



LA TROBE
UNIVERSITY

Centre for Health Communication and Participation

YEAR IN REVIEW 2018



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Suggested citation:

Centre for Health Communication and Participation (2019). *Year in Review 2018*. Centre for Health Communication and Participation, La Trobe University, Victoria.

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Finalised July 2019



**Open access to
Centre's articles,
tools, guides &
resources**




**Altmetrics ranked
5 papers for 2018
in top 5% of
audience reach**

2018 Achievements



**Increasing
stakeholder
engagement**



**166 people per day
download our Cochrane
reviews**



17 Cochrane author resources developed:

**Resources downloaded
average of 14 times/working day**

About the Centre

The Research Centre for Health Communication and Participation is based in the School of Psychology and Public Health at La Trobe University. 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.

The Centre is also home to the Cochrane Consumers and Communication Group, which is part of the international organisation, Cochrane. The Cochrane Group's expertise focusses on evaluating the evidence on ways people interact with and experience health care (broadly termed 'communication and participation').

Mission

The Centre for Health Communication and Participation conducts research to improve people's health and wellbeing through the generation and promotion of evidence-informed strategies for consumer communication and participation in health. We aim to strengthen the active involvement of consumers in health care, policy and research.

Strategic Directions

- 1.** To make the Centre integral to the landscape of consumer participation and communication in health through strategic partnerships with researchers, policy makers, funders and consumers.
- 2.** To ensure a high-performing, viable and sustainable Centre by actively seeking funding and collaboration opportunities, being innovative in our research approaches, and valuing staff, students, volunteers and collaborators.
- 3.** To strengthen the evidence base for communication and participation in health.
- 4.** To share and promote the work we do to create a cohesive platform of consumer participation and communication evidence which is of high-quality and accessible to a range of audiences.

Head of Centre's report



Associate Professor Sophie Hill PhD

Head, Centre for Health Communication and Participation
Joint Coordinating Editor (with Dr Rebecca Ryan), Cochrane Consumers and Communication Group

2018 was an excellent and productive year for our Centre. As you can see from the pages that follow, we did the things that research centres should do. We got grants, researched, wrote and edited papers, spoke, taught and trained, tweeted and blogged. Had the odd morning tea. I want to thank all our wonderful staff, Cochrane editors and referees, advisory groups, university and wider colleagues, and our funders for their help in realising our vision - to strengthen the active involvement of consumers in health care, policy and research.

This year I wanted to write about some of the driving themes in our work. First is stakeholder engagement. Our 'stakeholders' are consumers and carers (particularly those in advocacy or representational roles in health services), clinicians (particularly those in quality improvement and patient experience roles), policy makers (especially those in Victoria), and other researchers.

We have greatly increased our efforts into working with stakeholders to co-produce our research. We are putting more resources behind it, and staff are coming up with innovative, evidence-informed and thoughtful ways to engage with people across the Victorian and Australian health sectors. I can see so many impacts of this engagement. It has improved the work we produce and it has also energised us.

The second theme is ensuring our published work is easily found. We have put greater effort into different ways of communicating our work this year, but a key principle is that it must always

be available without charge or subscription. For a long time, we have paid the publishing fees to journals to ensure all staff-led articles are in open access journals so that consumers and consumer organisations can read our work easily. We are increasingly using Figshare, an open data housing platform, to host our reports and talks.

The third theme is application. Our work in 2018 has been building on what we have done before, and in line with our strategic directions we have been applying our knowledge and skills to undertake key research for government. This has included commencing a rapid review of evidence and practice associated with escalation of care, and producing Guidelines for producing or sourcing health information. Our collaborations have grown as a result and this has been very satisfying.

To conclude I want to thank my university and some key people. La Trobe has been going from strength to strength in recent years. It is a wonderful, friendly and dynamic place to be and our School of Psychology and Public Health is hugely supportive of our work and our team. For special mention are the Head of the School, Professor Stephen Kent, and our School Manager, Jacque Burnheim. Finally, I would like to thank some of the teams in the wider university for their expertise and good advice: Research Finance, IT Services and Support, the Office of the Pro Vice-Chancellor (Research Development), and Ethics, Integrity and Biosafety.

Building evidence for communication and participation: The Cochrane Consumers and Communication Group

Nested within the Centre is the Cochrane Consumers and Communication Group. This is the engine of our work to build evidence of both the effects of interventions but also evidence on the experiences and views of people about their health.

What is the Cochrane Consumers and Communication Group?

The Cochrane Consumers and Communication Group (The Group) is part of Cochrane. Cochrane (at Cochrane.org) is a global independent network of researchers, professionals, patients, carers, and people interested in health. Its mission is to promote evidence-informed health decision-making by producing high-quality, relevant, accessible systematic reviews and other synthesised research evidence. The main output of Cochrane is the Cochrane Library (at cochranelibrary.com) which is a high impact journal that is freely available to all Australians. Cochrane's work is internationally recognised as the benchmark for high-quality information about the effectiveness of health care.

The role of the Group is to coordinate the production and publication of reviews that fit under this broad scope: 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. We are therefore an editorial base and operate like 'a journal within a journal' – as all the reviews we approve are published on the Cochrane Library.

Some reviews are led by staff at our Centre, but most are led and undertaken by researchers from

around the world. In this section we report on some 2018 activities and performance highlights.

