consumer or carer issues.

Our work in Cochrane Consumers and Communication is to coordinate and support multiple teams of Cochrane authors to conduct their Cochrane reviews of the effects of communication or participation interventions. We also organise the peer review and publication process for them to appear in the high impact journal, Cochrane Database of Systematic Reviews, freely available to Australians in the Cochrane Library (at www.cochranelibrary.com). This is a substantial task because communication and participation interventions are complex and operate in socially divergent settings. We operate internationally but ensure we seek a high degree of participation in all aspects of this work from Victorian consumers, health professionals and policy makers. Our statistics for 2015 are: 578 active authors from 28 countries* and 121 referees from 15 countries* (*cumulative totals); three new reviews published; two updated reviews published; three protocols (plans for the review)

published; and we registered eight new review titles.

For the first time we report on the impact of these reviews. The statistics are exciting as they show that not only do our reviews get cited often in journals (indicating high use by other researchers) but a number of our reviews are downloaded 1000s of times a year, and several received very high Altmetric statistics. This shows that people are looking at, reading and forwarding our Cochrane reviews – they are in high circulation.

The first stage of the substantial Cochrane Consumers and Communication Review Priority-setting Project was completed, in which we consulted with consumers, health professionals and decision-makers about priority Cochrane review topics. The results from this project will influence our work for some years.

We continued to provide a very high level of support and methodological advice to our Cochrane authors, recognising that our reviews are profoundly complex and difficult. To help authors we prepared three new resources so that they can implement the latest methods in their reviews and meet the high standards the international Cochrane Collaboration expects.

Cochrane Consumers and Communication authors were supported with search strategy development for several large databases for each review and update. Quality control was provided for Cochrane Consumers and Communication searches, which

are detailed and constantly requiring updating due to new terminology in use.

An online video resource was produced to help the public understand the purpose and process of systematic reviews. The resource has since been translated into five languages and received over 5000 views in its first month of release.

We conducted a number of very valuable forums during the year and a wide range of people generously gave us feedback on our knowledge transfer strategy and outputs. This will lead to changes in our Evidence Bulletins.

Centre staff and student outputs and achievements were exciting. Claudia Meyer was awarded her PhD for a project titled Translating falls prevention knowledge for community-dwelling older people living with dementia and their carers—what works?

Research papers were published in high-impact journals by PhD candidates Dianne Lowe and Jessica Kaufman in Journal of Rheumatology and Journal of Clinical Epidemiology, respectively.

Research findings were presented by PhD candidates Bronwen Merner and Jessica Kaufman respectively at international conferences: Communication, Medicine and Ethics Conference (Hong Kong) and Cochrane Colloquium (Vienna).

PEOPLE

Staff



Dr Sophie Hill
Head, Centre for Health Communication
and Participation
Coordinating Editor, Cochrane
Consumers and Communication



Ann Jones
(July 2015–current)
Managing Editor, Cochrane Consumers
and Communication



Dr Rebecca Ryan
Research Fellow and Deputy
Coordinating Editor, Cochrane
Consumers and Communication

Dr Megan Prictor
(June–July 2015)
Managing Editor, Cochrane Consumers
and Communication



Anneliese Synnot
Research Fellow and Editor, Cochrane
Consumers and Communication

Dr Sue Cole
(January–June 2015)
Managing Editor, Cochrane Consumers
and Communication



John Kis-Rigo
Information Specialist, Cochrane
Consumers and Communication



Jessica Kaufman
Research Officer



Bronwen Merner
Graduate Assistant Teaching Fellow



Dianne Lowe
Research Officer



KowLin Leong
Senior Administrator



Jack Nunn
Research Officer

Higher Degree by Research students

Jessica Kaufman
Dianne Lowe
Bronwen Merner
Claudia Meyer
Peterson Junius Muriithi Nyaga
Molly O'Sullivan
Ania Sieracka

Honorary Associates

Dr Artur Manuel Muloliwa
Ministry of Health
Mozambique
Dr Michael Summers
Victoria, Australia

STRATEGIC DIRECTIONS BEYOND 2015

Future strategic directions for the Centre include:

Improving consumer experiences and outcomes of health care

- Facilitating and delivering Cochrane reviews identified as Australian and international priorities in the Setting priorities for Cochrane reviews on consumer and communication topics project
- Producing evidence maps and tools to aid improvement of the patient experience, linked to key findings of the Victorian Healthcare Experience Survey
- Initiating co-production of Cochrane reviews with consumers and carers
- Taking advantage of methodological and technological developments to aid our Cochrane authors

Undertaking innovative research on priority communication and participation issues

- Working with the Victorian health sector to develop standards for health information
- Researching carer involvement in patient safety
- Understanding public participation in genomics and connecting people online
- Supervising new student research into the scope for standards for diagnostic information

Building partnerships and collaborations to facilitate the translation of evidence into policy and practice

- Working with policy makers to produce Evidence Bulletins to ensure the findings are translated to Victorian health settings
- Developing an interactive online format for Evidence Bulletins so that we can tailor them to users' needs
- Participating in advisory committees for consumer participation policy and improving services for patients
- Assessing how our work has impact across various domains of policy and practice.

OUR RESEARCH PROGRAMS AND FLAGSHIP PROJECTS:

Activities and outputs for 2015

Cochrane Consumers and Communication

About us

Cochrane Consumers and Communication is part of Cochrane, an international, independent, not-for-profit organisation dedicated to making up-to-date, accurate information about the effects of health care readily available worldwide. Cochrane reviews have become internationally known as the pre-eminent rigorous quality standard for systematic reviews. These are published online at the Cochrane Library, a high impact journal freely available to all Australians.

