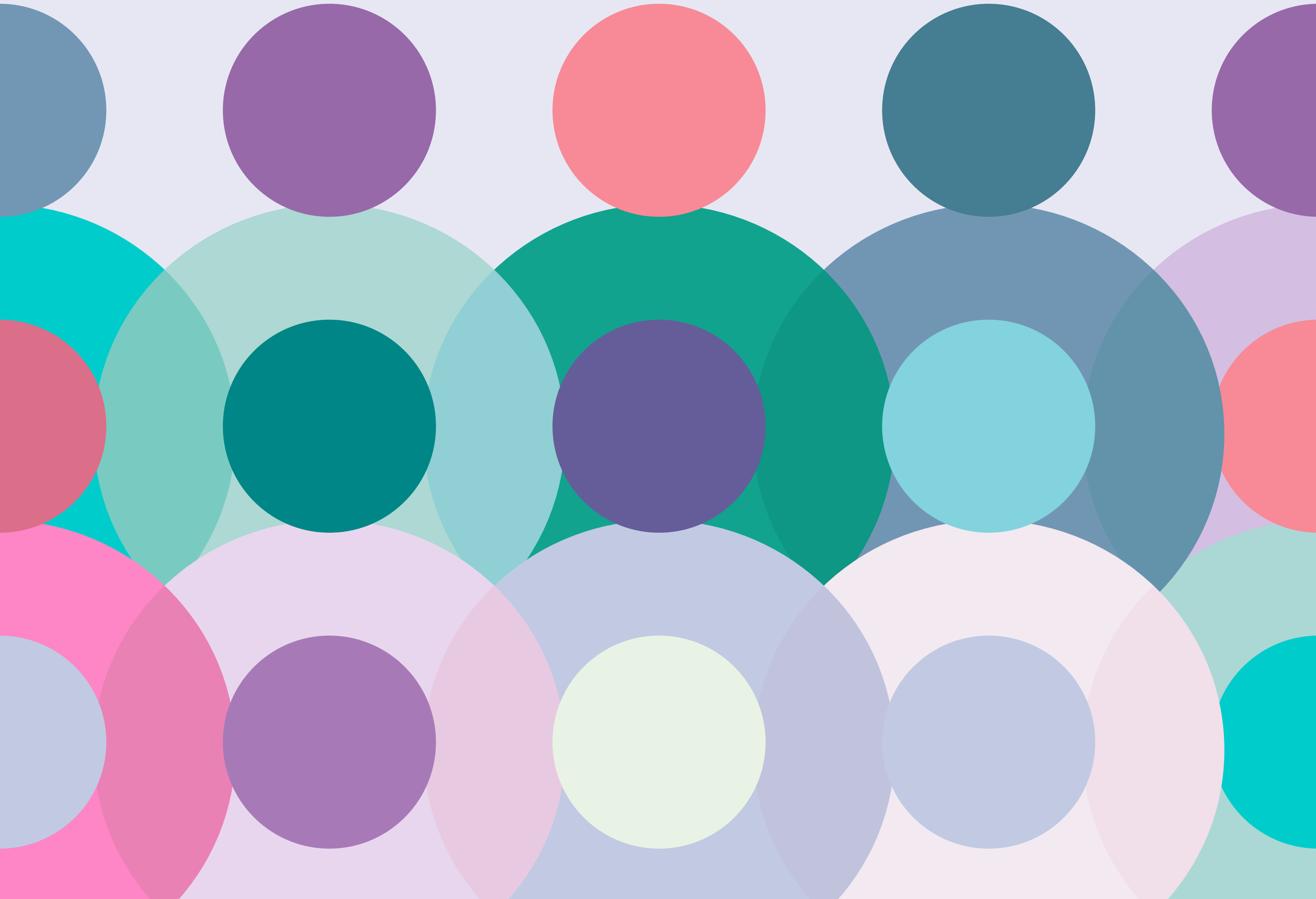
Australian Government
National Health and Medical Research Council

NHMRC

BUILDING A HEALTHY AUSTRALIA

CHF
Consumers Health Forum OF Australia

Support and resources for the Statement on Consumer and Community Involvement in Health and Medical Research



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This document is an annotated bibliography that provides links to guidance material that can help everyone embed consumer and community involvement (involvement) in research. It is intended to be read alongside the *Statement on Consumer and Community Involvement in Health and Medical Research* (the Statement). The material in this document is only some of the guidance material available. The resources will be checked regularly for currency and updated as required.

