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UNIVERSITY



# CENTRE FOR HEALTH COMMUNICATION AND PARTICIPATION

## Year in Review 2016

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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**Cochrane**  
Consumers and  
Communication

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# ABOUT THE 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, their family members and carers, organisations representing consumers' views, and the public.

We partner with consumers, health professionals and policy makers 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. Our researchers bring their diverse backgrounds and strong track records 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, and translate this evidence to health professional practice. 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.

The Centre collaborates with a range of 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. Recent areas of investigation have included:

- Improving communication about childhood vaccination in Australia and world-wide;
- Understanding the role of carers in upholding patient safety in hospital settings;
- Understanding the specific communication and participation needs for people with multiple health conditions;
- Examining current best-practice in the production of health information and applying those principles to develop information standards for Victoria; and
- Analysing the consumer-facing components of a personally controlled health record platform to determine areas for improvement.

Our Centre is also home to Cochrane Consumers and Communication, which is part of the international organisation, Cochrane. We provide the editorial base for high-quality systematic reviews of the evidence around interventions or approaches which affect the way consumers interact with each other, with health care professionals, health services, or health researchers.

This Year in Review 2016 presents our activities and outputs for 2016 and outlines our strategic directions for 2017.

# HEAD OF CENTRE'S REPORT

As I look back on 2016, I am amazed by the amount, quality and depth of work our Centre has achieved over the past twelve months. We continue to work towards our mission of improving the health of consumers by supporting their participation in health care through effective communication with health providers. We do this work in partnership with health services, researchers and policy makers in Australia and internationally through a wide variety of research projects. In 2016, we were thrilled to receive Funding and Service Agreement 2016-2019 from the Department of Health and Human Services Victoria, supporting our production of high quality evidence and information to support people's involvement in their health and health care.

2016 has seen us focus on how we communicate our work to a wider audience. In partnership with the Victorian Department of Health and Human Services we produced four Evidence Bulletins – our summaries of Cochrane Reviews, condensed and presented for clinicians and policy-makers. In response to an evaluation of the Bulletins, this year we included a section which clearly outlines how review findings apply to the Victorian healthcare context. The intent of including this section was to better facilitate the translation of research knowledge to practice, and so far feedback on this new inclusion has been very positive.

In communicating to a wider audience we have also thought about how the information coming out of our Centre looks and how we can present academic research in a non-academic way. To that end, we have worked with professional graphic designers to produce a number of outputs to share and promote our work. In creating the final report for the flagship Priority Setting Project, researchers, designers and stakeholders worked together to create a project summary that is inviting, interesting, and user-friendly. Additionally, in 2016 we created our first professionally produced Year in Review and Centre brochures,

which enable us to quickly and easily share information about our Centre with stakeholders and potential partners in an easily-accessible and attractive format. We aim to continue this focus on reaching new audiences in 2017, and are looking at innovative ways we can communicate online and share the work we do more broadly.

Another focus of 2016 has been how we can better support our Cochrane authors. To this end, we have created a range of resources for authors working on Cochrane Consumer and Communication reviews, and enhance the personal support and advice provided by our editorial team. These included advice tailored to reviews of complex interventions, covering areas that have typically been challenging in Consumers and Communication reviews. The resources were able to be tested in a complex review undertaken this year on the use of automated telephone communication systems in chronic and long term conditions.

This year we have also continued a large project on the development of Health Information Standards for the Victoria. This work commenced in 2014 with the Victorian Consultation on Health Literacy which identified that improving the quality of available health information was a high priority. 2016 has seen the drafting of development guidelines and standards on health information, with the aim of piloting the draft documents with a number of health services over the next two years.

In addition to these major areas of focus for the Centre, our staff and students continue to publish high-quality research across a number of important areas. Major publications have arisen from our PhD students, including from Dianne Lowe who published a paper on the health burden added by multimorbidity in musculoskeletal populations, and from Jessica Kaufman, who published a taxonomy of outcomes that could be measured to evaluate the effects of communication strategies related to childhood vaccination. Both of these publications appeared in the high-

impact and well-respected Journal of Clinical Epidemiology.

In 2016 we welcomed two new staff members – Tamsin Waterhouse (Research Fellow) and Louisa Walsh (Research Officer). We farewelled Ann Jones who has worked on our Cochrane editorial team since 2015 and we welcomed Bronwen Merner on to the editorial team in Ann's stead.

Two existing staff members commenced their PhDs with the Centre – Anneliese Synnot who is exploring stakeholder engagement in systematic reviews and was awarded a prestigious NHMRC Postgraduate Scholarship to allow her to undertake her PhD full time; and Jack Nunn who is looking at genomics research and how the public can be involved in shaping the future of this research, and was awarded a La Trobe Postgraduate Scholarship to facilitate this work.

We congratulate Dr Claudia Meyer on the completion of her PhD project looking into falls prevention knowledge translation for people with dementia and their carers. Claudia is now an Honorary Associate of the Centre. We also congratulate Ania Sieracka and Charissa Zaga for completing their minor theses as part of the Master of Public Health program.

Finally, I would like to thank everyone involved in the work of the Centre in 2016 – our funders, staff, Cochrane authors, editors and referees, advisory groups, students, consumers, consumer organisations, health services, government and La Trobe University for helping us achieve our mission. I look forward to working with all of you in 2017 and beyond.