We coordinate the preparation and publication of systematic reviews of interventions that affect the way people interact with health care professionals, services and researchers. We receive funding from the Department of Health and Human Services, Victoria, and the National Health and Medical Research Council.

Our reviews fall into six categories:

- Interventions directed to the consumer
- Interventions from the consumer
- Interventions for communication exchange between providers and consumers
- Interventions for communication between consumers
- Interventions for communication to the healthcare provider from another source, and
- Service delivery interventions.

Our international editorial team

Our team of highly experienced editors contribute to the preparation of our Cochrane reviews:

Assoc Prof Josip Car, Imperial College London, UK and Nanyang Technological University, Singapore

Prof Adrian Edwards, Cardiff University, UK

Dr Claire Glenton, Norwegian Knowledge Centre for Health Services, Norway

Assoc Prof Bronwyn Hemsley, University of Newcastle, Australia

Dr Dell Horey, La Trobe University, Australia

Prof Sandy Oliver, Institute of Education, University of London, UK

Dr Rebecca Ryan, La Trobe University, Australia

Dr Nancy Santesso, McMaster University, Canada

Dr Ruth Stewart, Institute of Education, University of London, UK and University of Johannesburg, South Africa

Ms Anneliese Synnot, La Trobe University, Australia

Dr Michael Taylor, Australian Catholic University, Australia

Dr Gian Luca di Tanna, London School of Hygiene and Tropical Medicine, UK (Statistics Editor)

Dr Jo McKenzie, Monash University, Australia (Statistics Editor, to June 2015)

We are also grateful to the late Dr Andrew Herxheimer who served as the Comments and Criticisms Editor with the Group for nearly 15 years.

FLAGSHIP PROJECT

Setting priorities for Cochrane reviews on consumer and communication topics

Anneliese Synnot, Sophie Hill, Molly O'Sullivan, Jack Nunn, Dianne Lowe with a steering group including consumer representatives, policy makers, health professionals, researchers and research funding body representatives.

In January 2015, we commenced a review priority-setting project, with the aims of identifying (1) priority topics for systematic reviews of interventions for communication and participation, as judged by Australian and international stakeholders and (2) the top five Australian priorities for new Cochrane reviews within Cochrane Consumers and Communication scope.

The project had three main activities:

- An international online survey to generate ideas for new systematic reviews
- A face-to-face workshop in Melbourne to refine the ideas and vote on the top priorities, and
- Evidence mapping to determine which topics are most suitable for Cochrane Consumers and Communication reviews.

Status

In June 2015, we invited consumers, carers, health professionals, policy makers and anyone with an interest in health communication and participation to complete an online survey. We asked respondents to identify one or more issues relating to health communication and participation, who were affected, and suggest any solutions they would like to see tested.

We were thrilled with the response: 151 people completed the survey, offering nearly 200 suggestions for future research. We received a broad mix of perspectives (including participants aged from 18 to 80 years, about a third of whom identified solely as consumers, carers or consumer advocates, and about half as health professionals). About three-quarters of participants were Australian.

In September 2015, we held a workshop in Melbourne, Australia with 28 people including consumers and carers, health professionals, health service managers, policy makers and researchers. After a round of voting, and small group work, we came away with the top 12 health communication and participation issues or topics, for future systematic reviews.

We are now working through these suggested topics, and looking for evidence gaps to identify those that are most suitable for Cochrane reviews.

Next steps

When announced, we will invite review teams to undertake our high-priority reviews. We are currently exploring funding and partnership avenues that will enable us to trial novel review production and participation approaches as part of the development of these reviews.

Publications

We have two papers in preparation.

Website

latrobe.edu.au/chcp/projects/research-priority-setting

Funding

Grants were obtained from La Trobe University (Building Healthy Communities Research Focus Area) and Cochrane Australia.

Impact of our reviews

The year 2015 was a particularly productive one with the publication of three new reviews, two updated reviews, eight new titles registered and three further titles in development (for further information about our outputs, see Appendix 1: Cochrane Consumers and Communication Reviews and Protocols).

We are pleased to report that due to the combined efforts of the authors, Cochrane Consumers and Communication and Cochrane, many of our reviews have generated a high level of interest.

Our 2015 impact report is compiled from times cited, downloads and Altmetrics data from 2014.

[To find the full reviews, go to www.cochranelibrary.com.]

Most cited reviews in 2014

Review title	Times cited in 2014
Mobile phone messaging for preventing and managing disease	36
Mobile phone messaging reminders for attendance at healthcare appointments	34
Interventions for providers to promote a patient-centred approach in clinical consultations	24
Mobile phone messaging for preventive health care	16
Consumer-providers of care for adult clients of statutory mental health services	14
Family-centred care for hospitalised children aged 0-12 years	9
Mobile phone messaging for communicating results of medical investigations	5
Interventions to promote informed consent for patients undergoing surgical and other invasive healthcare procedures	5
Mass media interventions for reducing mental health-related stigma	5
Personalised risk communication for informed decision making about taking screening tests	5

Most accessed reviews in 2014

Review title	Full text downloads
Interventions for enhancing medication adherence	8238
Decision aids for people facing health treatment or screening decisions	6411
Interventions for providers to promote a patient-centred approach in clinical consultations	4475
Family-centred care for hospitalised children aged 0-12 years	4096
Interventions to improve safe and effective medicines use by consumers: an overview of systematic reviews	2751
Mobile phone messaging for preventing and managing disease	2360
Mass media interventions for reducing mental health-related stigma	2230
Cultural competence education for health professionals	2155
Interventions to enhance adherence to dietary advice for preventing and managing chronic diseases in adults	1772
Mobile phone messaging reminders for attendance at healthcare appointments	1769

Alternative metrics (Altmetrics)

Altmetrics tracks social media sites such as Twitter, Facebook, blogs and newspapers for mentions of published Cochrane reviews

