

RESEARCH HANDBOOK FOR COMMUNITY PANEL MEMBERS

January 2024



Introduction and overview

Welcome to the Team!

Thank you for your interest in partnering with us as a community member, and welcome to the team!



My name is Dr Julie Ayre and I am a behavioural scientist and Research Fellow at Sydney Health Literacy Lab at the University of Sydney.

The [Sydney Health Literacy Lab](#) works with local communities and health services to make our health systems easier to use, health information easier to understand, and to empower people to actively engage in their own health care. We work across lots of different health conditions such as cancer, diabetes, heart disease and women's health.

So, where do you fit into all of this? We need people like you who can bring their lived experience to the table and guide our team to make sure that our work is relevant and meaningfully helps patients and carers. With a focus on health literacy, we also need people from different communities and cultural backgrounds to help us make sure that our research is more inclusive, respectful, and more of a two-way conversation.

Joining the community panel may be a good fit for you if you are curious about research, eager to make a difference in the healthcare system, and want to meet other people with similar goals. This short guide will help you better understand research and your role as a consumer on our team.

I look forward to working with you

Julie Ayre

Dr Julie Ayre, NHMRC Research Fellow (Emerging Leader 1)
Sydney Health Literacy Lab, Sydney School of Public Health, University of Sydney

What is health literacy and why is it important?

Health literacy is how people find and understand information about health and health care, and how they apply that information to their lives, use it to make decisions, and act on it.

Health literacy includes both an individual's personal health literacy skills (such as reading, writing, and interpreting health information), and the organisational structures (e.g. hospitals) and resources (e.g. health information) that enable them to access, understand, appraise, and use information and services in ways that promote and maintain good health.



When the health literacy environment does not meet the health literacy needs of the people it serves, this leads to:

- poorer access to health care and uptake of services
- poorer management of health conditions e.g. less knowledge about disease, more medication errors
- worse health outcomes, including higher chronic disease.

What programs of research can I get involved in?

As a community member, you may be asked to take part one or more of our key areas of research: Understanding health information, Shared decision making, Misinformation and critical thinking skills, Organisational health literacy

UNDERSTANDING HEALTH INFORMATION

Why is this topic important?

Most health information is written at a level that is too complex. In Australia, we aim for a school grade 8 reading level for health information designed for the general population.

What research does our team do about this topic?

Our research looks at how using simple words, images, and design elements can make information easier to understand and act on. We have worked with many NGOs and health services to improve the information they provide to communities. Our partners include: National Heart Foundation, National Diabetes Services Scheme, Hepatitis Australia, NPS MedicineWise, Western Sydney Diabetes, Western Sydney Local Health District.

SHARED DECISION MAKING

Why is this topic important?

Shared decision-making is when patients and clinicians work together to make a health decision that considers the medical evidence about a health issue, and the patient's personal values and preferences.

What research does our team do about this topic?

Our research looks at how we can encourage patients to ask questions about their care and treatment options. Our work involves: Question prompt lists (see '[Question Builder](#)' on the Health Direct Website, [Ask Share Know](#)), community skills training, and patient decision aids.

MISINFORMATION AND CRITICAL THINKING SKILLS

Why is this topic important?

Enormous amounts of health misinformation are spread online through the internet and social media. Countering misinformation involves having the skills to identify and critically evaluate online information sources.

What research does our team do about this topic?

Our research has looked at misinformation among Australians and the factors related to COVID-19 misinformation. We are currently looking at how health departments can create successful social media campaigns, and how to create online educational resources to help people critically evaluate health information.

ORGANISATIONAL HEALTH LITERACY

Why is this topic important?

Ultimately, health organisations and services must meet the health literacy needs of the community. Health services and organisations can support these needs by making their services as accessible and user-friendly as possible. This means making sure that when health staff give information, it makes sense to patients, whether that's spoken, in print, or online. It also means making sure that patients can easily navigate the healthcare system.

What research does our team do about this topic?

Our work has looked at new tools and staff training to improve uptake of health literacy practices in health services. Examples include the [Health Literacy Editor](#), peer to peer health literacy training for allied health professionals, and heart health check decision tools. We also support the [Health Literacy Hub](#), a community of practice that seeks to build capacity for health literacy practices amongst health care staff (based in Western Sydney, now with reach across Australia).

AND MANY MORE AREAS OF RESEARCH!

I've never taken part in research before. How does it work?

Research is an important part of improving health services. Through research, we can better understand problems and challenges. This helps us find creative and effective solutions. When we conduct research, we follow a precise series of steps called the **research process**. In our case, following the research process allows us to gather facts that can help improve health care delivery and health outcomes.