The Group accepts two types of systematic reviews: reviews of studies of the effects of communication and participation interventions, and reviews of qualitative studies of people's experiences and views about health communication or participation. The Group is fortunate to be supported by an international editorial team of experts in communication and participation issues and systematic reviews. See Our People on page 23. We have a world-wide network of 1,161 contributors from 50 countries. At time of publication, the Group has 63 published reviews and 30 published protocols.

The Group has also created 17 specialised methodological resources for review authors. During July 2018 - June 2019 these resources were downloaded 14 times/per working day on average. The Group has an Internal Editorial team, based in the Centre for Health Communication and Participation, which is led by the Joint Coordinating Editors Sophie Hill and Rebecca Ryan. They provide intellectual leadership internationally for the preparation and production of Cochrane reviews for health communication and participation. The coordination and publication of all Cochrane work within the Group is the responsibility of the Managing Editor, Bronwen Merner, and Assistant Managing Editors Louisa Walsh and Ann Jones. Information Specialist, Anne Parkhill, is responsible for developing and assuring the quality of all search strategies within reviews. Technical Editor, Dianne Lowe, is responsible for checking the quality of all reviews and preparing methodological resources.

Exploring new ideas to improve review methodologies in 2018

This year, Anne Parkhill, our Information Specialist, experimented with a new application called the '**RCT Classifier**' which may make the detailed searching for studies a less onerous task. The RCT Classifier is a software tool which finds articles about randomised controlled trials by searching health literature databases. And Dr Rebecca Ryan was our lead in the new Cochrane Public Health and Health Systems Network, where we have joined with other Cochrane Groups to discuss and address the challenges of Cochrane reviews in complex areas. We worked with Groups in the Network to persuade the Cochrane Editorial Board to give us more scope to experiment with reviews of qualitative studies (called qualitative evidence syntheses).

2017 High-performing Cochrane reviews

The publisher of the Cochrane Library, Wiley Blackwell, calculates the number of times reviews were cited in other journals, viewed or downloaded in the previous year. This gives us an indicator of their relevance and highlights are listed here. You can find the reviews on cochranelibrary.com.

59,976
Full text downloads of our
2017 Cochrane reviews

We would like to acknowledge the huge contribution and the value of the work done by Cochrane authors.

The following most frequently cited reviews in 2017 are included here (with the lead author):

- Personalised care planning for adults with chronic or long-term health conditions (Angela Coulter)
- Automated telephone communication systems for preventive healthcare and management of long-term conditions (Pawel Posadzki)
- Goal setting and strategies to enhance goal pursuit for adults with acquired disability participating in rehabilitation (William Levack)
- Email for clinical communication between healthcare professionals (Clare Goyder)
- Time-limited home-care reablement services for maintaining and improving the functional independence of older adults (Andy Cochrane)
- Training and supportive programs for palliative care volunteers in community settings (Dell Horey)
- Decision aids for people considering taking part in clinical trials (Katie Gillies)

Knowledge translations

- Cochrane Library Journal Club (2018, issue 78) featured the Jessie Kaufman's review, 'Face-to-face interventions for informing or educating parents about early childhood vaccination'.

Cochrane Reviews can be downloaded, and these were the high performers in 2017 (with lead author), with total downloads for this group reaching 59,976 downloads:

- Interventions for enhancing medication adherence (Robby Nieuwlaat) [13,000 downloads]
- Personalised care planning for adults with chronic or long-term health conditions (Angela Coulter) [7,041 downloads]
- Telephone follow-up, initiated by a hospital-based health professional, for postdischarge problems in patients discharged from hospital to home (Marian Smeulders) [6,226 downloads]
- Parents' and informal caregivers' views and experiences of communication about routine childhood vaccination: a synthesis of qualitative evidence (Heather Ames) [6,207 downloads]
- Decision aids for people facing health treatment or screening decisions (Dawn Stacey) [5,485 downloads]

- Cultural competence education for health professionals (Lidia Horvat) [4,987 downloads]
- Interventions for providers to promote a patient-centred approach in clinical consultations (Francesca Dwamena) [4,610 downloads]
- Goal setting and strategies to enhance goal pursuit for adults with acquired disability participating in rehabilitation (William Levack) [4,347 downloads]
- Family-centred care for hospitalised children aged 0-12 years (Linda Shields) [4,076 downloads]
- Mass media interventions for reducing mental health-related stigma (Sarah Clement) [3,997 downloads]

Reviews topics and protocols published or registered in 2018 by the Cochrane Consumers and Communication Group:

Reviews

- Kaufman, J., Ryan, R., Walsh, L., Horey, D., Leask, J., Robinson, P., Hill, S. (2018). Face-to-face interventions for informing or educating parents about early childhood vaccination. *Cochrane Database of Systematic Reviews*, Issue 5.
- Lewis, S.R., Pritchard, M.W., Schofield-Robinson, O.J., Evans, D.J.W., Alderson, P., Smith, A.F. (2018). Information or education interventions for adult intensive care unit (ICU) patients and their carers. *Cochrane Database of Systematic Reviews*, Issue 10.

Protocols

- Bengough, T., von Elm, E., Heyvaert, M., Hannes, K. (2018). Factors that influence women's engagement with breastfeeding support: a qualitative evidence synthesis. *Cochrane Database of Systematic Reviews*, Issue 9.
- Henderson, A., Ryan, R., Henderson, S., Young, J., Bradford, N.K., Bothroyd, J.I., Herbert, A. (2018). Interventions for interpersonal communication about end of life care between health practitioners and affected people. *Cochrane Database of Systematic Reviews*, Issue 9.
- Butterworth, J.E., Hays, R., Richards, S.H., Bower, P., Campbell, J. (2018). Interventions for involving older patients with multimorbidity in decision-making during primary care consultations. *Cochrane Database of Systematic Reviews*, Issue 9.