# OUR PEOPLE



**Dr Sophie Hill**

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



**Bronwen Merner**

Research Fellow  
Managing Editor, Cochrane Consumers and Communication (May 2016 - current)



**Tamsin Waterhouse**

Research Fellow



**Dr Rebecca Ryan**

Research Fellow  
Deputy Coordinating Editor, Cochrane Consumers and Communication



**Ann Jones**

Managing Editor, Cochrane Consumers and Communication (July 2015 – May 2016)  
Assistant Managing Editor, Cochrane Consumers and Communication (June 2016 – Dec 2016)



**Anneliese Synnot**

Research Fellow  
Editor, Cochrane Consumers and Communication



**John Kis-Rigo**

Information Specialist, Cochrane Consumers and Communication



**Jessica Kaufman**  
Research Officer



**Jack Nunn**  
Research Officer



**Dianne Lowe**  
Research Officer



**Louisa Walsh**  
Research Officer



**KowLin Leong**  
Senior Administrator

## Higher degree by research students

Rachael Hyder  
Jessica Kaufman  
Dianne Lowe  
Bronwen Merner  
Jack Nunn  
Peterson Junius Muriithi Nyaga  
Molly O'Sullivan  
Ania Sieracka  
Anneliese Synnot  
Charissa Zaga

## Honorary associates

Dr Artur Manuel Muloliwa  
Ministry of Health  
Mozambique  
Dr Michael Summers  
Dr Claudia Meyer

# STRATEGIC DIRECTIONS BEYOND 2016

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 project, 'Setting priorities for Cochrane reviews on consumer and communication topics'
- Initiating co-production of Cochrane reviews with consumers and carers
- Taking advantage of methodological and technological developments to aid our Cochrane authors
- Consulting with the Victorian health sector about health information standards
- Disseminating the findings of research into carer involvement in patient safety

## **Undertaking innovative research on priority communication and participation issues**

- Understanding public participation in genomics and connecting people online
- Supervising new student research into standards for diagnostic information
- Researching the experience and impact of consumer involvement in research priority setting

## **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
- 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
- Trialling innovative ways to increase the reach of our research and projects



# OUR RESEARCH

The Centre for Health Communication and Participation is involved in a wide range of research projects. We work with Victorian, Australian and International teams and include a wide range of stakeholders in our innovative communication and participation research.

Through our research we aim to improve health communication and participation by promoting policy development, decision making and clinical practice that is informed by consumer views and experiences and supported by evidence. In our work we partner with consumers, consumer organisations, health professionals, health care services, governments and universities to facilitate the transfer of research knowledge into policy and practice.

## 2016 research highlights

### Author Resources for Cochrane Consumers and Communication Group

This year we completed a series of resources for authors with Cochrane Consumers and Communication (CCC). These included advice tailored to reviews of complex interventions, covering areas that have typically been challenging in CCC reviews. The resources included advice on 'summary of findings' tables, using GRADE to assess the quality of evidence, and how to describe results consistently in reviews. These are designed to support authors with the Group, and to assist them to meet mandatory requirements in reviews on communication and participation.

Rebecca Ryan was involved as a co-author on a large review on automated telephone communication systems for disease prevention and management of long-term conditions. This review included over 130 trials, covering a huge range of disease areas and comparisons and gave Rebecca and the review team the opportunity to trial many of the new CCC author

resources while performing a complex and challenging review. The review was published in December 2016 and was co-produced as a podcast on the Cochrane Library.

### Carers' Contributions to Patient Safety of their Relatives in Australian Hospitals

Bronwen Merner's PhD research uses constructivist grounded theory methodology to explore and explain how carers contribute to reducing medical mistakes in hospital. The research has involved conducting intensive, individual interviews with 32 carers of adults recently admitted to hospital. Themes emerging from the research include how carers contribute in a unique and substantial way to patient safety in hospital, through monitoring the patient, participating in treatment decision-making, keeping the patient's treatment on track and facilitating the patient's own involvement in safety. These findings are likely to have implications for current patient safety policy and practice. Bronwen will complete her PhD in 2017.

### Communicate to Vaccinate

As part of the data collection and analysis for her PhD thesis, Jessica Kaufman undertook a series of focus groups and an international online survey to explore people's experiences with communication about childhood vaccination, and to understand their views about what makes it 'effective' or 'ineffective'. Participants included parents, healthcare providers, researchers and policymakers. This work aims to improve the way that communication for childhood vaccination is evaluated by identifying the most relevant and informative outcomes for researchers and evaluators to measure. Jessica will complete her PhD in 2017.

### Consumer Involvement in Musculoskeletal Models of Care

The Centre was invited to contribute a chapter to a special edition of Best Practice & Research Clinical Rheumatology dedicated to musculoskeletal models of care. Three of our researchers – Louisa Walsh, Sophie Hill and Dianne Lowe - were involved in leading and co-authoring the chapter on consumer

involvement in musculoskeletal models of care along with a team of Australian and International researchers. This journal chapter used a narrative review approach and illustrative case studies to outline best practice and provide advice about involving consumers in the development of musculoskeletal models of care.

### **Knowledge Translation project**

2016 saw the publication of two papers following the completion of a successful knowledge translation (KT) project collaboration between Centre researchers (Sophie Hill and Dianne Lowe) and the Cochrane Effective Practice and Organisation of Care review group in Canada.

