Remuneration and reimbursement guidelines for consumer involvement in health and medical research

Updated July 2025

1. Purpose

Health Consumers NSW is the peak organisation representing the interests of health consumers in NSW. Since 2011, Health Consumers NSW has supported consumers, carers and experienced consumer representatives in their work in partnering with health services, universities, and research institutes to involve health consumers in service improvement and health and medical research.

Explicitly valuing the contribution of consumers to health and medical research through remuneration and reimbursement is good practice and reflects the National Health and Medical Research Council (NHMRC) and Consumers Health Forum (CHF) of Australia *Statement on Consumer and Community Involvement in Health and Medical Research (2016)* (1). Furthermore, there is a spectrum of involvement of consumers and the community in health and medical research, ranging from inform, consult, advise, to leading the research.

These remuneration and reimbursement guidelines are for researchers, consumers, and organisations supporting or undertaking research activity that involves consumers and the community in health and medical research in NSW. There are existing pay rates for consumers involved in health services, but none in NSW for health research. They were developed in partnership with Sydney Health Partners and in consultation with health consumers, researchers, and clinicians.

2. Key Terms

The language that has been used in the field of consumer involvement in health and medical research is inconsistent and sometimes contested. There is also some debate about the use of the term "consumer" when referring to members of the wider community. The term "consumer and community involvement" or CCI is the terminology adopted and used by the Australian National Health and Medical Research Council (NHMRC) in its *Statement on Consumer and Community Involvement in Health and Medical Research* (first issued in 2002, last updated 2016) (1). The key terms used in these guidelines are listed below.

Consumer

A person who uses, has used, or is a potential user, of health services. Consumers may participate as individuals, groups, organisations of consumers, consumer representatives or communities (1, 2).

Consumer Researcher

A person who is actively involved in health and medical research and brings their lived experience to the research process. For example, in mental health "a consumer researcher refers to people who identify as having lived experience of mental health service use and have experience in, or a desire to undertake, mental health research. Consumer researchers range from the novice level to experienced researchers with doctoral qualifications and research track records" (3 p36).

Sometimes a consumer researcher may be called a 'Citizen Scientist', a person who is not a formally trained researcher who is involved in various stages of research. This involvement can occur in a broad range of disciplines such as ecology, geology, environmental science as well as health (4). Sometimes the terms consumer researcher and citizen scientist can be used interchangeably. Health consumer researchers are usually involved in health research.

Community

A group or groups of people or organisations who share common local or regional interests or characteristics. These may include, but are not limited to, culture, language, religion, beliefs, geographic location, gender or profession. Individuals may identify with more than one community and may represent a variety of interests (1).

Diversity

Diversity in health research often refers to culture, language, and religious diversity. However, diversity can also include race, sexuality, gender identity, age, disability, ethnicity, socio-economic status, and education (5). Consumers, community members and researchers may be members of many diverse groups.

Health and Medical Research

Research that aims to understand the causes, treatment and/or prevention of human diseases and/or the maintenance of human health. Health and medical research includes laboratory-based studies, clinical studies and group/community-based studies (6). It also includes translational health research which translates research evidence into policy and practice to improve health outcomes for consumers and health services (7).

Involvement

Involvement refers to a partnership between consumers and researchers, where consumers are actively involved in the research process (1, 8). It has been described as doing research 'with' or 'by' people who use health services, rather than 'to', 'about' or 'for' them (9). Consumers may be involved in a range of ways from being a consumer representative on a research committee, being a co-researcher doing the actual research, and co-writing research reports and presenting at conferences and seminars.

Remuneration

An amount of money paid to consumers for the work they have undertaken as part of their **involvement** in health and medical research.

Reimbursement

To repay or compensate a consumer for any reasonable money spent as a result of, or to enable their **involvement** in health and medical research.

3. Spectrum of consumer involvement in health and medical research

There is a spectrum of consumer involvement in health and medical research. Consumers can be involved in the planning, execution and translation of research (see Table 1) (10,11).