We registered the following titles for new review topics:

- Consumers and health providers working in partnership for the promotion of person-centred health services: a co-produced qualitative evidence synthesis (Lead Bronwen Merner)
- Decision coaching for people making health care decisions (Lead Janet Jull)
- Targeted client communication via mobile devices for improving maternal, neonatal, and child health (Lead Melissa Palmer)
- Targeted client communication via mobile devices for improving reproductive and sexual health (Lead Melissa Palmer)
- The effects of consumers and health providers working in partnership as an intervention for the promotion of person-centred health services (Lead Dianne Lowe)

Translating research into policy and practice

Knowing where to find or how to develop the right research tools or instruments is an issue faced by program managers and policy makers everywhere.

With the global spikes in vaccine preventable diseases, including measles, it has become increasingly important for public health officials to measure vaccine-related attitudes, acceptance, knowledge, decision-making and other drivers of uptake.

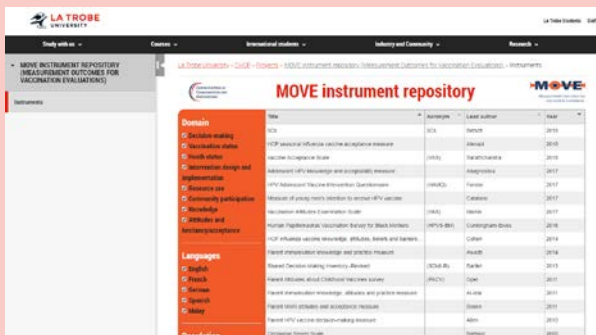
The Centre is supporting a collaborative project, MOVE (Measurement Outcomes for Vaccination Evaluations), that aims to do just that – undertake the collation and summarisation of available tools and provide Open Access to global practitioners.

In 2018, we established an international project advisory group including a representative from the WHO and leading researchers from Canada, Chile, Germany and Australia.

The first stage of project activities involved a systematic search for published validation studies of relevant instruments, which are being screened and summarised.

These are then included in a MOVE online repository (or platform) that will have Open Access and include:

- Assessment of the validation undertaken for each tool
- Populations and contexts of use
- Guidance on how to select and apply the most appropriate instruments for a given setting.



The MOVE online repository will improve the quality and efficiency of evaluating new interventions and reduce the development of unvalidated, single-use measurement instruments. Vaccine program managers and public health officials will be able to select and apply relevant measures without extensive time or expertise. MOVE will also support healthcare practitioners to screen people to determine their potential vaccine hesitancy, knowledge, or values and tailor communication strategies accordingly.

2018 Centre projects

Guidelines for producing or sourcing health information for patients

In 2018 the Health Information Guidelines project moved into a consultation phase. We worked with five hospitals across Victoria and consumer representatives to develop a final set of four guidelines with accompanying guidance information, links to relevant resources and worksheets for monitoring progress. The final draft was presented to Safer Care Victoria at the end of 2018. The final document is available via the Centre’s website for all Victorian health services to use.

Consumer engagement FAQ toolkit

In 2018 Louisa Walsh, along with Dr Sue Rogers from the La Trobe Institute for Molecular Science, finalised a practical toolkit to assist La Trobe University researchers new to consumer engagement in research. The finalised toolkit can be found through the Research Office, on the La Trobe Intranet, or by contacting our Centre. The Centre also has a webpage dedicated to providing practical resources for consumer participation in research, which can be found here:

<https://www.latrobe.edu.au/chcp/consumer-participation-in-research>

Co-producing Cochrane reviews on partnering for person-centred care

Person-centred care was identified as a priority topic for Cochrane Consumers and Communication Reviews in 2016. This project involves co-producing a Cochrane qualitative evidence synthesis on partnering with consumers at the governance level to promote person-centred healthcare organisations. The Stakeholder Panel working with us to co-produce the review include consumers, healthcare providers and policymakers. A second Cochrane Review, also with stakeholder input, is investigating the effectiveness of interventions to promote partnering at the governance level to promote person-centred healthcare organisations.

MOVE (Measurement Outcomes for Vaccination Evaluations)



In 2018, (as described above), we launched a new project at the Centre led by Dr Jessica Kaufman and involving Anne Parkhill, Dr Rebecca Ryan and Dr Sophie Hill. This project is called MOVE (Measurement Outcomes for Vaccination Evaluations). The aim of the MOVE project is to develop an online repository of survey tools for measuring and monitoring vaccination-related attitudes, acceptance, knowledge, decision-making and other drivers of vaccine uptake. This repository will help vaccination program officials and other stakeholders gather data on vaccination barriers and engagement strategies.

Escalating care when health is deteriorating

Safer Care Victoria asked the Centre to review the evidence on how to strengthen opportunities for patients, carers and family members to escalate care in Victorian health services. The rapid review will examine evidence from research and Australian practice and provide recommendations to inform plans to establish a central phone number and implementation framework.