This KT project included the development and evaluation of a training program on the use of the Rx for Change database and was made possible through a research grant provided by the Canadian Institutes of Health Research. The Rx for Change database, funded by the Canadian Agency for Drugs and Technologies in Health and housed on their website, contains searchable research evidence (i.e. summaries of critically appraised systematic reviews) about intervention strategies used to alter health behaviours including medicines prescribing and use. This innovative project included partnerships with Asthma Australia and NPS MedicineWise who participated in the training program in Australia.

### **Stakeholder Priorities for Research in Health Communication and Participation ('Priority Setting Project')**

Throughout this project, nearly 200 people had a say in the selection of the first five of our priority Cochrane Reviews. The priority topics and teams were announced in September 2016 to an enthusiastic reception from our stakeholders. The five reviews cover: improving communication about end of life care; patient, family and carer involvement in patient safety; improving

future doctors' communication skills; consumer engagement strategies; and promoting patient-centred care. These reviews are currently underway and are being led by author teams comprised of researchers from Australia and around the world. We are thrilled that all reviews are proceeding with the involvement of consumers and other stakeholders, such as health professionals, policy makers and students.

2016 also saw the commencement of Anneliese Synnot's PhD, in which she is building on the priority setting project, and evaluating the stakeholder engagement approach used by one of the priority review teams, led by Louise Wiles and Debra Kay at the University of South Australia / South Australian Health and Medical Research team.

**“Mighty inspiring work... thanks Annie, Sophie and team.”**

**John Lawrence, Change Consultant, J Lawrence and Associates**

### **The Health Literacy Demands of My Health Record**

Louisa Walsh and Sophie Hill are involved in a project examining the health literacy demands of the My Health Record, and how the record could facilitate health care for people with communication disability. This work forms part of a larger, NHMRC-funded project being run out of the University of Newcastle, and led by Associate Professor Bronwyn Hemsley. As part of this research, Louisa and Sophie have performed a content and quality analysis of the consumer-facing online information available for My Health Record, and a heuristic evaluation of the usability of My Health Record. Publications arising from this research will be available in 2017.

### **Victorian Health Information Standards**

The development of an information standard for Victoria commenced in 2016, with a review of tools and guidance for writing high quality and accessible health information. Two draft documents – a guide to producing and sourcing quality health information, and a consultation paper on the development of health information standards, have been developed in consultation with the Department of Health and Human Services Victoria, and Safer Care Victoria, the peak state authority for leading quality and safety improvement in health care. This project has great potential to improve quality and safety within Victorian health services through improved communication between consumers and service providers. The Victorian Health Information Standards project will continue in 2017/2018 and will include piloting the guide and standards within a number of health services.

# 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 Imperial College and Nanyang Technological University, Singapore

**Prof Adrian Edwards**, Cardiff University, UK

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

**Dr Bronwyn Hemsley**, University of Newcastle, Australia

**Dr Sophie Hill**, La Trobe University, 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)

## Impact of our reviews

In 2016, we facilitated the publication of two new Cochrane Reviews and four Cochrane protocols. We also registered five new titles. For further details, see Appendix 1: Cochrane Consumers and Communication Reviews, Protocols and Titles.

The Thompsons Reuter calculated Impact Factor in 2015 of the Cochrane Database of Systematic Reviews (CDSR) was 6.103 – the CDSR is the section of the Cochrane Library where all Cochrane reviews are published.

The most highly cited review in the CDSR is the review led by Prof Dawn Stacey, Decision aids for people facing health treatment or screening decisions, which was cited 146 times. Congratulations to our wonderful colleague, Dawn Stacey!

Our 2015 impact report is compiled from the times cited, downloads and Altmetrics data from 2016.

## Most cited reviews in 2015

REVIEW TITLE	TIMES CITED IN 2015
Decision aids for people facing health treatment or screening decisions. Dawn Stacey, et al	146
Interventions for enhancing medication adherence. Robby Nieuwlaat, et al	28
Personalised risk communication for informed decision making about taking screening tests. Adrian GK Edwards, et al	20
Mobile phone messaging reminders for attendance at healthcare appointments. Ipek Gurol-Urganci, et al	16
Interventions to enhance adherence to dietary advice for preventing and managing chronic diseases in adults. Sophie Desroches, et al	13
Interventions to promote informed consent for patients undergoing surgical and other invasive healthcare procedures. Paul Kinnersley, et al	12
Face to face interventions for informing or educating parents about early childhood vaccination. Jessica Kaufman, et al	11
Mass media interventions for reducing mental health-related stigma. Sarah Clement, et al	10
Interventions to improve safe and effective medicines use by consumers: an overview of systematic reviews. Rebecca Ryan, et al	9
Cultural competence education for health professionals. Lidia Horvat, et al	9

## Most accessed reviews in 2015\*

REVIEW TITLE/LEAD AUTHOR	FULL TEXT DOWNLOADS
Interventions for enhancing medication adherence. Robby Nieuwlaat, et al	6,069
Decision aids for people facing health treatment or screening decisions. Dawn Stacey, et al	5,037
Personalised care planning for adults with chronic or long-term health conditions. Angela Coulter, et al	4,321
Interventions for providers to promote a patient-centred approach in clinical consultations. Francesca Dwamena, et al	3,277
Family-centred care for hospitalised children aged 0-12 years. Linda Shields, et al	2,966
Cultural competence education for health professionals. Lidia Horvat, et al	2,960
Mass media interventions for reducing mental health-related stigma. Sarah Clement, et al	2,560
Mobile phone messaging reminders for attendance at healthcare appointments. Ipek Gurol-Urganci, et al	2,450
Mobile phone messaging for preventive health care. Vlasta Vodopivec-Jamsek, et al	2,359
Interventions to improve safe and effective medicines use by consumers: an overview of systematic reviews. Rebecca Ryan, et al	2,334

\*A proportion of full text downloads cannot be associated with an individual Cochrane review so data presented underestimates overall usage activity. Usage data were taken from the Wiley Online Library platform only.