Score	Review title	B	T	N	F
100	Decision aids for people facing health treatment or screening decisions**	4	105	0	8
99	Interventions for enhancing medication adherence	4	91	1	7
38	Interventions to improve safe and effective medicines use by consumers: an overview of systematic reviews	1	56	0	1
32	Interventions aimed at communities to inform and/or educate about early childhood vaccination	2	22	0	8
19	Interventions for improving patients' trust in doctors and groups of doctors	0	27	0	1
15	Cultural competence education for health professionals	1	11	0	1
7	Audio-visual presentation of information for informed consent for participation in clinical trials	0	7	0	1

B=blogger T=Twitter N=news outlets F=Facebook walls

**This review has an Altmetric score of 100 placing it in the top 5% of all research outputs scored by Altmetrics.

Supporting Cochrane Consumers and Communication authors

Internal editorial team

Cochrane Consumers and Communication authors are supported through the review process by our dynamic editorial team. The internal team based at la Trobe University comprises:

- Dr Sophie Hill, Coordinating Editor
- Ann Jones, Managing Editor
- Dr Rebecca Ryan, Research Fellow and Deputy Coordinating Editor
- Anneliese Synnot, Research Fellow and Editor
- Dianne Lowe, Research Officer
- John Kis-Rigo, Information Specialist.

How we support our authors

In 2015, we continued to provide a high level of support to authors to ensure the publication of accurate, high quality Cochrane reviews. This support included:

- Conducting editorial, statistical, methodological and data checks for 17 titles that had either been published, or are currently in development: four protocols, eight new reviews, five updated reviews
- Preparing or performing searches and/or screening for reviews
- Conducting detailed assessment of 18 title proposals for new reviews
- Providing author team support (via Skype, email and face-to-face meetings) to review author teams on analysis, translation, synthesis, risk of bias and GRADE assessments, summary of findings tables development and review methods

- Supporting the completion of a very large (130+ trials) draft review as co-author, including screening and data checking, applying GRADE, developing summary of findings tables and editing and commenting on the full draft review
- Commencing a stocktake of all registered review titles. The main aim of the stocktake was to identify stalled reviews with the objective of contacting authors to explore the best course of action for these reviews. This will be continued into 2016.
- Development of a new resource to complement the Cochrane Handbook, targeting areas that are often problematic for our authors. This resource contains sections on:
 - How to use GRADE to assess quality of the evidence
 - Preparing summary of findings tables; and
 - Presenting and reporting results.

These resources will be available for authors in 2016.

Specialist methodological support for authors

We developed and refined several resources to help authors complete their reviews smoothly:

Title registration proposals

Substantial revisions were made to the title registration process and form. As well as simplifying the form for authors, the revisions also helped to clarify the reasons for rejecting titles (albeit a very small number) that are not suitable for a Cochrane review.

Authors' resources

In 2015, we revised the processes, workflows and forms around developing search strategies for our reviews.

In response to the needs of our authors we revised and developed a number of further resources to assist with the production of high quality reviews and the implementation of methods. These resources included:

- Substantial revision of the Cochrane Consumers and Communication Data Extraction Template to better support reviews of complex interventions and to ensure they meet new guidelines and standards.

Review update guidance

Work commenced on researching and re-writing guidelines for authors updating reviews. Cochrane methods and reporting requirements continue to evolve, and the guidelines provide current advice for both existing author teams and new teams taking on updates. The new guidelines will be published in 2016.

Brainstorming session to improve our engagement

We convened an inaugural brainstorming session to improve our engagement with Cochrane Consumers and Communication members (including authors, referees and interested parties) and other stakeholders in Melbourne on 23 June 2015. We welcomed feedback from 19 people who attended and their ideas will form the basis of engagement strategies in 2016. Sophie Hill held information sessions in the Department of Health and Human Services Victoria and feedback on the Evidence Bulletins will be used to develop the more interactive format in 2016.

Innovative research projects focusing on health communication and participation

About our research projects

Our research projects aim to improve health communication and participation by promoting policy and decision-making that is informed by evidence as well as consumers' views and experiences. In our research, we partner with consumer organisations, health professionals, health care services, governments and universities in Australia and internationally to facilitate the transfer of research knowledge into policy and practice.

In 2015, we conducted research on a range of priority issues in health communication and participation including:

- Improving communication about childhood vaccination (see Communicate to Vaccinate)
- Exploring the prevalence, health burden and medicines-related communication experiences of people with multiple health conditions
- Investigating how carers contribute to patient safety in Australian acute hospitals
- Translating falls prevention knowledge for people with dementia and their carers
- Exploring consumer participation in quality and safety in Australian hospitals
- Understanding the views of regulators of private medical clinics in Kenya
- Investigating health care communication as a component of clinical practice guidelines

How we partner with consumers

We use a range of innovative methods to partner with consumers and other groups (such as health professionals, health service managers and policy makers) in our research projects. We work with consumers in the following ways:

- Involving consumer representatives from across the health care sector in identifying priority research topics
- Partnering with consumers as co-researchers or steering committee members on research projects
- Hosting public events and brainstorming sessions with consumers to generate ideas for improved engagement with the consumer sector
- Running workshops to develop the skills and knowledge of consumers in interpreting health research
- Seeking feedback from consumers about our resources.

FLAGSHIP PROJECT

Communicate to Vaccinate (COMMVAC 2)

Jessica Kaufman and **Sophie Hill**, with international partners from Norway, Switzerland, Chile, France, Mozambique, and Nigeria. **Rebecca Ryan** is a co-supervisor for Jessica's PhD but is not a member of the COMMVAC 2 project.