THE RESEARCH PROCESS

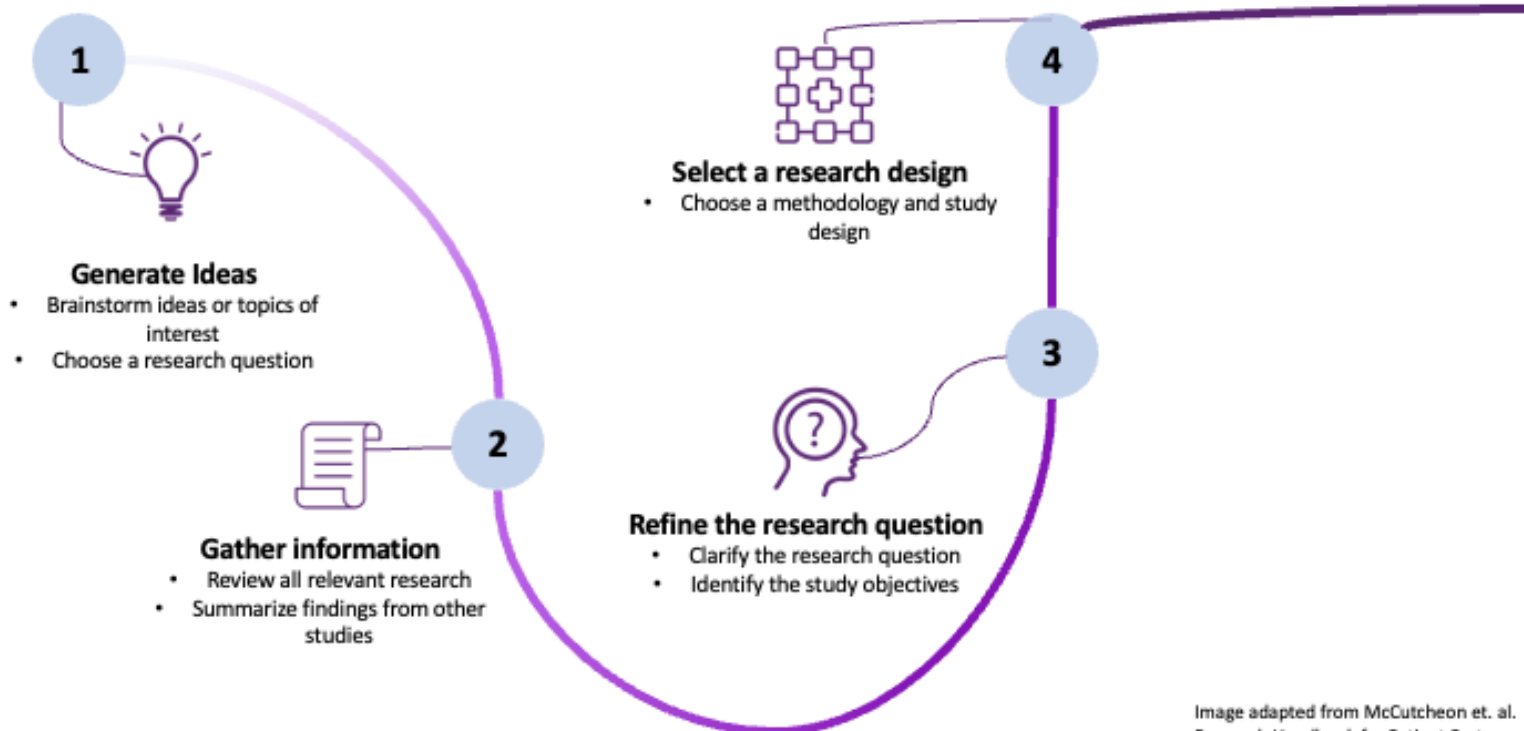