## Alternative metrics (Altmetrics)

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

SCORE	REVIEW TITLE/LEAD AUTHOR	B	T	N	F
109	Personalised care planning for adults with chronic or long-term health conditions. Angela Coulter, et al	2	136	7	0
27	Decision aids for people considering taking part in clinical trials. Katie Gillies, et al	0	38	1	0
17	Training and supportive programs for palliative care volunteers in community settings. Dell Horey, et al	0	27	2	0
15	Email for clinical communication between healthcare professionals. Clare Goyder, et al	0	22	1	0
13	Provision of a surgeon's performance data for people considering elective surgery. Amanda Henderson, et al	0	6	0	1
9	Parents' and informal caregivers' views and experiences of routine early childhood vaccination communication: qualitative evidence synthesis. Heather MR Ames, et al	0	11	0	0
7	Goal setting and strategies to enhance goal pursuit for adults with acquired disability participating in rehabilitation. William MM Levack, et al	0	7	0	0
2	Effects of changing practitioner empathy and patient expectations in healthcare consultations. Jeremy Howick, et al	0	2	0	0
1	Consumer-delivered training in intimate examination skills for healthcare students and professionals. James MN Duffy, et al	0	2	0	0

### Supporting Cochrane Consumers and Communication authors

Cochrane Consumers and Communication authors are supported through the review process by our highly experienced editorial team. The internal editorial team based at La Trobe University includes:

**Dr Sophie Hill**, Senior Research Fellow and Coordinating Editor

**Dr Rebecca Ryan**, Research Fellow and Deputy Coordinating Editor

**Bronwen Merner**, Research Fellow and Managing Editor

**Ann Jones**, Assistant Managing Editor

**Anneliese Synnot**, Research Fellow and Editor

**Dianne Lowe**, Research Officer and Editorial Assistant

**John Kis-Rigo**, Information Specialist

### Editorial support

In 2016, 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: seven protocols, six new reviews, four updated reviews
- Developing, translating and updating search strategies for five reviews

- Conducting detailed assessment of 10 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.

- Co-authoring two reviews (including one review with more than 130 trials) and one title proposal.

**“And please pass on our thanks again to [the editorial base] – [their] input has really improved our review (and I have learnt a lot in the process).”**

**Dr Andy Cochrane**, Maynooth University  
Department of Psychology, National University  
of Ireland Maynooth and Cochrane lead author

### Online author resources

In 2016, we released a range of new online resources to support Cochrane Review authors. These resources were developed by our team’s Deputy Co-ordinating Editor, Dr Rebecca Ryan.

The resources were developed in response to common areas that proved challenging for our review teams, and to help fill gaps in the practical how-to implementation of methods, particularly in cases where the review interventions are complex.

The new resources were:

- Summary of findings – a how-to guide to preparing summary of findings tables;
- How to GRADE – a step-by-step guide to help work through assessment of the quality of the evidence;
- Describing results – a practical guide to describing results consistently, including a list of common problems to avoid when presenting results; and
- Identifying comparisons – a brief guide, with examples, on identifying comparisons in reviews of complex interventions.

We also revised several of our existing author resources, to improve their usability and to ensure they are up to date. The updated resources were:

- Protocol template and review template – these provide standardised wording and supplementary information to support authors when completing all sections of the protocol and review respectively
- Several short methodological guides with a focus on supporting authors of reviews of complex interventions:
  - Examples of narrative synthesis and Examples of theoretical models;
  - Heterogeneity and subgroup analysis;
  - Meta-analysis; and
  - Narrative data synthesis and analysis.

The resources are intended to be used alongside the Cochrane Handbook for Systematic Reviews of Interventions.

We have received some excellent feedback about our author resources from our authors as well as other Cochrane Groups.

**“You guys do amazing resources”**

**Prof Declan Devane**, Chair of Midwifery, School of Nursing and Midwifery, National University of Ireland Galway and Cochrane author.

**“I just wanted to say how impressed I am with these resources... your guides are so clearly written and accessible, particularly the SoF [Summary of Findings] guide. My colleague forwarded the link to our colleagues at the Centre of Evidence Based Dermatology, too.”**

**Laura Prescott**, Managing Editor,  
Cochrane Skin Group

### 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 2017.

# GETTING KNOWLEDGE INTO POLICY AND PRACTICE

## Evidence bulletins

Dianne Lowe prepared four Evidence Bulletins during 2016, summarising reviews published during the year and of relevance to the Victorian health system.

- Interventions aimed at community to inform and or educate about early childhood vaccinations. Lead author, Ingvil Saerterdal: March 2016.
- Face to face interventions for informing or educating parents about early childhood vaccination. Lead author, Jessica Kaufman: March 2016.
- Audio-visual presentation of information for informed consent for participation in clinical trials. Lead author, Anneliese Synnot: April 2016.
- Personalised care planning for adults with chronic or long-term health conditions. Lead author, Angela Coulter: August 2016.