This document includes resources from the Health Research Hub, a digital platform of involvement guidance material. It also includes resources suggested by stakeholders during the 2025 draft Statement consultation. The resources are mapped to specific sections of the Statement, but many of them are also relevant to multiple values, principles, and stakeholder groups.

Disclaimer

This support and resources document includes links to, and information about, resources provided by external organisations. These links and resources are provided for information and convenience only. The inclusion of a resource does not constitute endorsement or recommendation by the National Health and Medical Research Council of the organisation, resource, product, service, or views expressed.

NHMRC takes reasonable care in identifying relevant resources but is not responsible for the content, accuracy, currency, availability or reliability of external websites or third-party material. Users should make their own assessment of whether any linked information is suitable for their circumstances.

Inclusion

Value
1

Principle 1: Involving consumers and communities across all stages and types of research.

Involvement should be considered a routine part of research, rather than something that is optional or an add-on. Involvement is also not one-size-fits-all; some resources that can guide implementation in different types and stages of research are below.

1. Health Translation Queensland. Framework for Consumer and Community Involvement in health research. healthtranslationqld.org.au/our-work/our-consumer-and-community-involvement-program/draft-framework-for-consumer-and-community-involvement-in-health-research (accessed 2 February 2026).

This is a short document aimed at researchers and their institutions. It outlines the stages of the research cycle and provides guidance on involving consumers and communities at each stage, supported by specific examples. It also offers guidance on building relationships, reducing barriers to involvement, and taking a trauma-informed approach; relevant to Principles 2, 4, and 5 of the Statement.

2. International Association for Public Participation Australasia. The IAP2 framework. healthresearchhub.com/quality-improvement-in-healthcare/approaches-to-consumer-and-community-involvement/ (accessed 12 January 2026).

This widely used framework outlines 5 levels of involvement. It explains that higher levels of involvement give consumers and communities more decision-making power and gives examples of each level in practice.

3. NSW Government: Agency for Clinical Innovation. Co-design toolkit. aci.health.nsw.gov.au/projects/co-design (accessed 14 January 2026).

This toolkit explains the co-design method and when it is appropriate to use it. While aimed at health services, the guidance can be applied to various research projects. The toolkit also explains how co-design interacts with Aboriginal ways of learning.

4. National Health Research Hub, powered by Monash University, in partnership with Australian Health Research Alliance (AHRA). Involvement in non-clinical or laboratory-based research. healthresearchhub.com/health-and-medical-research/considerations-for-non-clinical-researchers/ (accessed 15 January 2026).

This resource provides guidance on the different involvement approaches researchers can take in laboratory-based or basic science research. It acknowledges that involvement of individual consumers is appropriate in some projects and draws on case studies to support this. It also provides guidance on other involvement methods that are appropriate for basic science, such as involving consumer organisations.

5. Sydney Health Partners. Language guide for consumer and community involvement in health research at Sydney Health Partners. sydneyhealthpartners.org.au/knowledge-hub/resources/shp-language-guide-for-consumer-and-community-involvement-in-health-research/ (accessed 30 January 2026).

This resource provides definitions of commonly used terms in involvement. It provides an in-depth explanation of some concepts mentioned in the Statement, including the difference between research participation and involvement.

6. The Kids Research Institute Australia. The Aboriginal & Torres Strait Islander research standards. www.thekids.org.au/our-research/Indigenous-health/aboriginal-research-standards/ (accessed 30 January 2026).

This resource includes a detailed explanation of the Aboriginal and Torres Strait Islander Research Standards and how they interact with each stage of the research cycle.