Communication is essential to childhood vaccination uptake and effective communication can help address barriers to vaccination such as misinformation, vaccine hesitancy and hard-to-reach populations. Producing globally-relevant evidence-based guidance about communication for childhood vaccination is the overall goal of the international COMMVAC 2 project, which includes several sub-studies carried out around the world.

The focus of the Centre-led sub-study in this project (which is also Jessica Kaufman's PhD project) is establishing the range of communication outcomes important to measure when determining the effects of childhood vaccination communication interventions. Currently, the outcomes measured in vaccination communication studies are diverse, ambiguous, or do not reflect the perspectives of all related stakeholders. This is a problem that stems from the research world, but has wide-ranging ramifications in terms of public health policy and clinical practice. Without appropriate outcome measurement, research may not be relevant to the people it is aiming to impact, and cannot substantially influence and improve intervention design or delivery.

Status

Through qualitative literature analysis, we have produced a taxonomy or framework of outcomes related to vaccination communication. We conducted six focus groups with people involved in vaccination communication, including parents, policy makers and researchers. Focus group participants discussed their experiences with communication about vaccination and their perspectives on what makes communication effective.

Next steps

We will conduct one more focus group with health providers then analyse the results to identify key themes and additional outcomes to add to the taxonomy. We will then carry out an international online survey to find out which outcomes are the most important to people involved in vaccination communication around the world.

Publications

Kaufman J, Ryan R, Bosch-Capblanch X, Cartier Y, Cliff J, Glenton C, Lewin S, Rada G, Ames H, Muloliwa AM, Oku A, Oyo-Ita A, Hill S. (2015). Outcomes mapping study for childhood vaccination communication: too few concepts were measured in too many ways. *Journal of Clinical Epidemiology*, doi: 10.1016/j.jclinepi.2015.10.003. <http://www.sciencedirect.com/science/article/pii/S0895435615004679>

Ames H, Njang DM, Glenton C, Fretheim A, Kaufman J, Hill S, Oku A, Cliff J, Cartier Y, Bosch-Capblanch X, Rada G, Muloliwa A, Oyo-Ita A, Lewin S. (2015). Mapping how information about childhood vaccination is communicated in two regions of Cameroon: What is done and where are the gaps? *BMC Public Health*, 15:1264. <http://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-015-2557-9>

Website

commvac.com

Funding

The COMMVAC 2 project is funded by the Research Council of Norway (project no. 220873).

GETTING KNOWLEDGE INTO POLICY AND PRACTICE

Evidence Bulletins

We continued our in-depth evaluation of Cochrane Consumers and Communication Evidence Bulletins. Evidence Bulletins, first published in 2007, provide accessible summaries of Cochrane reviews about communicating with and involving consumers and carers in health care. Each Bulletin summarises one recently published or updated review and presents a summary of the key results, the relevance to Australian health care, and related resources.

By the start of 2015, we had sought detailed feedback about the Evidence Bulletins from relevant stakeholders using focus groups. We held five focus groups with 22 staff and community advisory committee members across five Victorian health services.

Participants' feedback indicated that the Evidence Bulletins were well received, in particular the new section on the relevance of the Bulletin to the Victorian and Australian health care context. A number of suggestions were made to improve the format of Bulletins.

At the June 2015 brainstorming session we discussed ways of improving the reach and relevance of the Bulletins. This was followed by a feedback session in July with Department of Health and Human Services Victoria staff. Advice from participants at these sessions will result in Bulletins being better tailored to our stakeholders' needs.

Committees and reference groups

In 2015, Sophie Hill was involved in the following committees and reference groups:

Steering Committee. Patient Information Videos project, North East Metropolitan Integrated Cancer Service, Victoria.

Participation Advisory Committee, Department of Health and Human Services Victoria.

Program Committee, Australasian Cochrane Symposium, Melbourne, 25–26 November, 2015.

Seminars and workshops

Centre for Health Communication and Participation staff delivered or contributed to the development of three workshops in 2015:

Bosch-Capblanch, Oliver S, Hill S. (2015) *Challenges and solutions when carrying out mixed methods literature reviews in resource constrained settings.* 23rd Cochrane Colloquium, Vienna, Austria, 3–7 October 2015.

Elliott JH, Synnot A, Thomas J, Simmonds M, Pestridge C, Mavergames C, Hill S, Vandvik PO, Tendal B. (2015) *Living Cochrane Reviews: now, later or never?* 23rd Cochrane Colloquium, Vienna, Austria, 3–7 October 2015.

Hemsley B, Georgiou A, McCarthy S, Balandin S, Carter R, Hill S, Higgins I, van Vliet P. (2015) *PCEHR-FIT: Foundation, Implementation, and Translation: Including Adults with Communication Disabilities in PCEHR.* ISDM-ISEH Conference, Sydney, 19–22 July 2015.

Invited presentations

Staff were invited to deliver the following invited presentations and workshops:

Hill S. *Health literacy demands and opportunities in My Health Record: Lessons from Victorian experiences. E-health records and people with disabilities.* Health HISA NSW inaugural event, Newcastle NSW, 20 November 2015. Invited presentation.

Hill S. *Why embed health literacy principles into health systems and organisations? Lessons from Victorian experiences.* Health literate Organisations. Eastern Region, Melbourne, 19 November 2015. Invited presentation.

Hill S. *Connecting evidence and experience: What difference could we make?* Victorian Patient Experience Forum, Department of Health and Human Services Victoria, Melbourne, 13 November 2015. Invited presentation.

Synnot A, Tong A, Hill S. *Practical approaches to research priority setting.* Australasian Cochrane Symposium, Melbourne, 25–26 November 2015. Invited workshop.

Submissions

Sophie Hill, Head of the Centre for Health Communication and Participation, was invited to provide, or contribute to, the following submissions:

Hill S. Invited comment on National Safety and Quality Healthcare Standard 2. By the Australian Commission on Safety and Quality in Health Care, March 2015.