All Evidence Bulletins can accessed through our website: [latrobe.edu.au/chcp/evidence-bulletins](http://latrobe.edu.au/chcp/evidence-bulletins)

## Committees and reference groups

In 2016, Centre for Health Communication and Participation staff represented the Centre on a diverse range of committees and reference groups.

**Hill S.** Renal Education Advancement Project Working Group. Victorian Renal Health Clinical Network, Department of Health and Human Services, Victoria.

**Hill S.** Cochrane Knowledge Transfer Strategy Working Group. Cochrane.

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

**Hill S.** Kaleidoscope Project: a national research priority setting partnership for childhood chronic disease Steering Committee. Better Treatment 4 Kids Network (BT4K).

**Hill S.** Patient Information Videos Project Steering Committee. North East Metropolitan Integrated Cancer Service.

**Hill S, Synnot, A, Ryan R.** Piloting Living Systematic Reviews within Cochrane Network. Cochrane Australia.

**Kaufman J.** General vaccination communication research. Research network. Collaboration on Social Science and Immunisation (COSSI)

**Synnot A.** Development of Consumer Involvement Statement of Principles. Working group. Cochrane UK.

**Ryan R.** Abstracts committee for the 2016 Cochrane Colloquium.

## Seminars and workshops

In 2016, Centre staff presented the following seminars and workshops:

**Ryan, R.** Complex interventions workshop, Cochrane Effective Practice and Organisation of Care Satellite (Australia). 16 May.

**Synnot A, Merner B.** Workshop with authors of 'Consumer involvement' priority review about co-creating the review with consumer and other stakeholders. South Australian Health

and Medical Research Institute, Adelaide, 11 July.

**Hill, S.** Health Communication: Lessons and Resources relevant to improving health literacy. Seminar. Integrated Care Network Forum, Melbourne, 14 September.

**Hill, S.** (Co-chair and co-convenor, panel member). Health Literacy and Health Professional Education Symposium. University of Melbourne. 13 September.

**Synnot, A.** Co-creation with consumers and other stakeholders: reflections on what worked in a health research priority-setting project. Seminar. Department of Health and Human Services, Melbourne, 14 November.

## Invited presentations

In 2016, Centre staff were invited to present at the following events:

**Merner, B., Hill, S., Taylor, M.** Presentation of preliminary findings - Carers' involvement in patient safety to Department of Health staff. Department of Health and Human Services Victoria, Melbourne, 14 January.

**Merner, B., Hill, S.** Presentation of preliminary findings - Carers' involvement in patient safety to Carers Victoria staff. Carers Victoria, Melbourne, 22 February.

**Kaufman, J.** Presentation of CommVacc project at Social Science in Immunisation meeting, Brisbane, Australia, 6 June.

**Hill, S.** Health communication: Lessons and resources. Loddon Mallee Regional Forum. June 2016.

**Kaufman J (presenter), Hill S.** Communicate to Vaccinate: a research project building evidence for the implementation and evaluation of communication for childhood vaccination. Invited presentation. Strategies to increase vaccine acceptance and uptake, Annecy, France, 26-28 September.

**Lowe, D.** Multimorbidity and musculoskeletal conditions. Seminar. MOVE (the new Voice of Arthritis and Osteoporosis Victoria) Elsternwick, 16 September.

**Hill, S.** Panel discussion. Partnering with consumers: Innovations and Evidence. Deakin University, 12 December 2016.

## Submissions

In 2016, Centre staff made the following submissions to government:

**Hill, S. Taylor M, Merner B.** Submission to the Department of Health and Human Services Review of Hospital Safety and Quality Assurance in Victoria. April 2016.

**Hill, S.** Response to Department of Health and Human Services Victoria regarding the Review of Hospital Safety and Quality Assurance. October 2016.

## Reports

In 2016, Centre staff provided the following reports:

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

## Conferences

In 2016, Centre staff made or contributed to the following presentations and posters at Australian and international conferences:

**Hemsley B, Rollo M, Balandin S, Georgiou A, Hill S.** (2016) Health literacy: Conceptual models and theoretical issues for application in the field of developmental disability. Poster. IASSID World Congress. Melbourne, 15-19 August.

**Hemsley B, Georgiou A, Adams N, Rollo M, McCarthy S, Hill S, van Vliet P, & Balandin S.** (2016). Consumer health informatics for people who use AAC: Views on e-health records at home. Biennial Conference of the International Society for Augmentative and Alternative Communication, Toronto, 8-11 August.

**Hemsley B, Dahm M, Georgiou A, Bryant L, Balandin S, Hill S.** (2016). Health documentation in I/DD supported accommodation: A conceptual review and proposed consumer informatics model for health information management. Paper presented at IASSIDD Conference in Melbourne, August 2016. *Journal of Intellectual Disability Research* 60(7-8): 680.

**Hemsley, B., Steel, J., Georgiou, A., Hill, S., & Balandin, S.** (2016). Choking risk and repeated hospitalisation: Critical case results. *Journal of Intellectual Disability Research*, 60(7-8), 680-680. Paper presented at IASSIDD Conference in Melbourne, August 2016. *Journal of Intellectual Disability Research* 60(7-8): 680.

**Synnot A, Ryan R, Hill S.** Now what? After a systematic review priority setting exercise: The Cochrane Consumers and Communication experience. Long oral presentation. 24th Cochrane Colloquium, Seoul, 23-27 October.