At The Kids Research Institute Australia (The Kids), Aboriginal health is everyone's business. Improving the health and wellbeing of Aboriginal and Torres Strait Islander children and families is an overarching priority at The Kids, and their needs are integrated into all relevant areas of work. Underpinning this commitment is their Aboriginal Cultural Governance Framework which outlines 5 strategies, one of which is the Aboriginal and Torres Strait Islander Research Standards (the Standards). The Standards provide guidance for conducting research in genuine partnership with Aboriginal and Torres Strait Islander Peoples and communities, ensuring Aboriginal voices are central throughout the research lifecycle. The Standards further highlight the principles of Indigenous Data Sovereignty and Indigenous Cultural and Intellectual Property, supporting ethical, respectful and culturally informed research practice.

7. Health Research Hub. Success stories. healthresearchhub.com/resource-category/success-stories/ (accessed 25 February 2026).

This resource consists of case studies reporting on successful involvement in a range of projects and research types, including in basic science, clinical, and health services research, and with priority populations.

Respect for lived experience

Value

2

Principle 2: Recognising lived experience expertise as equal to scientific knowledge.

The below resources provide guidance on ways that respect for lived experience can be embedded in research: through power-sharing, shared decision-making, remuneration, and recognition.

8. Health Research Hub. Approaches to involvement. healthresearchhub.com/resource-category/involvement-approaches/ (accessed 13 January 2026).

This resource provides explanation of different involvement approaches, including ones that place consumers and communities in decision-making roles. It also includes case studies that show what different approaches look like in practice.

9. Research Australia and the Australian National University. Recognising consumers' contributions to health research. researchaustralia.org/wp-content/uploads/2026/03/Final-report-of-remuneration-project-2025.pdf (accessed 27 March 2026).

This report explains the development of a framework to recognise consumer and community contributions through financial and non-financial means. It suggests payment rates and payment methods, and identifies other ways of recognition, such as consumer co-authorship and professional development opportunities.

10. National Health and Medical Research Council. Consumer and community representatives in peer review for Targeted Calls for Research and Clinical Trials and Cohort Studies. www.nhmrc.gov.au/research-policy/consumer-and-community-involvement/consumer-and-community-representatives-peer-review-targeted-calls-research-and-clinical-trials-and-cohort-studies (accessed 28 January 2026).

This resource explains how consumers and community members are involved in peer review in NHMRC funding schemes. Peer review is a key decision-making role where consumers and community members can have a say in what research gets funded.

Trust and reciprocity

Value

3

Principle 3: Building relationships that benefit both the research and consumers and communities.

The below resources provide guidance on effectively building relationships in research, supported by case studies that demonstrate the benefits to consumers, communities, and the research.

11. Health Research Hub. Partnering with researchers and clinicians. healthresearchhub.com/consumer-and-communities/partnering-with-researchers-and-clinicians/ (accessed 13 January 2026).

This resource is aimed at consumers and community members. It explains what their involvement will look like at different levels and in different contexts, and how consumers and community members can initiate relationships with researchers.

12. Health Research Hub. Partnering with consumers. healthresearchhub.com/quality-improvement-in-healthcare/partnering-with-consumers/ (accessed 13 January 2026).

This resource is aimed at researchers. It provides guidance on initiating relationships with consumers and community members, including priority populations, and emphasises the importance of long-term relationships.

13. Sydney Health Partners. Connecting researchers and consumers. sydneyhealthpartners.org.au/knowledge-hub/resources/connectingresearchersandconsumers/ (accessed 2 February 2026).

This resource is designed to connect consumers, community members, and researchers. It provides contact information for consumer engagement teams at health services in NSW and consumer organisations.

14. Beks H, Amos T, Bell J, Ryan J, Hayward J, Brown A, et al (2022). Participatory research with a rural Aboriginal Community Controlled Health Organisation: Lessons learned using the CONSIDER statement. Rural and Remote Health, vol. 22. doi.org/10.22605/RRH6740 (accessed 10 April 2026).

This article is about working with Aboriginal Community Controlled Health Organisations (ACCHOs), who play a key role in leading and governing research involving their communities. It discusses use of a framework – the CONSIDER statement – to reflect on research conducted with Aboriginal and Torres Strait Islander Peoples and ACCHOs. The article highlights the need for trust building, flexible timelines and research methodologies, and protection of Indigenous intellectual property.