Table 1 – Phases and stages of health and medical research and levels of consumer involvement (inform to empower)

	Stages of research		
Level of involvement	**Planning – Agenda Setting and Determining**	**Execution – Research Design, Recruitment and Participation, and Data Analysis**	**Translation – Dissemination, Implementation and Evaluation**
Inform (for example, informing consumers via websites, social media, newsletters)	Consumers are informed about research priorities, research design, data analysis and dissemination of results, implementation and evaluation.		
Consult (for example, consulting consumers via focus groups, surveys)	Consumers give feedback about research priorities, the research design, data analysis and dissemination of results and are informed about how their input influences these activities.		
Advise (for example, involving consumers via workshops, forums and polling)	Consumers provide advice about research priorities and how to recruit participants and disseminate results		
Collaborate/ Partner (for example, partnering with consumers via committees, co-design processes, consumer researchers as co-investigators)	Consumers are partners in identifying and deciding research priorities, the research design, data analysis and dissemination of research findings.		
Empower/ Lead the research (for example, consumers commission and lead the research)	Consumers decide research priorities, develop recruitment strategies, undertake data collection and analysis, and disseminate research findings.		

Source: Adapted from (10,11)

Consumer remuneration and reimbursement amounts

Health Consumers NSW recommends that consumers **involved** in health research be remunerated for their contribution and reimbursed for expenses. This could be by cash payment, direct bank transfer or gift card.

Where possible, it is important to accommodate the consumer's preference for payment or reimbursement, however, this needs to be balanced with the finance systems and tax implications for organisations, and the tax implications for health consumers.

Every organisation is different; there may be circumstances where it is not possible to pay consumers. For example, if a consumer is a Board member established to manage a Trust Fund for research into specific conditions (and board members cannot benefit from the Trust Fund), the consumer may not be permitted to be paid. In this circumstance, it is appropriate to reimburse costs for their involvement.

The recommended payment rates for involving consumers in health and medical research (see Table 2) are based on the NSW Classification and Remuneration Guidelines for NSW Government Boards and Committees (2021) (12) and the Australian Government Remuneration Tribunal (Remuneration Allowances for Holders of Part-time Public Office) Determination 2022 legislation (13).

Health Consumers NSW has reviewed these rates, as well as consumer remuneration policies for health and medical research from other States and Territories and peak consumer organisations (14,15,16). Health Consumers NSW recommends the following remuneration for consumers involved in health and medical research in NSW (see Table 2).

Table 2 – Level of consumer involvement, remuneration activity, payment rates, and examples of good practice

Level of consumer involvement	Remuneration Activity	Payment rate	Example of Good Practice
Empower/lead the research	• Consumers lead the research project, undertake the data collection, analysis and dissemination of results • Chair or Co-Chair of Board or governance committee	$64.50 hr	Savio is a Lived Experience Researcher who works with a network of researchers working in community mental health and drug and alcohol research. Savio is working on a research project exploring the experiences of people who live with mental health issues in accessing the National Disability Insurance Scheme (NDIS). Savio is working with a team of Lived Experience Researchers and peer workers to recruit participants, interview people, analyse data and report on the research findings to improve the experiences of people who live with mental health issues in accessing the NDIS. Nimali is a consumer representative on a research advisory group and is paid $430 per day including preparation time for her involvement on the research advisory group.

Level of consumer involvement	Remuneration Activity	Payment rate	Example of Good Practice
Collaborate/ Partner – **Strategic Leadership role**	• Involvement in governance, strategy, policy, training and evaluation in CCI. For example: – Providing strategic advice on consumer involvement in health and medical research (eg participating in an Advisory Committee) – Providing health professional, consumer or researcher CCI training. – Member of Board or governance committee	$60/ hr	Peter has been a consumer representative for over 10 years and is the Chair of the Consumer Advisory Panel for a Research Centre. Peter is paid $60 per hour for chairing the Committee. Peter travels to attend the meeting and all travel and accommodation costs are paid by the Health Research Translation Centre. Mary is a consumer and provides training to researchers on involving consumers in health and medical research. Mary is paid $60 per hour and is reimbursed for travel to and from the training venue.