**Morley R, Rees S, Synnot A.** Developing a statement of principles for consumer involvement in Cochrane. Workshop. 24th Cochrane Colloquium. Seoul, 23-27 October.

**Merner B, Synnot A, Lowe D, Ryan R, Nunn J, Hill S.** Combining knowledge translation interventions for maximum impact. Poster. 24th Cochrane Colloquium. Seoul, 23-27 October.

**Nunn J, Hill S, Merner B.** Successful multi-language free online-animated learning resource. Poster. 24th Cochrane Colloquium. Seoul, 23-27 October..

**Hemsley B (presenter), Georgiou A, Hill S, & Balandin S.** (2016). Documentation of patient communication in hospital medical records: a protection or a threat to patient safety for adults with communication disability. Platform paper presented at the International Safety and Quality in Healthcare (ISQUA) Conference. Tokyo, 16-19 October.

**Merner B, Synnot A, Lowe D, Ryan R, Nunn J, Hill S.** Cochrane Consumers and Communications: Integrating knowledge translation throughout the review cycle. 24th Cochrane Colloquium. Seoul, 23-27 October.

**Oliver S., Mukdarut B, Ryan R.,** Workshop title: Shaping systematic review to meet users' interests: getting started. 24th Cochrane Colloquium. Seoul, 23-27 October..

**Lowe D., Synnot A., Merner B., Hill S.,** Evidence summaries of Cochrane Consumers and Communication review: what do our stakeholders want? 24th Cochrane Colloquium. Seoul, 23-27 October.

## Publications

Staff and students of the Centre disseminated their research in a range of peer-reviewed journals in 2016:

**Shields N and Synnot A** (2016). Perceived barriers and facilitators to physical activity for children with disability: a qualitative study. *BMC Paediatrics*. DOI:10.1186/s12887-016-0544-7

**C Colombo, G Filippini; A Synnot; S Hill; R Guglielmino; S Traversa; P Confalonieri; P Mosconi; I Tramacere.** (2016). Development and assessment of a website presenting evidence-based information for people with multiple sclerosis: the IN-DEEP project. *BMC Neurology*. DOI : 10.1186/s12883-016-0552-0



**Lowe DB, Taylor MJ, Hill SJ** (2016). Changing definitions altered multimorbidity prevalence, but not burden associations, in a musculoskeletal population. *Journal of Clinical Epidemiology*. DOI: 10.1016/j.jclinepi.2016.03.016

**Ryan RE, Hill SJ** (2016). Making rational choices about how best to support consumers' use of medicines: a perspective review. *Therapeutic Advances in Drug Safety*. DOI: 10.1177/2042098616651198

**Hemsley B, Georgiou A, Carter R, Hill S, Higgins I, van Vliet P, Balandin S** (2016). Use of the My Health Record (MyHR) by people with communication disability in Australia: a review to inform the design and direction of future research. *Health Informatics Journal of Australia*.

**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** (2016). 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

**Santesso N, Morgano GP, Jack SM, Haynes RB, Hill S, Treweek S, Schunemann HJ and the DECIDE Workpackage 3 Group** (2016). Dissemination of Clinical Practice Guidelines: A Content Analysis of Patient Versions. *Medical Decision Making*. DOI: 0272989X16644427

**Oku A, Oyo-Ita A, Lewin S, Glenton C, Fretheim A, Ames H, Kaufman J, Hill S, Cartier Y, Cliff J, Muloliwa A, Rada G, Bosch-Capblanch X** (2016). Communication strategies to promote the uptake of childhood vaccination in Nigeria: A systematic map. *Global Health Action*. DOI: 10.3402/gha.v9.30337

**Hemsley B, Georgiou A, Hill S, Rollo M, Steel J, & Balandin S** (2016). An Integrative Review of Patient Safety in Studies on the Care and Safety of Patients with Communication Disabilities in Hospital. *Patient Education and Counselling*. DOI: 99(4):501-511.

**Colquhoun HL, Helis E, Lowe D, Belanger D, Hill S, Mayhew A, Taylor M, Grimshaw JM** (2016) Development of training for medicines-oriented policy makers to apply evidence. *Health Research Policy and Systems*. DOI 10.1186/s12961-016-0130-3

**Colquhoun H, Lowe D, Helis E, Belanger D, Ens B, Hill S, Mayhew A, Taylor M, Grimshaw J** (2016) Evaluation of a training program for medicines-oriented policy makers to use a database of systematic reviews. *Health Research Policy and Systems*. DOI: 10.1186/s12961-016-0140-1

**Posadzki P, Mastellos N, Ryan R, Gunn LH, Felix LM, Pappas Y, Gagnon MP, Julious SA, Xiang L, Oldenburg B, Car J** (2016). Automated telephone communication systems for preventive healthcare and management of long-term conditions. *Cochrane Database of Systematic Reviews* 2016, Issue 12. Art. No.: CD009921. DOI: 10.1002/14651858.CD009921.pub2.