Priority Cochrane reviews

Reviews on topics prioritised through the Cochrane Consumers and Communication Group's Priority Setting Exercise gathered momentum in 2018. Author teams are working to evaluate the evidence on diverse topics that our stakeholders indicated were important. This includes reviews on consumer engagement in healthcare policy, research and services; consumer involvement in care escalation; communication at end of life, and medical students' interpersonal communication. More information about priority reviews is available here: <https://cccrg.cochrane.org/about-us/priority-reviews>

ABC (Applying Big Data to Communication in health)

In 2018 Dr Sophie Hill and Dr Rebecca Ryan began preliminary research to investigate big data in the health communication and participation context. This project - ABC (Applying Big Data to Communication in health) - aims to work closely with an advisory stakeholder group to explore the potential applications of big data sources, including ways in which such data might be an input to evidence synthesis and knowledge translation activities of the Centre.

Stakeholder involvement to set priorities for health communication and participation research

In 2018, Anneliese Synnot published the first paper about the priority-setting research in the BMJ Open journal (at bmjopen.bmj.com/content/bmjopen/8/5/e019481.full.pdf), and spoke about the work at the international Cochrane Colloquium (see page 11 for a link to a video of the presentation).

Committees and reference groups

One of the important ways we get evidence into policy and practice is by participating in advisory committees formed by leading agencies in Victoria, within Cochrane, or joining with other researchers.

In 2018, staff represented the Centre on a diverse range of committees and reference groups.

- Hill S. Advisory Group, Cochrane Knowledge Translation Strategy, Cochrane.
- Hill S. Steering Committee, Kaleidoscope Project: a national research priority setting partnership for childhood chronic disease, Better Treatment 4 Kids Network (BT4K).
- Hill S. Patient and Family Council, Safer Care Victoria.
- Hill S. Expert Panel member, Research and Innovation Program, BehaviourWorks Australia and Victorian Managed Insurance Authority.
- Hill S, Synnot A, Ryan R. Living Evidence Network: Piloting Living Systematic Reviews within Cochrane. Cochrane Australia, Cochrane Australia.
- Hill S, Merner B. Community Information/Consumer Guidelines Working Group, Voluntary Assisted Dying Act Implementation Taskforce, Department of Health and Human Services.
- Kaufman J. Steering Committee, Collaboration on Social Science and Immunisation (COSSI), vaccination social science research network.
- Nelson N. Escalation of Care: Stakeholder Dialogue. BehaviourWorks Australia, Monash University.
- Ryan R. ICONS-Quant Project Advisory Group (Cochrane Strategic Methods Fund), Medical Research Council/Chief Scientist Office Social &

Public Health Sciences Unit, University of Glasgow.

- Ryan R. Cochrane Scientific Committee, Cochrane.
- Synnot A. Scientific Committee (formally titled the Themes and Content Committee) Cochrane Colloquium, 16-18 September 2018, Edinburgh, Cochrane.
- Synnot A. Cochrane Knowledge Translation Working Group on Embedding Prioritisation, Cochrane.

Submissions into policy reviews

Another key way we influence decision makers is to prepare submissions, drawing from evidence. These are our submissions for 2018.

- Hill, S. Comment from the Centre for Health Communication and Participation on the Partnering in Health Care Framework, Safer Care Victoria.
- Nunn, J. Submission to the Commonwealth Department of Health's public consultation on the 'Implementation Plan for the National Health Genomics Policy Framework', Commonwealth Department of Health.
- Synnot, A., Walsh, L., Hill, S. on behalf of the Centre for Health Communication and Participation to the National Health and Medical Research Council's Consultation on the draft 'Consumer involvement' module for 'Guidelines for Guidelines'.
- Synnot, A., Walsh, L., Hill, S., Ryan, R. and Merner, B. on behalf of the Centre for Health Communication and Participation, La Trobe University on the Second Australian Medical Research and Innovation Priorities 2018-2020, Medical Research Future Fund.

Communicating our work

At the Centre for Health Communication and Participation we have a strong focus on making our research accessible and as far-reaching as possible.

This is not only good for us and our work, but also important for health and research equity – ensuring anyone who would benefit from the research we do is able to access and use it.

To do this, we make all our publications – including student publications - open access.

We budget for open access fees in journals, publish all major presentations, reports or resources we develop on our Figshare platform, and translate and communicate our research through our website, blogs and newsletters. We also have active Twitter and Facebook pages to maximise the audience with which we can share our research and other key research in our field.

We also think it is important not only to share our research, but to draw the curtain back and demystify the research process.

On our platforms you will also see that we share guides, resources and tools that we have developed for our own research practice that we think could help many other researchers.

We shared our latest research with a growing audience on Twitter, Facebook, YouTube and by newsletter.

Social media and digital communications

Communication networks for the Centre have increased their audience reach through social media with the Cochrane Consumers and Communication Twitter account @CochraneCCRG. Followers increased to 1463 by December 2018 and the Facebook page reached 166 followers.

Excitingly, the YouTube video created by Jack Nunn and Sophie Hill for Cochrane “What are Systematic Reviews?” has been viewed 100,000 times by December 2018.

Cochrane Consumers and Communication published 3 newsletters: April, September and December 2018. By December 2018, there were 1159 subscribers to the Cochrane Consumers and Communication online newsletter.

Staff gave or joined others to talk about research findings and issues at a wide range of venues and events in 2018.