Response of Project Team PCEHR Research Collaboration (**Hemsley B, Georgiou A, Balandin S, Hill S, Allan M, McCarthy S, Kraal B, Wilson N, Higgins I, Rollo M, Adams N.**) Proposed changes to the legislative framework for personally controlled electronic health record system and healthcare identifiers, June 2015.

Reports

Staff from the Centre provided the following reports:

Allen C, Arbuthnott K, Bhaumik S, Bosch-Capblanch X, Bradley D, Clarke M, Gupta S, Head K, Hill S, Lang S, Lewin S, Nevitte A, Nunn J, Robertshaw L, Santos J. (2015) *Report of the World Health Organization flash literature review: Guidance on emergency risk communications*. Unpublished report to World Health Organization. June.

Lowe, D. (2015) *Summary of key findings – The multimorbidity medicines journey: mapping the problems and needs of people with arthritis+ for using and managing medicines*. Unpublished report to Arthritis and Osteoporosis Victoria. June.

Conferences

We were involved in a number of conferences in 2015. In particular, the 23rd Cochrane Colloquium in Vienna featured several presentations and posters from our staff and students.

Global Health and Vaccination Conference, Oslo (17–18 March 2015)

Ames H (presenter), **Muloliwa AM, Lewin S, Oku A, Oyo-Ita A, Glenton C, Fretheim Atle, Kaufman J, Hill S, Cartier Y, Cliff J, Rada G, Bosch-Capblanch X.** (2015). *Vaccination communication in Cameroon*. Is routine vaccination being neglected? Oral presentation.

Ames H (presenter), **Muloliwa AM, Lewin S, Oku A, Oyo-Ita A, Glenton C, Fretheim Atle, Kaufman J, Hill S, Cartier Y, Cliff J, Rada G, Bosch-Capblanch X.** (2015). Communicate to Vaccinate (COMMVAC) 2: Mapping communication interventions in Cameroon. Oral presentation.

Kaufman J, Muloliwa AM, Lewin S, Oku A, Oyo-Ita A, Glenton C, Fretheim Atle, Ames H, Hill S, Cartier Y, Cliff J, Rada G, Bosch-Capblanch X. (2015). *How do we know what works?* Developing a map of outcomes to improve the evaluation of communication strategies for childhood vaccination. Poster.

Lewin S (presenter), **Oku A, Oyo-Ita A, Glenton C, Fretheim Atle, Ames H, Kaufman J, Hill S, Cartier Y, Cliff J, Muloliwa AM, Rada G, Bosch-Capblanch X.** (2015). *Understanding vaccine hesitancy and the role of communication strategies in addressing this*. Oral presentation.

Muloliwa AM, Lewin S, Oku A, Oyo-Ita A, Glenton C, Fretheim Atle, Ames H, Kaufman J, Hill S, Cartier Y, Cliff J, Rada G, Bosch-Capblanch X. (2015). *Synthesis of health systems barriers and facilitators to scaling up vaccination communication interventions in low-income settings: Cameroon, Mozambique and Nigeria*. Poster.

Muloliwa AM (presenter), **Lewin S, Oku A, Oyo-Ita A, Glenton C, Fretheim Atle, Ames H, Kaufman J, Hill S, Cartier Y, Cliff J, Rada G, Bosch-Capblanch X.** (2015). *Vaccination communication in Mozambique using a communication taxonomy to understand the range of strategies used*. Oral presentation.

Oku A (presenter), **Ames H, Muloliwa AM, Lewin S, Oyo-Ita A, Glenton C, Fretheim Atle, Kaufman J, Hill S, Cartier Y, Cliff J, Rada G, Bosch-Capblanch X.** (2015). *Vaccination communication in Nigeria*. Policymakers' perspectives on scaling up strategies for parents and communities. Oral presentation.

Oku A, Ames H, Muloliwa AM, Lewin S, Oyo-Ita A, Glenton C, Fretheim Atle, Kaufman J, Hill S, Cartier Y, Cliff J, Rada G, Bosch-Capblanch X. (2015). *Communication strategies to promote the uptake of childhood vaccination in Nigeria: A systematic map*. Poster.

7th International Shared Decision Making Conference & 4th International Society for Evidence-Based Health Care Conference, Sydney (19–22 July 2015)

Hemsley B, Georgiou A, McCarthy S, Balandin S, Carter R, Hill S, Higgins I, van Vliet P. (2015) PCEHR-FIT: Foundation, Implementation, and Translation: Including Adults with Communication Disabilities in PCEHR.

Kaufman J, Ryan R, Glenton C, Cartier Y, Bosch-Capblanch X, Cliff J, Lewin S, Ames H, Muloliwa AM, Oku A, Oyo-Ita A, Rada G, Hill S. (2015) Outcomes in trials of vaccination communication interventions: measuring too few concepts in too many ways. Poster.

Communication, Medicine and Ethics Conference, Hong Kong (25–27 June 2015)

Merner B (presenter), Hill S, Taylor M. (2015) Uncovering the contribution of carers to patient safety in the Australian acute hospital setting – Preliminary findings'. Oral presentation.

Health Informatics Conference, Brisbane (3–5 August 2015)

Hemsley B, Georgiou A, Balandin S, Carter R, Hill S, Higgins I, van Vliet P, McCarthy S. (2015). The Personally Controlled Electronic Health Record (PCEHR) for adults with severe communication impairments: Findings of pilot research. Paper. Shortlisted for the Branko Cesnik Scientific Award.