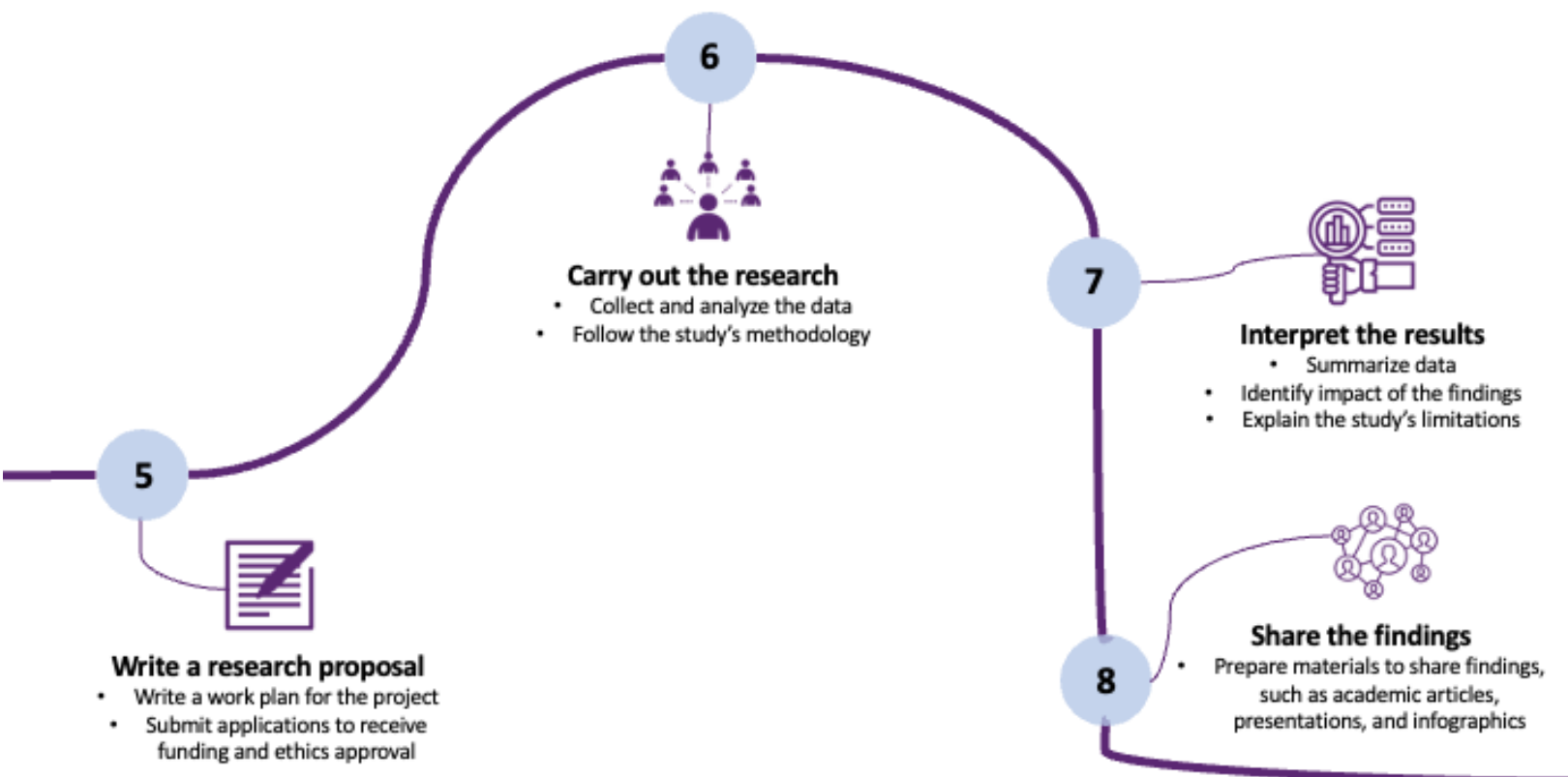