15. National Health and Medical Research Council. Videos and case studies for the review of the Consumer Statement. www.nhmrc.gov.au/about-us/publications/statement-consumer-and-community-involvement-health-and-medical-research/case-studies (accessed 13 January 2026).

NHMRC has co-produced a range of case studies with consumers and researchers. The case studies provide real-world examples of the benefits involvement brings to consumers, communities, and research. The case studies describe how lived experience has transformed research methodology in a range of projects, ensuring the outcomes are relevant and impactful.

16. Snijder M, Wagemakers A, Calabria B, Byrne B, O'Neill J, Bamblett R, et al (2020). We walked side by side through the whole thing: A mixed-methods study of key elements of community-based participatory research partnerships between rural Aboriginal communities and researchers. Aust. J. Rural Health, vol. 28, no. 4, pp.338–350. onlinelibrary.wiley.com/doi/full/10.1111/ajr.12655 (accessed 30 January 2026).

This article reports the results of a study that examined community-based participatory research methods in rural Aboriginal communities. It highlights the need for impactful research to be built on equal relationships and the complementary expertise of communities and researchers.

Equity and diversity

Value

4

Principle 4: Supporting equitable involvement by addressing barriers that have traditionally excluded diverse voices.

The following resources view diversity through a strengths-based lens and offer practical ways to ensure equitable involvement.

17. Health Research Hub. Key resources: Inclusive engagement. healthresearchhub.com/key-resources/ (accessed 13 January 2026).

The *Inclusive engagement* tab on this webpage lists multiple resources that can guide researchers when working with priority populations.

18. The Australian Centre for Health, Independence, Economic Participation and Value Enhanced Care for adolescents and young adults with cerebral palsy (CP-ACHIEVE). Navigating consumer involvement in health and disability research. www.mcri.edu.au/research/strategic-collaborations/centres/centre-research-excellence-cerebral-palsy (accessed 13 January 2026).

CP-ACHIEVE was a program funded by the NHMRC's Centres of Research Excellence scheme. This detailed resource provides guidance on embedding and funding involvement in research, supporting researchers, and building safe environments and relationships. Many of the resource's strategies and case studies have broad application to health and disability research.

19. Western Australian Health Translation Network Consumer and Community Involvement Program. Involving people with disability in research: The CP-ACHIEVE Story (webinar). healthresearchhub.com/cp-achieve/ (accessed 13 January 2026).

In this webinar, consumers and researchers involved in the CP-ACHIEVE program share the successes and challenges of their involvement program, and offer strategies for creating a safe, accessible research environment for people with disability.

20. National Health and Medical Research Council. Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders. www.nhmrc.gov.au/about-us/publications/ethical-conduct-research-aboriginal-and-torres-strait-islander-peoples-and-communities (accessed 30 January 2026).

This resource explains the importance of community leadership in research conducted with Aboriginal and Torres Strait Islander Peoples. It acknowledges the need to consider diversity between and within communities. It also highlights the need for reciprocal relationships, cultural safety, and transparency in the research process; relevant to Principles 2, 5 and 6 of the Statement.

21. National Health and Medical Research Council. Keeping research on track II. www.nhmrc.gov.au/about-us/publications/keeping-research-track-ii (accessed 30 January 2026).

This resources explains how the *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders* can be put into practice in research.

22. Health Consumers NSW and Research4Me. Involving health consumers in health and medical research: Enablers and challenges from a consumer perspective. hcnsw.org.au/training-resources/resources/publications/involving-health-consumers-in-health-and-medical-research-enablers-and-challenges-from-a-consumer-perspective/ (accessed 30 January 2026).

This resource reports on a workshop that identified barriers to involvement in research and key enablers that can help overcome them. It also addresses topics that are relevant to other sections of the Statement, including the importance of consumer and researcher training, defined consumer roles in research, and use of accessible language.

23. Chauhan A, Leefe J, Shé, ÉN, Harrison R (2021). Optimising co-design with ethnic minority consumers. Int J Equity Health, vol. 20, no. 240. doi.org/10.1186/s12939-021-01579-z (accessed 30 January 2026).