Level of consumer involvement	Remuneration Activity	Payment rate	Example of Good Practice
Collaborate/ Partner/Advise	Engaging directly in a health and medical research project. For example: • Working as a consumer researcher on a health research project • Standing member on an advisory group or committee for a research project. • Ongoing and regular involvement in dedicated research project • Participating in Codesign workshops • Presenting a consumer perspective at a conference or in a research working group; • Being a member of an interview panel.	$54/ hr	David lives with prostate cancer and is a consumer representative on a Project Steering Group for a health data research project in partnership with a University. David is paid $50 an hour and is reimbursed for travel costs to attend the Project Steering Committee meetings. Claudia lives with kidney disease and is invited to participate in a series of co-design workshops on identifying priorities for kidney research. Claudia is paid $50 an hour for attending and preparing for the co-design workshop

Level of consumer involvement	Remuneration Activity	Payment rate	Example of Good Practice
Consult	Engaging in activities such as providing feedback or advice on a health and medical research project. For example: • Reviewing documents • Appraising grants • Providing advice on a one-off basis • Priority setting activities	$43.50/ hr	Shanvi is a breast cancer survivor and is asked to review an information sheet for consumers on a breast cancer clinical trial. Shanvi is paid $40 per hour and is also provided access to respite care as she is the full time carer of her mother.
Inform	• Learning about engaging in Consumer and Community Involvement (CCI) in health and medical research • Attending a symposia or research event	No payment, however, Health Consumers NSW can provide research training online to consumers for free.	Bruce has been involved in consumer groups in the Local Health District and wants to get more involved in health research. Bruce attends an online introductory training on consumer involvement in health and medical research run by Health Consumers NSW. Bruce also attends a forum about consumers in research and is not paid for this attendance.

Adapted from: (13,14,15)

These rates should be increased annually as per the NSW Classification and Remuneration Guidelines for NSW Government Boards and Committees.(12).

Consumers should be reimbursed for any costs related to their involvement. Consumer reimbursement costs should be discussed and agreed prior to the commencement of the research activity. Examples of costs that consumers could be reimbursed include:

- Parking
- Travel expenses
- Overnight accommodation costs, if people need to travel significant distances to attend specific events
- Support worker costs (if a person needs a support person to travel with them or support them to participate in a meeting)
- Interpreter and translation costs (including language and or Auslan interpreters), where possible the research team should arrange for an interpreter and for information to be translated into their language before the consumer attends a meeting or event
- Childcare
- Respite care costs.

Fees and reimbursements should also be organised when:

- consumers incur costs to attend meetings that are subsequently postponed or cancelled (such as costs involved in arranging respite or childcare for the meeting).
- consumers arrive at the designated meeting place and have not been adequately informed of the postponement, cancellation, or change of location of the meeting.

4. Good practice in consumer remuneration and reimbursement

The payment or reimbursement arrangements should be explained to consumers before the beginning of their involvement in the research project. This information needs to include the name and contact details of a staff member allocated to this task.

Some consumers may prefer not to be paid or reimbursed. Where possible, it is important to accommodate the consumer's preference for payment or reimbursement, however, this needs to be balanced with the tax implications and financial accounting systems for your organisation.

It may be important for some consumers to receive assistance for travel expenses before attending the meeting or activity. It is best to discuss this with them in advance.

Payment and reimbursement needs to be made promptly. Consumers should not have to follow up with an organisation on outstanding reimbursement and payment.