Conference talks

- Synnot, A. Partnering with consumers in research: current evidence and examples, Australian and New Zealand Musculoskeletal (ANZMUSC) Clinical Trials Network Annual Scientific Meeting, Melbourne. 21-22 March.
- Parkhill, A. Advanced search strategy design for complex topics: strategy development, text analytics and text mining training day. York Health Economics Consortium, University of Melbourne. 10 April.
- Hyder, R., Callinan, S., Hill, S. The first intervention: Audiologists sharing information at new-born diagnosis, Audiology Australia Conference, Melbourne. 22 May.
- Lowe, D., Taylor, M., Hill, S. Consumer-initiated strategies for realigning healthcare communication interactions: a grounded theory analysis (5 mins presentation), Primary Health Care Research Conference, Melbourne. 1-3 August.

- Merner, B., Colombo, C., V., Gaulden, C., Graham-Weisner, L., Hill, S. Co-production in action: improving the relevance of a Cochrane Review on person-centred care, Cochrane Colloquium, Edinburgh. 16-18 September.
- Merner, B. Co-production – an author’s perspective, Consumer involvement in Cochrane - knowledge translation in action workshop, Cochrane Colloquium, Edinburgh. 16-18 September.
- Synnot, A., Kay, D., Wiles, L., Hillier, S., Luker, J., Tong, A., Hill, S. Engaging consumers and other stakeholders in a Cochrane Review: a mixed-methods evaluation, Cochrane Colloquium, Edinburgh. 16-18 September.
- Pollock, A., Campbell, P., Struthers, C., Synnot, A., Nunn, J., Hill, S., Goodare, H., Morris, J., Watts, C., Morley, R. Development and application of the ACTIVE framework to describe stakeholder involvement in systematic reviews, Cochrane Colloquium, Edinburgh. 16-18 September.
- Pollock, A., Campbell, P., Struthers, C., Synnot, A., Nunn, J., Hill, S. Goodare, H., Morris, J., Watts, C., Morley, R. Stakeholder involvement in systematic reviews: a scoping review, Cochrane Colloquium, Edinburgh. 16-18 September.
- Synnot, A. Patient or healthcare consumers’ involvement and shared decision-making, Cochrane Colloquium, Edinburgh. 16-18 September.
- Merner, B., Hill, S., Taylor, M. Wrestling for control: Carers' contributions to preventing medical errors in hospital, Department of Psychology and Public Health Research Festival. La Trobe University, Bundoora. 3 December.



Anneliese Synnot,
Priority-setting presentation
Cochrane Colloquium, 17 September 2018,
Edinburgh, UK

Video can be accessed through the Cochrane Knowledge Translation website and YouTube at https://www.youtube.com/watch?v=hsHM02d_Ms8&feature=youtu.be.

Staff gave or joined others to talk about research findings and issues at a wide range of venues and events in 2018.



- 11 conference talks
- 5 seminars
- 1 workshop

Conference talks

- Synnot, A. Partnering with consumers in research: current evidence and examples, Australian and New Zealand Musculoskeletal (ANZMUSC) Clinical Trials Network Annual Scientific Meeting, Melbourne. 21-22 March.
- Parkhill, A. Advanced search strategy design for complex topics: strategy development, text analytics and text mining training day. York Health Economics Consortium, University of Melbourne. 10 April.
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- Synnot, A. Patient or healthcare consumers’ involvement and shared decision-making, Cochrane Colloquium, Edinburgh. 16-18 September.
- Merner, B., Hill, S., Taylor, M. Wrestling for control: Carers’ contributions to preventing medical errors in hospital, Department of Psychology and Public Health Research Festival. La Trobe University, Bundoora. 3 December.

Conference posters

- Lowe, D., Taylor, M., Hill, S. Consumer-initiated strategies for realigning healthcare communication interactions: a grounded theory analysis, Primary Health Care Research Conference, Melbourne. 1-3 August.
- Muloliwa, A.M., Cliff, J., De Maria, F., Oku, A., Oyo-Ita, A., Glenton, C., Ames, H., Kaufman, J., Hill, S., Cartier, Y, Bosch-Capblanch, X., Rada, G., Lewin, S. Comunicação para vacinação em zonas rurais e urbanas da província de Nampula, Moçambique [Communication for vaccination in rural and urban areas of the province of Nampula, Mozambique], XVI Jornadas Nacionais de Saúde (XVI NATIONAL HEALTH DAYS), Maputo, Mozambique. 17-20 September.
- Synnot, A., Kay, D., Wiles, L., Hillier, S., Luker, J., Tong, A., Hill, S. Co-producing a Cochrane Review to optimize research currency and relevance, NHMRC Symposium on Research Translation, Sydney. 27-28 November.

Seminars

- Merner, B. Carers' contributions to preventing medical errors in hospital, Health Seminar Series, Department of Public Health. La Trobe University, Melbourne. 5 May.
- Merner, B., Hill, S., Taylor, M. Carers' contributions to preventing medical errors in hospitals, Safer Care Victoria Lunch and Learn Seminar Series, Melbourne. 28 August.
- Hill, S., Walsh, L. New Guidelines for raising the quality of health information for consumers. Safer Care Victoria, Melbourne. 11 December.
- Kaufman, J. Monitoring acceptance and evaluating strategies to promote vaccination – why, what and how to measure? Collaboration on Social Science and Immunisation (COSSI) Knowledge Exchange Meeting, Melbourne and live-streaming. 12 November.
- Merner, B. Wrestling for control: Carers' contributions to preventing medical errors in hospital. Research Festival, School of Psychology and Public Health, La Trobe University. December.