23rd Cochrane Colloquium, Vienna (3–7 October 2015)

Colquhoun H (presenter), Helis E, Belanger D, Ens B, Hill S, Lowe D, Mayhew A, Taylor M, Grimshaw J. (2015). Influencing policy for promoting appropriate prescribing and medicines use: training key decision makers to use a database of systematic reviews. Rapid oral presentation.

Kaufman J, Ryan R, Glenton C, Bosch-Capblanch X, Cartier Y, Cliff J, Lewin S, Rada G, Ames H, Muloliwa AM, Oku A, Oyo-Ita A, Hill S. (2015) A map of outcomes in trials of communication interventions for childhood vaccination: measuring too few concepts in too many ways. Oral presentation.

Muloliwa AM, Cartier Y, Ames H, Oku A, Bosch-Capblanch X, Cliff J, Glenton C, Hill S, Kaufman J, Oyo-Ita A, Rada G, Lewin S. (2015). Synthesis of health system barriers and facilitators to scaling up vaccination communication interventions in Cameroon, Mozambique and Nigeria. Poster.

Nunn J, Synnot A, McDonald S, Allen K, Hill S. (2015) Building partnerships with the public by learning about Cochrane evidence. Poster.

Oku A, Oyo-Ita A, Lewin S, Glenton C, Fretheim Atle, Ames H, Kaufman J, Hill S, Cartier Y, Cliff J, Muloliwa A, Rada G, Bosch-Capblanch X. (2015). Can an evidence-informed taxonomy be used to map interventions in 'real world' settings: application of the Communicate to Vaccinate taxonomy in Nigeria. Oral presentation.

O'Sullivan M, Synnot A, Hill S. (2015). Developing and applying priority-setting criteria for complex interventions across diseases. Poster.

Synnot A (presenter), O'Sullivan M, Hill S. (2015). Setting priorities for Cochrane reviews in health communication and participation. Oral presentation.

4th Annual NHMRC Symposium on Research Translation jointly with CIPHER, Sydney, (27–28 October 2015)

Synnot A, Hill S, O'Sullivan M. (2015). Involving policymakers and the public to set Cochrane review priorities. Poster.

Publications

Staff and students of the Centre for Health Communication and Participation disseminated their research in a range of journals in 2015:

Kaufman J, Ryan R, Bosch-Capblanch X, Cartier Y, Cliff J, Glenton C, Lewin S, Rada G, Ames H, Muloliwa AM, Oku A, Oyo-Ita A, Hill S. (2015). Outcomes mapping study for childhood vaccination communication: too few concepts were measured in too many ways. *Journal of Clinical Epidemiology*, DOI: 10.1016/j.jclinepi.2015.10.003.

Ames H, Njang DM, Glenton C, Fretheim A, Kaufman J, Hill S, Oku A, Cliff J, Cartier Y, Bosch-Capblanch X, Rada G, Muloliwa A, Oyo-Ita A, Lewin S. (2015) Mapping how information about childhood vaccination is communicated in two regions of Cameroon: What is done and where are the gaps? *BMC Public Health* 15:1264.

Hemsley B, Balandin S, Sheppard JJ, Georgiou A, Hill S. (2015) A call for dysphagia-related safety incident research in people with developmental disability. *Journal of Intellectual and Developmental Disability*, DOI: 10.3109/13668250.2014.994172.

Hemsley B, Georgiou A, Balandin S, Carter R, Hill S, Higgins I, Van Vliet P, McCarthy S. (2015) The Personally Controlled Electronic Health Record (PCEHR) for adults with severe communication impairments: Findings of pilot research studies. *Health Technology and Informatics* 214:100-106.

Lowe DB, Taylor MJ, Hill SJ. (2015) Communication vulnerabilities in working-age Australians with musculoskeletal conditions, a cross-sectional analysis. *Journal of Rheumatology*, 42(8):1484-1493, 1 Aug 2015.

Meyer C, Hill K, Hill S, Dow B. (2015) Translating falls prevention knowledge for community-dwelling people living with dementia: Design protocol for a mixed-method intervention. *Journal of Alzheimer's Disease & Parkinsonism* 5:185, doi: 10.4172/2161-0460.1000185.

Tong A, Crowe S, Chando S, Cass A, Chadban SJ, Chapman JR, Gallagher M, Gillis J, Hawley C, Hill S, Howard K, Johnson D, Kerr PG, Mathew T, McKenzie A, Parker D, Perkovic V, Polkinghorne K, Pollock C, Strippoli GFM, Tugwell P, Walker RG, Webster A, Wilson A, Wong G, Craig JC for the CEPOR COLLABORATION, Research priorities in chronic kidney disease: a partnership among patients, caregivers, clinicians, researchers and policy makers. *American Journal of Kidney Diseases*. 66(2):212-222.

Peer reviewing

Centre staff were engaged as peer reviewers (or were invited to be peer reviewers) for the following journals:

Health Expectations (Sophie Hill)

Vaccine (Jessica Kaufman)

Expert Review of Vaccines (Jessica Kaufman)

Cochrane Database of Systematic Reviews (Ann Jones, Jessica Kaufman)

Weather and Climate Extremes (Dianne Lowe)

PLOS ONE (Dianne Lowe)

Membership of editorial boards

Cochrane Coordinating Editors' Board (Sophie Hill)

Research Involvement and Engagement (Sophie Hill)

Health Expectations (Sophie Hill)

Podcasts

Cochrane aims to produce as much evidence as possible in multimedia formats. In 2015, two Cochrane Consumers and Communication reviews were produced as podcasts and uploaded to the Cochrane website (<http://www.cochrane.org/multimedia/podcasts/>). The podcasts were:

- Coulter A. Effects of personalised care planning for people with long-term conditions
- Saeterdal I. Interventions aimed at communities for informing and/or educating about early childhood vaccination

Online video resource

To help consumers and carers understand the purpose and process of Cochrane reviews, we developed an online video resource for our website entitled 'What are systematic reviews?' The resource is available at: <http://cccr.org/cochrane.org/about> and will also be used for training purposes.