**Stacey D, Hill S, McCaffery K, Boland L, Lewis K, Horvat L**. Shared decision making interventions: Theoretical and empirical evidence with implications for health literacy. In: Logan R (ed), *Health literacy: New directions in research, theory, and practice*. IOS Press. Accepted 21 December 2016. [Invited chapter]

**Walsh L, Hill S, Wluka A, Brooks P, Buchbinder R, Cahill A, Dans L, Lowe D, Taylor M, Tugwell P** (2016) Harnessing and supporting consumer involvement in the development and implementation of Models of Care for musculoskeletal health. *Best Practice and Research Clinical Rheumatology*. DOI: 10.1016/j.berh.2016.09.004

## Peer reviewing

In 2016, Centre staff were engaged as peer reviewers for the following journals:

Australian Health Review (SH)

Australian Journal of Primary Health (AS)

Journal of Clinical Epidemiology (JK)

Conference abstracts: World Congress on Public Health (AS, BM)

BMJ Open (RR)

Cochrane Database of Systematic Reviews (Infectious Diseases) (RR)

Journal of Healthcare Communications (RR)

Paediatric Allergy, Immunology and Pulmonology (RR)

Medical Decision Making (RR)

Transplantation (AS)

Health Expectations (SH)

Research Involvement and Engagement (SH)

Cochrane Colloquium Abstracts Committee (RR)

## Membership of editorial boards

Cochrane Coordinating Editors' Board (Sophie Hill, Rebecca Ryan)

Research Involvement and Engagement (Sophie Hill, Jack Nunn)

Health Expectations (Sophie Hill)

## Podcasts

Cochrane aims to produce as much evidence as possible in multimedia formats. In 2016, two Cochrane Consumer and Communication reviews were produced as podcasts translated into multiple languages. These were:

**Levack, W**. Goal setting for adults receiving clinical rehabilitation for disability (English, Russian, Portuguese versions)

**Posadzki P**, Automated telephone communication system. (Chinese and Spanish version).

All podcasts can be found on the Cochrane website:

[cochrane.org/multimedia/podcasts](http://cochrane.org/multimedia/podcasts)

## Translations

In 2016, the following translations of Cochrane Consumer and Communication reviews were produced:

**Posadzki, P.** Automated telephone communication systems for preventive healthcare and management of long-term conditions (Polish)

**Posadzki, P.** Automated telephone communication systems for preventive healthcare and management of long-term conditions (Spanish)

## Social media

At the end of 2016, the Cochrane Consumers and Communication Twitter account @CochraneCCRG had 1047 followers.

A YouTube Video created by Nunn J and the CHCP team for Cochrane "What are Systematic Reviews" and uploaded in January 2016 had been viewed >25,000 times by Dec 2016.

## Newsletters

By December 2016, there were 1113 subscribers to the Cochrane Consumers and Communication quarterly online newsletter.

## Media mentions

In 2016, the Centre's work received the following mentions in mainstream and industry media outlets:

- The Communication Initiative featured information about **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. (2016) Outcomes mapping study for childhood vaccination communication: too few concepts were measured in too many ways. Journal of Clinical Epidemiology** in their e-magazine, The Drum Beat. The Drum Beat has 46,000 subscribers and is designed for the international development community and anyone interested in communication for social development and change.

- The Priority Setting report was highlighted as a newsfeed article (most prominent) in the Primary Health Care Research and Information Service (PHCRIS) weekly e-newsletter.
- The priority setting project was mentioned in Crikey in the article "Cochrane Colloquium Seoul: Croakey wrap" by Shauna Hurley.
- An article about the priority-setting project was circulated to nearly 2000 members of Contact, Help, Advice and Information Network (CHAIN), an online international network for people working in health and social care.
- Annie Synnot was interviewed about the priority-setting project for Elements newsletter (Dec issue), produced by Cochrane Australia.
- Annie Synnot was interviewed about the priority-setting project for a Cochrane blog series on prioritisation approaches.

# EDUCATION AND TRAINING

## Teaching

In 2016, Centre staff continued their strong commitment to contribute to La Trobe University's postgraduate teaching programs. The following staff delivered the following highly-rated lectures and subjects:

**Hill, S.** Guest lecture for China Health Program. La Trobe University, 29 July.

**Hill S, Ryan R, Kaufman J.** Master in Public Health core subject, Evidence-based Public Health (PHE5EBP). La Trobe University.

**Lowe, D.** Guest lecture for Environmental Influences on Health (PHE5ENV). La Trobe University. 5 September.

## Postgraduate study

Our Higher Degree by Research Program had another successful year. Congratulations to Ania Sieracka and Charissa Zaga for completing their minor theses as part of the Master of Public Health program. We welcomed Anneliese Synnot and Jack Nunn to the Doctor of Philosophy program under the principal supervision of Sophie Hill.

The Centre's Higher Degree by Research projects covered a variety of topics, including:

- **Consumer participation in quality and safety in Australian hospitals.** Sieracka A. (Master in Public Health). Supervised by Dr Sophie Hill.
- **Comparing the Quality of Care reports from Victorian metropolitan public health services before and after the introduction of the 'Partnering with Consumers' National**

### **Safety and Quality Health Service (NSQHS) Standard.**

Zaga C. (Master in Public Health). Co-supervised by Professor Sandra Leggat (Department of Public Health, La Trobe) and Dr Sophie Hill.