Panels

- Synnot, A. Australian Medical Council workshop for specialist medical colleges on the topic of engaging stakeholders in delivering high quality medical training and education. Australian Medical Council, Melbourne, 17 February.
- Gallagher, K., Moy, C., Walsh, L., Al-Khafaji, M. My Health Record webinar series webinar 5: Digital inclusion and health literacy: Digital inclusion. Consumers Health Forum of Australia, 13 September. [At <https://chf.org.au/hub-my-health-record-webinar-series#web5>]
- Oliver, S., Graziosi, S., Roche, C., Hill, S., Welch, V. Blind-spot analysis and evidence-based initiatives: shining a light on methodological innovations, Global Evidence and Implementation Summit, Melbourne. 22-24 October.

Workshop

- Synnot, A. Knowledge translation, dissemination and stakeholder engagement: increasing the reach, impact and relevance of your research. Cochrane Australia Learning Week. Cochrane Australia. Melbourne. 7 June.

Other speaking activities or participation

- Synnot, A., Trish Greenhalgh Masterclass. La Trobe University, Melbourne. 13 March.
- Hill S. Invited participation in the Partnering in Healthcare - Priorities Summit, Safer Care Victoria, 21 March.
- Merner, B. Victorian Managed Insurance Agency Priority Setting Workshop. Victorian Managed Insurance Agency, Melbourne. 27 April.
- Nunn, J. Genomics Research and Involving People, Three Minute Thesis Competition. School of Psychology and Public Health, La Trobe University, Melbourne. 06 June. [Awarded people's Choice in round]
- Synnot, A. Democratising health research, Three Minute Thesis Competition. School of Psychology and Public Health, La Trobe University, Melbourne. 06 June. [Awarded winner in round]
- Merner, B. KT Fields Network leaders' round table, Cochrane Colloquium, Edinburgh. 16 September.
- Hill, S. Broadening engagement, Campbell Collaboration Board meeting, Melbourne, 25 October.

"Your slides about consumer participation in research are absolutely fantastic!

I would like to share them with Huntington's Disease researchers and other stakeholders in this area to enhance their understanding of the importance and potential for such collaboration."

Quality and Community Engagement Coordinator, Huntington's Victoria, regarding presentation by A. Synnot

- 15 peer-reviewed journal articles published
- 3 reports translating research into practice

Published works

[Note: these include peer-reviewed journal articles where we have either joined teams elsewhere or led ourselves]

- Concannon, T.W., Grant, S., Welch, V., Petkovic, J., Selby, J., Crowe, S., Synnot, A., Greer-Smith, R., Mayo-Wilson, E., Tambor, E., Tugwell, P. (2018). Practical guidance for involving stakeholders in health research. *Journal of General Internal Medicine*. doi:10.1007/s11606-018-4738-6
- Dahm, M. R., Georgiou, A., Balandin, S., Hill, S., Hemsley, B. (2018). Health information and the quality and safety of care for people with disability: An analysis of Australian reports of reviewable deaths in residential care. *Journal of Patient Safety*. doi:10.1097/pts.0000000000000550
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- Merner, B. Hill, S. Voluntary assisted dying community and consumer information: Summary of user-testing results. Report to the Voluntary Assisted Dying Community and Consumer Information Working Group, 7 December.
- Consumer Engagement FAQs for La Trobe University Researchers is a La Trobe internal document which may assist in establishing productive and meaningful consumer engagement in research projects. (Rogers, S., & Walsh, L.)

Building capacity for improving communication and participation

Stakeholder co-production of health care research

Involving non-research stakeholders (including consumers, clinicians and policymakers) in producing and disseminating health research is increasingly encouraged to reduce the research/practice gap. Since 2017, an international research team led by Bronwen Merner, Sophie Hill and Dianne Lowe from the Centre have been working on a project entitled 'Maximising relevance: a case study in working with stakeholders to co-produce health care research that is grounded in practice'. This project involves co-producing a Cochrane qualitative review (called a qualitative evidence synthesis) with a national Australian stakeholder panel of healthcare leaders, clinicians and consumers. The stakeholder panel includes representatives from Safer Care Victoria, the Australian Commission for Safety and Quality in Healthcare and health services across the country as well as consumer and carer representatives from different states.

Since commencing the review in 2017, the research team has collaborated with the stakeholder panel on three formal occasions (two teleconferences and one face-to-face meeting). To develop the plan for conducting the review, known as 'the protocol', stakeholders were involved in shaping the type of review and the range of studies that should be included. They also made sure the review was grounded in the needs of consumers and health services.

In November 2018, stakeholders participated in a face-to-face meeting in Melbourne that focused on the data collection phase of the review and

trained the stakeholders in how to select eligible studies for the review.

So far, this project has led to the publication of one Cochrane protocol, and the submission of another protocol also developed with stakeholder input, investigating the effectiveness of working in partnership. An article about the process of co-production has also been published on the Cochrane Community blog. The research team also presented about this review at the Cochrane Colloquium in Edinburgh in September 2018.



Word cloud of feedback received after the PCC stakeholder workshop, November 2018.



"Well done on the work you've done so far and on creating a truly collaborative environment in which to do this work. As a stakeholder I feel that my input has been valued."