Image adapted from McCutcheon et. al.
Research Handbook for Patient Partners



Funding

Researchers can apply for funding to help them carry out their projects. There are different types of organizations that give funding (e.g. grant agencies, universities, government agencies and private companies).

Research ethics

Research ethics is a set of guidelines and policies to make sure that research is done responsibly. This includes ensuring that all participants are safe and treated with dignity. Researchers must always get ethics approval before starting their study.

Who are ‘consumer representatives’? Why should I become a consumer representative?

You may have heard of the term ‘health consumer’ before. A health consumer is any member of society who uses or is a potential user of health services, including the family and carers of patients and clients. A consumer representative is someone who represents the perspectives and experiences of many consumers in society.

Consumer representatives have different backgrounds and health care experiences.

Consumer representatives might be persons that live with or have lived with an illness, while others are caregivers or family members. Consumers also have other backgrounds (like government, business, or a student) that help them be good advocates for person-centred care.

Though the term ‘consumer’ is widely used, including by many peak bodies, it is not a term that everyone is familiar or comfortable with. We have named our panel a ‘community panel’ as this term was preferred by the panel members.



As a Consumer in the Skills Training and Education to Prevent Stillbirth (STEPS) study, I have had opportunities to actively participate, give valuable and meaningful contribution and voice my opinions and personal experiences to be an advocate in a study that I am passionate about. My participation in STEPS over the last 2 years has been personally rewarding and I feel that I have and will continue to contribute to studies and projects that will aid in Stillbirth prevention and awareness.

Gayathri

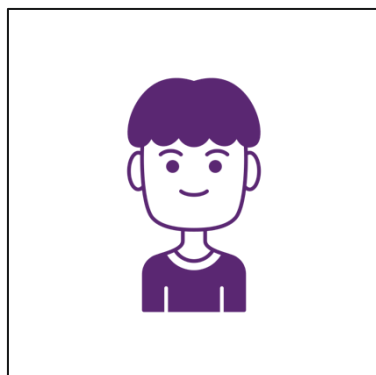
As a community member, you bring many skills to the table. Your lived experience in the healthcare system is essential to help guide our research. In addition to being experts in healthcare journeys, consumers may have other skills they can use as well, like business insights and writing skills.

When researchers and people with lived experience partner in health research, conversations about the healthcare system have more meaning. Community members help focus the research on what is important for the community to improve health care and the experiences of people within the health care system. This is called “patient-oriented research”. We need your unique thoughts to ensure that our research focuses on the true needs of patients and caregivers.



As a retired registered nurse/lecturer in nursing, being involved as a health consumer had been an extremely rewarding experience. This role has allowed me the opportunity to actively contribute to the research projects and feel a valued member of the team. Our role is to help empower patients to be actively involved in their own health care journey.

Karen



It was awesome to take part in the sciatica decision aid study! I have been open to a new world of approaching pain and its many ailments! It was a pleasure being considered for this study, to help others and provide trained professionals with some insight!

Steven

As a panel member, what are my responsibilities?

Panel members can be involved at all levels of the research process. This allows us to learn from each other and make sure that we focus on the true needs of patients and caregivers. Working together in this way is called co-design.



Ask the research team for any information or support you need. No questions is too small



Give guidance to the research team



Participate in planning how to share research findings



Participate in meetings by providing feedback and sharing your opinions



Respect the privacy of patient partners and other team members



Contribute to writing research papers



Attend meetings when possible



Help us build a network of consumers who have varied lived experiences and perspectives



Provide input and feedback on documents. No opinion is too small.

A Note on Privacy and Confidentiality

As a member of the research team, you may have access to private (anonymised) data. You must follow the policies set by privacy offices within our institution and by the research ethics boards.

Always remember that:

- When collecting participant data, we are put in a position of trust. By using common sense and good judgement, we can make sure that the integrity of the research is maintained, and private information is protected.
- Privacy also includes respecting and not repeating the stories and experiences shared by consumers.

How will the research team support me?

Research Team members take on the task of making sure that panel members are supported and have what they need to be involved.

If you choose to join our team, we will:

- Listen to you
- Be patient and respectful
- Value your time
- Respect your privacy
- Recognise your expertise
- Provide summaries of meetings (including actions and impact) and follow-up when someone was not able to attend
- Provide you with the resources you need to succeed
- Help you build new skills
- Create a safe and open environment for collaboration

How will you recognise my contribution?

We will recognise your contributions by:

- Naming you in all acknowledgements of research outputs and dissemination materials (e.g. publications, presentations, lay summaries).
- Offering you the option to be an author if you have an interest in research and wish to contribute to writing academic papers.
- Providing an honorarium for your time (\$50 per 1 hour, in the form of a gift card)

Who should I contact if I have questions?

For more information, please contact julie.ayre@sydney.edu.au

Glossary

Co-design: A process where researchers, healthcare practitioners and consumers come to together to create items for the research project, such as a survey .7

Primary care: Day-to-day healthcare given by a health care provider, such as a GP or a health care provider in a long-term care centre.

Patient: This term is used to refer to both individuals living and receiving care in the community and residents in long-term care.

Research: The act of answering important questions by gathering information in a way that can be repeated by other groups.

Research process: A series of steps taken to ensure the research is thorough and can be repeated by others.

Person-centred care: A model of care that puts patients at the forefront of their personal health care by showing respect for and responding to individual values, needs, and wants to guide all care decisions. It allows patients to move freely along a care pathway with the support of caregivers, health care partners in primary care and other areas, health care organizations, and community services when needed most in their care journey. This is sometimes referred to as “patient-centred care”.

Patient-oriented research: Research that engages people with lived experience as consumers to identify what is important to improve healthcare systems and practices

Self-management: Emphasizes the role that patients have in managing their own healthcare. Patients benefit from being engaged in their own care.