This article discusses diversity within priority populations, with a focus on ethnic minority groups. It notes that within communities there are voices that are often unheard, and it offers strategies to overcome barriers to their involvement.

Safety

Value

5

Principle 5: Ensuring involvement in research does no harm to consumers and communities by prioritising their wellbeing.

The resources below outline ways to create a safe research environment for everyone involved. Many of the documents listed under value and principle 4 are also relevant to ensuring safety.

24. Victorian Government. Framework for trauma-informed practice: Supporting children, young people and their families. healthresearchhub.com/resources/framework-for-trauma-informed-practice-2022/ (accessed 13 January 2026).

This framework provides an explanation of trauma and trauma-informed practice. It is not aimed specifically at a research audience, but offers guidance that can support trauma-informed practice in any field.

25. Health Research Hub. Key elements of effective involvement: Ensuring ethical standards and research integrity. healthresearchhub.com/health-and-medical-research/partnering-with-consumers/ (accessed 13 January 2026).

The *Ensuring ethical standards and research integrity* tab on this webpage contains adapted frameworks that can guide researchers in ethical involvement and harm minimisation.

26. Mathias H, Duff E, Schulz P, et al. Rural community-based participatory research with families of people who use drugs: Key considerations from a multi-provincial research partnership. Harm Reduct J, vol. 22, no. 92. doi.org/10.1186/s12954-025-01247-3 (accessed 30 January 2026).

This article discusses ensuring safety in community-based research with families of people who use drugs in rural Canada. It examines themes including intersectionality, hesitancy to engage in research among populations who experience stigma, and the importance of early involvement to establish trust. The themes in this article are also relevant to Principles 3 and 4 of the Statement.

27. Lived Experience Australia and Community Mental Health Drug and Alcohol Research Network. Safe research partnership with people with lived and living experience. www.livedexperienceaustralia.com.au/safe-research-partnerships (accessed 25 February 2026).

This resource consists of 3 documents that can help everyone involved in research to create a safe environment. One of these documents is aimed at people with lived or living experience (the Statement uses the term consumers and communities). It offers guidance on how people with lived or living experience can prepare for their role in research, and how to navigate power dynamics and protect their wellbeing.

The other 2 documents are aimed at researchers. One is a checklist of recommendations for researchers when working with people with lived and living experience. Many of the recommendations are also relevant to other aspects of the Statement, such as demonstrating respect for lived experience and the importance of establishing roles and expectations early in a project. The other document provides a framework that researchers can use to ensure a safe environment when working with people who have lived or living experience of mental illness or ill-health.

Value

6

Transparency and accountability

Principle 6: Committing to honest communication throughout research.

The below resources offer practical guidance material on continuous and honest communication throughout the research cycle, with an emphasis on establishing agreements in the early phases of research.

28. Australian Clinical Trials Alliance and Clinical Trials: Impact & Quality (CT:IQ). Toolkit for researchers and research organisations: Providing feedback to consumers. involvementtoolkit.clinicaltrialsalliance.org.au/toolkit/undertaking/providing-feedback-to-consumers/ (accessed 30 January 2026).

This resource emphasises the importance of communication with consumers and communities throughout research. This webpage is part of a broader Toolkit that provides guidance on involvement in clinical trials. It is available at: involvementtoolkit.clinicaltrialsalliance.org.au/toolkit/.

29. Australian Clinical Trials Alliance and Clinical Trials: Impact & Quality (CT:IQ). Involvement resources. involvementtoolkit.clinicaltrialsalliance.org.au/toolkit/resources/#involvement-resources (accessed 2 February 2026).

This webpage includes downloadable resources that researchers and their institutions can adapt. Some resources are especially relevant to value and principle 6: *Consumer involvement agreement, Ground rules,* and *Interview script.*

30. Health Research Hub. Strategies for evaluation and success. healthresearchhub.com/health-and-medical-research/approaches-to-consumer-and-community-involvement/ (accessed 13 January 2026).