- Stakeholder feedback, PCC Stakeholder Workshop Nov 2018

Teaching activity in
 2 post graduate courses
 1 undergraduate course

Academic recognition
 2 PhDs awarded
 3 students placed at Centre
 1 PhD scholarship

Journal contributions
 Contributions to 18 journals
 Members of 3 editorial boards
 2 peer review panel grants

Undergraduate and postgraduate teaching at La Trobe University

- Hill S. Instance coordinator for Systematic Review and Evaluation of Healthcare Research (RMD5EHR), Doctor of Public Health (Professional Doctorate).
- Lowe D. Guest Lecturer for Environmental Influences on Health (PHE5ENV), Master of Public Health.
- Walsh L. Lecturer for Systematic Review and Evaluation of Healthcare Research (RMD5EHR). Doctor of Public Health (Professional Doctorate).
- Walsh L. Lecturer for Community Health Promotion (PHE2CHP), Bachelor of Health Science.

Postgraduate research program

The Centre continues to work with PhD candidates and our Higher Degree by Research Program had another successful year with Bronwen Merner and Dianne Lowe being awarded their PhDs. Dr Bronwen Merner's thesis has since been used to inform evidence-based practice to establish Victoria's first central consumer-initiated escalation of care phone number and program.

Awarded

- Dianne Lowe. Prevalence, health burden and medicines-related communication experiences of multi-morbidity among the working-age population with musculoskeletal conditions. (Primary supervisor: S Hill; co-supervisor: M Taylor (ACU)). Conferred 17 May 2018.
- Bronwen Merner. The contribution of carers to the prevention of medical errors in the hospital setting. (Primary supervisor: S Hill; co-supervisor: M Taylor (ACU)). Conferred 17 May 2018.

Students at the Centre

- Hyder, R. Communicating Hearing test diagnosis information to parents. Master of Public Health. (Primary supervisor: S Hill; co-supervisor: S Callinan).
- Nunn, J. Genomics research and involving the public. PhD. (Primary supervisor: S Hill, Jan-Nov; co-supervisor P Lacaze, Monash)
- Synnot, A. Involving stakeholders to set priorities for health communication and participation research. PhD. (Primary supervisor: S Hill; co-supervisor A Tong, University of Sydney)

Scholarships

- Louisa Walsh, Research Officer in the Centre, was awarded a National Health and Medical Research Council Postgraduate Scholarship for 3 years, from 2019-2021. [\$111,974]. Her score was 5.456 and she was in the top quartile.

Research Progress Panel

- Hill S. Chair of Research Progress Panel for Christine Murray. Professional Doctorate. School of Nursing, La Trobe University

Peer reviewing grants

- External referee, NHMRC Project grants: external assessment (Hill S).
- External reviewer, Arthritis Research UK (Hill S).

Editorial Board membership

- Member Editorial Board, Health Expectations (Hill S)
- Member Editorial Board, Research Involvement and Engagement (Hill S, Nunn J)
- Associate Editor, BMC Public Health (Health behaviour, health promotion and society) (Kaufman J)

Our refereeing contribution to other journals

- BMJ EBM (Ryan R)
- Health Expectations (Hill S, Ryan R)
- Journal of Nursing Management (Ryan R)
- Journal of Medical Internet Research (Walsh L)
- Qualitative Health Research (Lowe D, Merner B, Synnot A)
- EMJ Rheumatology (Lowe D)
- BMC Public Health (Kaufman J)
- Epidemiology & Infection (Kaufman J)
- Research Involvement and Engagement (Synnot A)
- American Journal of Managed Care (Ryan R)
- Journal of Paediatrics (Kaufman J)
- Health Information Management Journal (Walsh L)
- Research Involvement and Engagement (Nunn J)
- BMJ Open (Hill S, Synnot A)
- PLOS One (Hill S)
- Ethics and Behaviours (Synnot A)
- Vaccine (Kaufman J)

Funding

Current grants

The Centre for Health Communication and Participation was supported by a Funding and Service Agreement from the Department of Health and Human Services Victoria for July 2016 to June 2019. Cochrane Consumers and Communication received funding from the National Health and Medical Research Council program for support for Cochrane Groups for July 2017-June 2020. The Centre also received support from the La Trobe University Targeted Funding for Research Centres.

New grants

- Centre for Health Communication and Participation (Hill S). Development of consumer/community information. Department of Health and Human Services. [\$138,000]
- Centre for Health Communication and Participation (Hill S, Ryan R, Nelson N.) Strengthening patient and carer use of a centralised escalation service. Safer Care Victoria. [\$40,803]
- Merner B, Hill S, Lowe D. National Stakeholder Panel meeting for co-production of two Cochrane Reviews on person-centred care. Building Healthy Communities - Research Focus Area Grant. Collaboration Ready scheme, La Trobe University. [\$7,964]
- Tugwell, P., White, H., Campbell, P., Chang, S., Concannon, T., Dans, L., Ghersi, D., Graham, I., Maxwell, L., Jull, J., Morley, R., Mustafa, R., Petkovic, J., Pollock, A., Potie, K., Schunemann, H., Synnot, A., Welch, V., Chalkidou, K., Lydiatt, A., Pardo Pardo, J. Stakeholder Engagement in Guideline Development. Canadian Institutes of Health Research Project Grant. 2018-2021. [CAD\$ 393,260]

Partnerships and collaboration

Advisory groups are playing an increasingly important role on our work. Their roles are mainly advisory but in some cases their role has moved on the spectrum of participation to more of a role of sharing some of the research tasks with us.

The increased connection with so many people from Victoria, Australia and internationally has meant a greater sense of partnership in our work. It has meant that we are more confident our research will reflect the needs of people about their health or in using our research.

In line with La Trobe University's new Research Framework, an external Advisory Committee for the Centre was established. We are very grateful for the excellent advice given by its members.