Website

In 2015, we reviewed and updated the Cochrane Consumers and Communication website and adopted Cochrane's new template.

Social media

Our social media presence continued to grow in 2015. By the end of the year, our Cochrane Consumers and Communication Twitter account (@CochraneCCRG) had 685 followers (a significant increase in followers from the previous year). We use the Twitter feed to promote our reviews, evidence bulletins, authors' resources, and other items of interest.

Newsletters

The Cochrane Consumers and Communication quarterly online newsletter was emailed to nearly 800 mailing list subscribers in 2015.

EDUCATION AND TRAINING

Teaching

In 2015, we continued our strong commitment to contribute to La Trobe University's postgraduate and undergraduate teaching programs.

The following staff delivered the following highly-rated postgraduate subjects:

- Evidence-based Public Health (PHE5EBP), Core Masters of Public Health subject, Subject coordinator (Sophie Hill) and lecturers (Sophie Hill, Annie Synnot, Jessica Kaufman) and assessment (Dianne Lowe), 70+ students
- Service Users' Perspectives (PHE5SUP), Subject Coordinator and lecturer in distance education (Sophie Hill), responsible for 1 module, in collaboration with Dr Paul O'Halloran (3 modules), 34 students.

In addition, Bronwen Merner, Graduate Assistant Teaching Fellow, was a facilitator for the following subjects in the Core First Year of the Health Sciences undergraduate degree program:

- Introduction to Professional Practice (HLT1IPP), 30 students
- Social Determinants of Health (PHE1SDH), 30 students.
- The following staff members also delivered guest lectures:

Sophie Hill was a guest lecturer in the China Health Program in the Department of Public Health at La Trobe University.

Jessica Kaufman and Dianne Lowe were guest lecturers in the undergraduate subject Applied Health Research (PHE2AHR) at La Trobe University.

Dianne Lowe gave a guest lecture in the postgraduate subject Environmental Influences on Health (PHE5ENV) at La Trobe University.

Postgraduate study

Our Higher Degree by Research program had another very successful year. Congratulations to Claudia Meyer, who was awarded her Doctor of Philosophy degree under the principal supervision of Sophie Hill. In addition, we welcomed Molly O'Sullivan, who commenced her minor thesis as part of the Master of Public Health program, also under Sophie Hill's supervision. The Centre's Higher Degree by Research students continued their strong record in disseminating their research, including in peer-reviewed publications, conference presentations and posters.

The Higher Degree by Research projects covered a variety of topics including:

“What should we be measuring?” Identifying and selecting outcomes to measure the effects of communication for childhood vaccination

Jessica Kaufman (PhD candidate) supervised by Dr Sophie Hill (principal supervisor) and Dr Rebecca Ryan (co-supervisor).

A mixed method exploration of the prevalence, health burden and medicines-related communication experiences of multimorbidity among the working-age population with musculoskeletal conditions

Dianne Lowe (PhD candidate) supervised by Dr Sophie Hill (principal supervisor) and Dr Michael Taylor (co-supervisor, ACU).

Carers' contributions to the patient safety of their relatives in acute hospital settings

Bronwen Merner (PhD candidate) supervised by Dr Sophie Hill (principal supervisor) and Dr Michael Taylor (co-supervisor, ACU)

Translating falls prevention knowledge for community-dwelling older people living with dementia and their carers—what works?

Claudia Meyer (PhD candidate) supervised by Dr Sophie Hill (principal supervisor) and co-supervisors Professor Keith Hill, Curtin University and Associate Professor Briony Dow, National Ageing Research Institute.

Regulation of private medical clinics in Kenya: Insights from regulators and directions for improved regulatory outcomes

Peterson Junius Muriithi Nyaga, Doctor of Public Health, supervised by Dr Sophie Hill (principal supervisor) and Associate Professor Simon Barraclough (co-supervisor), La Trobe University

Consumer participation in quality and safety in Australian hospitals

Ania Sieracka, Master of Public Health candidate, supervised by Dr Sophie Hill

Investigating health care communication as a component of the clinical practice guidelines relevant to young Australians

Molly O'Sullivan, Master of Public Health candidate, supervised by Dr Sophie Hill

Training

Jack Nunn, Research Officer at the Centre, designed and delivered the following highly-rated workshops in 2015:

Centre for Health Communication and Participation in collaboration with Cochrane Australia. Improving health care with evidence: Involving the public in research and decision making. Trainer: Jack Nunn. Melbourne, 23 June 2015 (30 people)

Centre for Health Communication and Participation. Medical writing training, Health Technology Assessment section, Pharmaceutical Benefits Advisory Board, Australian Department of Health. Trainer: Jack Nunn. Canberra, 25-26 June, 2015 (28 people).

Service to other Universities

Sophie Hill was an external assessor for the proposed Master of Public Health program at the Australian Catholic University.

Research Progress Panels

Sophie Hill was the Chair of a Research Progress Panel for a PhD candidate, Nerida Hyett, at La Trobe University. Nerida is researching international case studies of community participation in health.

CURRENT GRANTS, CONSULTANCIES AND AWARDS

The Centre for Health Communication and Participation receives a funding and service agreement from the Department of Health and Human Services Victoria for 2013-2016. The Cochrane Consumers and Communication Group received funding from the National Health and Medical Research Council program for support for Cochrane for 2013-2016, extended to June 2017.

Peer reviewed grants supporting our projects

2015-2016: Hill S, Lannin N, Synnot A. Setting priorities for Cochrane reviews in health communication and participation. Building Healthy Communities—Research Focus Area Grant, La Trobe University.