References

1. National Health and Medical Research Council and Consumers Health Forum of Australia (2016), *Statement on Consumer and Community Involvement In Health And Medical Research* (Issue September), downloaded from https://www.nhmrc.gov.au/about-us/publications/statement-consumer-and-community-involvement-health-and-medical-research

2. Health Consumers NSW,(2020), *Health Consumers NSW*, downloaded from https://www.hcnsw.org.au/consumers-toolkit/who-is-a-health-consumer-and-other-definitions/

3. Happell, B., Gordon, S., & Roper, C., Ellis, P., Waks, S., Warner, T., Scholz, B., Plantania-Phung, C., (2020), Establishing an expert mental consumer research group: perspectives of nonconsumer researchers, *Perspectives in Psychiatric Care*, 57 (1), pp 33-42, https://doi.org/10.1111/ppc.12520, Available from https://minerva-access.unimelb.edu.au/items/cdcdf58f-607a-5bcc-a26b-8db7b04f3bef

4. Australian Citizen Science Association, https://www.citizenscience.org.au

5. Dune, T., Mcleod, K., Williams, R., (eds) (2021), *Culture, Diversity and Health in Australia, Towards Culturally Safe Health Care*, Routledge, London and New York

6. Australian Research Council (ARC) (2020), *ARC Medical Research Policy Version 2020.1,* Australian Research Council, downloaded from https://www.arc.gov.au/about-arc/program-policies/medical-research-policy

7. National Health and Medical Research Council (NHMRC), Research Translation downloaded from Research translation | NHMRC

8. Cancer Australia and Cancer Voices Australia, (2011), *National Framework for Consumer Involvement in Cancer Control*, Cancer Australia, downloaded from https://www.canceraustralia.gov.au/sites/default/files/publications/national_consumer_framework_web_504af020f2184.pdf

9. Research Design Service North West, Public Involvement Glossary, downloaded from https://www.rds-nw.nihr.ac.uk/public-involvement/glossary/

10. South Australian Health and Medical Research Institute (SAHMRI) (2020: 8-9), *A Consumer and Community Engagement Framework for the South Australian Health and Medical Research Institute,* Available from https://sahmri.org.au/assets/20200515_SAHMRI-Consumer-and-Community-Engagement-Framework_Version2.pdf

11. Mckenzie and Henley (2014) and (2007) *Consumer and community participation in health and medical research: A practical guide for health and medical research organisations,* Available from *https://www.telethonkids.org.au/globalassets/media/images/pagessections/research/help-shape-our-research/the-green-book-mar08.pdf*

12. NSW Government, Classification and Remuneration Guidelines for NSW Government Boards and Committees- Policy Guidelines (2021), NSW Government, Public Service Commission, Available from https://www.psc.nsw.gov.au/sites/default/files/2021-04/Classification%20and%20Remuneration%20Framework%20Guidelines%20%20April%202021.pdf

13. Australian Government, *Remuneration Tribunal (Remuneration Allowances for Holders of Part-time Public Office) Determination 2022*, Australia, Australian Government, available from PTO 2022 - Compilation No. 4.pdf (remtribunal.gov.au)

14. Monash Partners, *Monash Partners Remuneration and Reimbursement Guidelines Consumer and Community Involvement Activity*, Monash Partners, downloaded on 30 March 2022 https://monashpartners.org.au/wp-content/uploads/2020/05/Remuneration-Guidelines-1.pdf

15. VCCC Alliance, Model of Consumer Engagement, VCCC Alliance, Victoria, Available from https://vcccalliance.org.au/assets/about-vccc/Consumer-engagement/Documents/2021/bd9d1d3455/200921Model-of-CEngagement.pdf

16. Australian Government National Mental Health Commission (2019), Paid Participation Policy. Available from https://www.mentalhealthcommission.gov.au/getmedia/affffd63-8100-4457-90c7-8617f2d3c6d6/Paid-Participation-Policy-revised-March-2019

Additional Resources

Australian Clinical Trials Alliance Involvement Toolkit Budget Cost Calculator

https://involvementtoolkit.clinicaltrialsalliance.org.au/media/sbbhec00/toolkit-cost-calculator.xlsx

Involve UK

Budgeting for involvement

https://www.invo.org.uk/posttypepublication/budgeting-for-involvement/

https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/