- **Communicating Hearing test diagnosis information to parents.** Hyder R. (Master in Public Health). Co-supervised by Dr Sophie Hill and Dr Sarah Callinan (Centre for Alcohol Policy Research, La Trobe).
- **How do we know what works? Identifying and prioritising stakeholder-relevant outcomes to measure the effects of communication for childhood vaccination.** Kaufman J (PhD candidate). Supervised by Dr Sophie Hill and co-supervised by Dr Rebecca Ryan.
- **Prevalence, health burden and medicines-related communication experiences of multimorbidity among the working-age population with musculoskeletal conditions.** Lowe D. (PhD candidate). Supervised by Dr Sophie Hill and co-supervisor Dr Michael Taylor (Australian Catholic University).
- **The contribution of carers to the prevention of medical errors in the hospital setting.** Merner B. (PhD candidate). Supervised by Dr Sophie Hill and co-supervisor Dr Michael Taylor (Australian Catholic University).
- **Genomics research and involving the public.** Nunn J. (PhD candidate). Supervised by Dr S Hill and co-supervised by Dr Rebecca Ryan and Dr Paul Lacaze (Monash University).

- **Involving stakeholders to set priorities for health communication and participation research.** Synnot A. (PhD candidate). Supervised by Dr Sophie Hill and co-supervised by Associate Professor Allison Tong (University of Sydney).
- **Regulation of private medical clinics in Kenya: Insights from regulators and directions for improved regulatory outcomes.** Nyaga PJM. Doctor of Public Health. Supervised by Dr Sophie Hill and co-supervised by Associate Professor Simon Barraclough (Department of Public Health, La Trobe).
- **Investigating health care communication as a component of the clinical practice guidelines relevant to young Australians.** O'Sullivan M. (Master in Public Health). Supervised by Dr Sophie Hill.

# CURRENT GRANTS AND SCHOLARSHIPS

The Centre for Health Communication and Participation received a Funding and Service Agreement from the Department of Health and Human Services Victoria for 2016-2019. Cochrane Consumers and Communication receives funding from the National Health and Medical Research Council program for support for Cochrane for 2013-2017.

## Grants supporting our projects

- 2016-2018: Holland A, Taylor N, Shields N, Morris ME, Leggat S, Shiell A, Hill S. CRE in Community Rehabilitation. La Trobe University Big Bid Funding Scheme.
- 2016: Synnot A. Contributing to an international knowledge production strategy for Cochrane. La Trobe University Building Healthy Communities Research Focus Area, Research Enabling grant.
- 2016. Hill S. Reflections on consumer participation and engagement advocacy: maximising the consumers' input in a multiple sclerosis health information project. La Trobe University Building Healthy Communities Research Focus Area, Publication-enabling scheme.
- 2016-2018. Hill S. Targeted Funding proposal to facilitate increased publication output, La Trobe University.
- 2016: Pollock A, Campbell P, Struthers C, Synnot A, Hill S, Nunn J, Goodare H, Morris J, Morley R (2016) ACTIVE (Authors and Consumers Together Impacting on eVidencE), Cochrane Learning & Support Development.

## Scholarships

- Synnot A. Stakeholder involvement to set priorities for health communication and participation research. NHMRC Public Health and Health Services Postgraduate Research Scholarship. 2017-2019
- Nunn J. La Trobe University Postgraduate Research Scholarship.

# APPENDIX

Cochrane Consumers and Communication reviews, protocols and registered titles published in 2016

## New and updated reviews published in 2016

### New reviews

AUTHORS / TITLE	PUBLISHED
Posadzki P, Mastellos N, Ryan R, Gunn LH, Felix LM, Pappas Y, Gagnon M, Julious SA, Xiang L, Oldenburg B, Car J. Automated telephone communication systems for preventive healthcare and management of long-term conditions.	Issue 12, 2016
Cochrane A, Furlong M, McGilloway S, Molloy DW, Stevenson M, Donnelly M. Time-limited home-care reablement services for maintaining and improving the functional independence of older adults.	Issue 10, 2016

### Protocols

AUTHORS / TITLE	PUBLISHED
McCalman J, Campbell SK, Chamberlain C, Strobel NA, Bainbridge RG, Wenitong M, Ruben A, Edmond KM, Marriott R, Tsey K, Keith K, Shields L. Family-centred interventions for Indigenous early childhood well-being by primary healthcare services.	Issue 12, 2016
Evans DJW, Lewis SR, Alderson P, Smith AF. Information or education interventions for adult intensive care unit (ICU) patients and their carers.	Issue 12, 2016
Gilligan C, James EL, Snow P, Outram S, Ward BM, Powell M, Lonsdale C, Cushing AM, Silverman J, Regan T, Harvey P, Lynagh MC. Interventions for improving medical students' interpersonal communication in medical consultations.	Issue 11, 2016
Cross AJ, Elliott RA, George J. Interventions for improving medication-taking ability and adherence in older adults prescribed multiple medications.	Issue 10, 2016

## Registered titles

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### AUTHORS / TITLE

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**Ammenwerth E, Lannig S, Hörbst A, Schnell-Inderst P.** Adult patient access to electronic health records.

**Henderson A, Ryan R, Henderson S, Young J, Bradford N, Bothroyd JI, Herbert A, Pedersen, L.**  
Interventions for improving communication about end of life care among health professionals and patients and their families or carers.

**Butterworth JE, Bower P, Campbell J.** Interventions for involving older patients with multimorbidity in decision-making during primary care consultations.

**Mackintosh NJ, Sandall J, Sevdalis N, Davis RE, Keddle J.** Interventions to increase patient and family involvement in escalation of care for acute life threatening illness in community health and hospital settings.

**McGeown HR, Heffernan C, Panjwally A.** Social media interventions for impacting knowledge, attitudes and behaviours around vaccination uptake.

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[latrobe.edu.au/chcp](http://latrobe.edu.au/chcp)