2015: Dowsett G, Lucke J, Power J, Wallace J, Ellard J, Richmond J, Lewin S, Hill S, Tucker J, Slavin S, Cogle A. An HIV Cure: ethical and social consequences of cure-focused research, Building Healthy Communities Research Focus Area Grant, La Trobe University.

2013-2015: Hemsley B, Georgiou A, Hill S. Keeping people with communication disability safe in hospital. National Health and Medical Research Council Project grant, No 1042635.

2014-2017: Hemsley B, Balandin S, Georgiou A, Hill S. Personally Controlled Electronic Health Records for young adults with communication disabilities: charting the course for successful child to adult health service transition. Application 1058094, NHMRC Project grant.

2013-2016: Lewin S, Hill S, Bensaude De Castro Freire S, Bosch-Capblanch X, Carlsen B, Cliff J, Etokidem, Lin V, Muloliwa A, Oyo-Ita A, Rada G. 'Communicate to vaccinate' (COMMVAC) 2: Implementing communication interventions to improve childhood vaccination uptake in low income countries. Global Health and Vaccination Research (GLOBVAC). Research Council of Norway, Project Number: 220873.

Other grants supporting our work

2015: Centre for Health Communication and Participation. Development of consumer training learning events. Cochrane Australia.

2015: Centre for Health Communication and Participation. Cochrane Consumers and Communication Group Priority Setting Project. Cochrane Australia.

2015: Clarke M, Hill S. Flash Survey of international and national guidance in the field of emergency risk communications. WHO.

Consultancies

In 2015, the Centre for Health Communication and Participation undertook two consultancies:

Training in Evidence Communication for Pharmaceutical Benefits Advisory Committee (Jack Nunn).

Workshop facilitation. Knowledge broker training day. Australian Catholic University (Sophie Hill).

Awards

Congratulations to Dianne Lowe and her colleagues who were awarded second prize in the review section of the 3rd International Journal of Environmental Research and Public Health 2015 Best Paper Award for their 2011 article reviewing early warning systems and adaptation advice aimed to reduce human health consequences of heatwaves. (Lowe D, Ebi K, Forsberg B. (2011) Heatwave early warning systems and adaptation advice to reduce human health consequences of heatwaves. International Journal of Environmental Research and Public Health 8(12), 4623-4648; doi:10.3390/ijerph8124623).

APPENDIX 1:

Cochrane Consumers and Communication Reviews and Protocols

Over the course of another busy year, Cochrane Consumers and Communication facilitated the publication of three new reviews, two updated reviews, eight registered titles and three titles in development.

To access the full reviews, go to www.cochranelibrary.com

New and updated reviews published in 2015

New reviews

Authors / Title	Published
Coulter A, Entwistle VA, Eccles A, Ryan S, Shepperd S, Perera R. Personalised care planning for adults with chronic or long-term health conditions	Issue 3, 2015
Levack WMM, Weatherall M, Hay-Smith EJC, Dean SG, McPherson K, Siegert RJ. Goal setting and strategies to enhance goal pursuit for adults with acquired disability participating in rehabilitation	Issue 7, 2015
Horey D Street AF O'Connor M, Peters L, Lee SF. Training and supportive programs for palliative care volunteers in community settings	Issue 7, 2015

Updated reviews

Authors / Title	Published
Atherton H, Sawmynaden P, Sheikh A, Majeed A, Car J. Email for clinical communication between healthcare professionals	Issue 2, 2015
Henderson A, Henderson S. Provision of a surgeon's performance data for people considering elective surgery	Issue 2, 2015
Horey D Street AF O'Connor M, Peters L, Lee SF. Training and supportive programs for palliative care volunteers in community settings	Issue 7, 2015

Titles registered in 2015

Whilst not all of this work will proceed to publication as a Cochrane review, we have decided for the first time to report our registered titles and titles in development as an indicator of the work which is in the editorial pathway. The work associated with helping teams shape their concerns into Cochrane titles is a hidden but valuable part of our work.

Alves TL, Mintzes B, Mantel-Teeuwisse AK, Paschke A, Leufkens BGM.

Unbranded advertising of prescription medicines and attitudes, knowledge, health service use, costs and health outcomes.

Corry M, Smith V, Neenan K, Brabyn S.

Telephone interventions, delivered by healthcare professionals, for informal caregivers of adults with diagnosed illnesses.

Cusack L, Del Mar CB, Chalmers I,

Hoffmann TC. Educational interventions to improve people's understanding of key concepts in assessing the effects of healthcare interventions.

Evans DJW, Lewis SR, Butler A,

Alderson P, Smith AF. Information and education interventions for improving outcomes in adult ICU patients and their carers.

Fairbairn KF, Horey D, Gyte GML,

Bishop Velarde AD. Interventions for improving trust in health practitioners (non-doctor).

Gilligan C, Harvey P, Outram S, Snow P, Lonsdale C, James EL, Ward BM, Powell M, Cushing AM, Silverman J, Lynagh MC, Regan T. Interventions for improving medical students' communication skills in patient-doctor consultations/clinical consultations/clinical encounters.

Lajoinie A, Kassai Koupai B, Henin E,

Nguyen KA, Gueyffier F, Maucort-Boulch D, Janiaud P. Comparing the effect of solid and liquid dosage forms of oral medications on medication adherence in children.

McCalman J, Campbell SK, Strobel NA,

Ham R, Bainbridge RG, Wenitong M, Ruben A, Chamberlain C, Edmond KM, Marriott R, Tsey K, Keith K, Shields L. Family-centred models of care by primary healthcare services for early childhood well-being.

Titles in development in 2015

Methods of providing research results for people participating in research

Mothers' barriers and facilitators towards breastfeeding: a qualitative evidence synthesis

Safety netting for adults in general practice