The tab: *Managing for success* on this webpage lists common challenges, often communication-related, that can inhibit effective involvement. The tab: *What to do if things go wrong* provides guidance on conflict resolution, and highlights the importance of involvement early in research to minimise issues.

Resources for consumers and community members

The following resources provide information for consumers and community members about research and how to get involved.

31. Health Research Hub. Consumers and community members: Getting started. healthresearchhub.com/consumer-and-communities/getting-started/ (accessed 13 January 2026).

This resource explains some of the ways that involvement can benefit consumers. It also outlines some responsibilities consumers and community members have when they are involved in research.

32. Australian Clinical Trials Alliance and Clinical Trials: Impact & Quality (CT:IQ). Consumers. involvementtoolkit.clinicaltrialsalliance.org.au/consumers (accessed 30 January 2026).

This webpage includes stories from consumers who have been involved in research and information on clinical trials in multiple languages. It also includes a link to a Consumer Involvement Pack that explains what consumers and community members can expect when involved in research.

33. Cancer Council. Consumers in research training. www.cancer.org.au/online-resources/elearning/consumers-in-research-training (accessed 2 February 2026).

This online course consists of 4 modules designed to prepare consumers and community members to be involved in research.

Resources for researchers

34. Health Research Hub. Key elements of effective involvement. healthresearchhub.com/health-and-medical-research/partnering-with-consumers/ (accessed 14 January 2026).

The tab: *Finding the right consumers for your research* provides strategies to identify suitable consumers and community members. The tab: *Ways of involving consumers and community members* emphasises the importance of planning for involvement and lists ways it can be done at different research stages.

35. Sydney Health Partners. Guide: Describing and assessing consumer involvement in health research in funding applications. sydneyhealthpartners.org.au/knowledge-hub/resources/guide-describing-and-assessing-consumer-involvement-in-health-research-in-funding-applications/ (accessed 30 January 2026).

This resource contains guidance on describing and assessing involvement in grant applications. It was developed to support researchers applying to Sydney Health Partners for funding, but could also be used to guide applications to other research funders. It also includes guiding questions that can assist researchers in involvement planning and ensuring genuine involvement.

Roles and responsibilities

36. Involve. Community cohesion and participation – a practical framework. www.involve.org.uk/resources/knowledge-base/resources/community-cohesion-and-participation-practical-framework (accessed 30 January 2026).

This framework guides working with communities. It emphasises the need to meet communities where they are, gain an understanding of the local context, and ensure all voices are heard.

37. Australian Genomics. Guidelines for community involvement in genomic research. doi.org/10.25374/MCRI.29826473 (accessed 6 March 2026).

This is a detailed resource written from the perspective of community members. It provides recommendations to researchers on how to involve community members in genomics research. It focuses on building relationships, setting clear expectations, acknowledging contributions, evaluating involvement, and research translation.

38. Monash Partners. eLearning modules for consumer and community involvement. monashpartners.org.au/education-training-and-events/cci/ (accessed 14 January 2026).

This online training course consists of 6 modules designed to help researchers embed involvement in research.

39. Arnstein L, Wadsworth AC, Yamamoto BA, Stephens R, Sehmi K, Jones R, et al (2020). Patient involvement in preparing health research peer-reviewed publications or results summaries: A systematic review and evidence-based recommendations. Res Involv Engagem, vol. 6, no. 34. doi.org/10.1186/s40900-020-00190-w (accessed 30 January 2026).

This article reports on a systematic review of involvement in authoring publications and lay summaries. It identifies recommendations for researchers to consider when including consumers and community members as co-authors on publications.

40. Involve. How can CQC meaningfully assess public engagement in the health and social care sector? www.involve.org.uk/our-work/our-projects/how-can-cqc-meaningfully-assess-public-engagement-health-and-social-care (accessed 16 March 2026).

This report summarises the results of research undertaken by Involve exploring what quality involvement looks like in health and social care systems in the United Kingdom. While it focuses on health systems, many of the topics it reports on are relevant to involvement in research. These include avoiding tokenism, planning, and hearing diverse voices.