External Advisory Committee, Centre for Health Communication and Participation

Name	Representative Role
Susan Biggar	A community member with considerable expertise in researching and promoting consumers perspectives and patient-centred care
Noni Bourke	Chief of Organisational Support & Development, Bass Coast Health, Victoria
Mary Draper AM	A community member with considerable expertise in hospital governance, quality and safety and researching and promoting consumer perspectives
Associate Professor Sophie Hill (Chair)	Head, Centre for Health Communication and Participation
Professor Stephen Kent	Head of School of Psychology and Public Health, College of Science, Health and Engineering, La Trobe University
Louise McKinlay	Director, Consumers as Partners, Safer Care Victoria
Professor Miranda Rose	Academic Coordinator-Research, College of Science, Health and Engineering (SHE) College, Nominee of the Pro Vice Chancellor, College of SHE, La Trobe University

We would like to thank the many consumers and organisational representatives who engaged in opportunities to co-produce, inform, review and advise on our work in 2018.

MOVE (Measurement Outcomes for Vaccination Evaluations) Advisory Group:

- A/Prof Cornelia Betsch (Germany)
- Dr Dan Costa (Australia)
- Prof Julie Leask (Australia)
- A/Prof Margie Danchin (Australia)
- Steve McDonald (Australia)
- Lisa Menning (Switzerland)
- Anne Parkhill (Australia)
- A/Prof Gabriel Rada (Chile)
- Dr Rebecca Ryan (Australia)
- Prof Peter Tugwell (Canada)

Consumer-Initiated Escalation of Care Advisory Group

- Khanh Do, Manager, Consumer Partnerships and Diversity, Western Health
- Andrea Doric, Eastern Health Clinical Lead, Clinical Deterioration and Resuscitation
- Cherann Edwards, Senior Project Officer, Consumers as Partners Branch, Safer Care Victoria
- Hilary Kerrison, Consumer, Bass Coast Health
- Adriana Mulla, Consumer, Western Health
- Anna Muldowney, Senior Policy Advisor, Carers Victoria
- Vickie Veitch, Principal Policy Advisor, Consumers as Partners Branch, Safer Care Victoria
- Kirsten Weinzierl, Operations Manager, Bass Coast Health

Co-producing health care research grounded in practice: Stakeholder Advisory Panel

- Leslie Arnott, Consumer representative, Victoria
- Susan Biggar, Australian Health Practitioner Regulation Agency (AHPRA), Melbourne, Australia and Consumer Representative, Melbourne
- Noni Bourke, Chief of Organisational Support & Development, Bass Coast Health, Victoria
- Paul Bryden, Consumer representative, Queensland
- Renee Chmielewski, Manager, Planning and Patient Experience, The Royal Victorian Eye and Ear Hospital, Victoria
- Leia Earnshaw, Consumer representative, ACT
- Marie Gill, Gill and Wilcox consultancy, Victoria
- Fiona Martin, Clinical Practice Lead/Health Psychologist, Catholic Care, Victoria
- Nathalie Martinek, Practitioner Trauma & Fatigue: Prevention & Recovery Professional Mentor & Mediator for Physicians & other health professionals (until October 2018)
- Louise McKinlay, Director, Patient Experience & Partnerships, Safer Care Victoria
- David Menzies, Manager, Chronic Disease Programs, South Eastern Melbourne Primary Health Network, Victoria
- Nancy Messino, Clinical Trials Quality Officer, Victorian Comprehensive Cancer Centre, Victoria
- Anne Mussared, Consumer representative, South Australia
- Naomi Poole, Program Manager, Partnering with Consumers, Australian Commission on Safety and Quality in Health Care, New South Wales
- Nora Refahi, Consumer representative, Victoria
- Lorraine Smith, School of Pharmacy, Faculty of Medicine and Health, University of Sydney, Camperdown, New South Wales
- Roshni Sonawane, Consultant Paediatrician, Rockingham General Hospital and Wexford Specialist clinics, Murdoch, Western Australia
- Cheryl Wardrope, Patient Safety and Quality Service, Children's Health Queensland Hospital and Health Service, South Brisbane, Queensland

Our People



(left to right: Rebecca Ryan, Jessica Kaufman, Anneliese Synnot, Dianne Lowe, Jack Nunn, Anne Parkhill, Sophie Hill, Louisa Walsh)

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Head, Centre for Health Communication and Participation

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Administrator

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Senior Administrator

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- Dr Michael Summers, Public Policy Advocacy & Program Evaluation Consultant, Victoria
- Dr Claudia Meyer, Research Fellow, Bolton Clarke Research Institute, Victoria

The international editorial team for the Cochrane Consumers and Communication Group

- Dr Heather Ames, Norwegian Institute of Public Health, Norway
- Associate Professor Josip Car, Imperial College London, UK, and Imperial College and Nanyang Technological University, Singapore
- Professor Adrian Edwards, Cardiff University, UK
- Professor Bronwyn Hemsley, University of Technology Sydney, University of Newcastle, Australia
- Associate Professor Sophie Hill, La Trobe University, Australia
- Dr Dell Horey, La Trobe University, Australia
- Dr Jessica Kaufman, La Trobe University, Australia
- Dr Dianne Lowe, La Trobe University, Australia
- Professor Sandy Oliver, Institute of Education, University of London, UK
- Dr Rebecca Ryan, La Trobe University, Australia
- Associate Professor Nancy Santesso, McMaster University, Canada
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