Roles and responsibilities

Resources for research institutions

41. Reeder S, Teede H, Cahill A, Ng A, Jones A. Consumer and community involvement implementation guide for research organisations: Embedding consumer and community involvement in health and medical research into organisational systems. healthresearchhub.com/resources/monash-centre-for-health-research-implementation-monash-partners-consumer-and-community-involvement-implementation-guide-for-research-organisations/ (accessed 2 February 2026).

This implementation guide was developed through a national survey and outcomes of the first consultation process for the review of the Statement, which was facilitated by AHRA in 2024. It details how and why to embed involvement in institutional policies, strategies, and procedures. A collection of the resources cited in this guide are available at: healthresearchhub.com/resource-category/implementation-guide/.

Resources for multiple stakeholder groups

42. Department of Health, Disability and Ageing: Medical Research Future Fund Consumer Reference Panel. Principles for consumer involvement in research funded by the Medical Research Future Fund. www.health.gov.au/resources/publications/principles-for-consumer-involvement-in-research-funded-by-the-medical-research-future-fund (accessed 19 March 2026).

This resource was developed by the MRFF's Consumer Reference Panel for consumers, researchers, research institutions, and other health and medical research stakeholders. It sets out principles for consumer involvement that should be referenced when applying for MRFF grant funding. The Statement is intended to be complementary to the MRFF Principles, rather than duplicative.

43. Canberra Health Services Office of Research and Education. Partnering with our consumers in health research. www.canberrahealthservices.act.gov.au/about-us/canberra-health-services-research/partnering-with-our-consumers-in-research (accessed 19 March 2026).

This website contains a suite of resources aimed at consumers, carers and health services researchers. The Researcher Toolkit provides practical guidance on building relationships with consumers and carers.

The Consumer and Carer Research Partner Toolkit is aimed at consumers and carers who are new to research. It explains the roles and rights of consumers and carers in research, supported by real-life examples. It also provides explanation of the levels of involvement, the difference between research participation and involvement, and the stages of the research cycle.

44. Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS). The AIATSIS code of ethics for Aboriginal and Torres Strait Islander research. aiatsis.gov.au/research/ethical-research/code-ethics (accessed 13 April 2026).

Two resources are available for download at this link: the *AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander research* and *A guide to applying the AIATSIS code of ethics for Aboriginal and Torres Strait Islander research.* Both are aimed at researchers and ethics committees and guide the ethical conduct of research with Aboriginal and Torres Strait Islander Peoples, with an emphasis on Indigenous leadership, self-determination, and governance.

Roles and responsibilities

45. Morey K, Franks C, Pearson O, Glover K, Brown A. Research ACCORDing to whom? Developing a South Australian Aboriginal and Torres Strait Islander health research accord. First Nations Health and Wellbeing – the Lowitja Journal, vol 1. www.lowitjajournal.org.au/article/S2949-8406(23)00003-7/fulltext (accessed 26 March 2026).

This article explains the development of a South Australian Aboriginal and Torres Strait Islander health research accord. It discusses 9 principles designed to guide researchers, research institutions, government, and ethics committees in the ethical conduct of research with Aboriginal and Torres Strait Islander Peoples.

46. Western Australian Health Translation Network Consumer and Community Involvement Program. Consumer and community involvement in health research online course. www.retprogram.org/training/consumer-and-community-involvement-in-health-research (accessed 14 January 2026).

This short online course provides an introduction to involvement. It is suitable for anyone involved in research.

47. Western Australian Health Translation Network. Involving consumers in health and medical research – A practical handbook for organisations, researchers, consumers and funders. www.retprogram.org/training/consumer-and-community-involvement-in-health-research (accessed 14 January 2026).

This resource provides implementation guidance for all stakeholder groups mentioned in the Statement. It can be used to help stakeholders understand their own role and that of other stakeholders.

48. WAHTN Consumer and Community Involvement Program. Events and Training. involvementprogram.org/events-and-training/ (accessed 25 February 2026).

This website lists upcoming training courses (called Masterclasses) for consumers, community members, and researchers. It also offers Community Conversations events designed for people with lived experience of a specific health issue. Some Masterclasses and Community Conversations are held online while others are in-person (in Western Australia only).