Australian Government
National Health and Medical Research Council

Review of the 2016 *Statement on Consumer and Community Involvement in Health and Medical Research*

Environmental Scan

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Introduction

This Environmental Scan provides a snapshot of the global literature relating to consumer and community involvement in health and medical research. This paper is produced in the context of NHMRC's review of the 2016 *Statement on Consumer and Community Involvement in Health and Medical Research* (The Statement) in 2023-2024. The Statement provides the key to developing stronger partnerships between researchers, consumers and community members at all levels of health and medical research in Australia, by providing guidance to research institutions, researchers, consumers and community members. NHMRC has undertaken this environmental scan at the request of the Consumer Statement Advisory Committee (CSAC), NHMRC's committee of consumer and community experts who provide advice on consultation and engagement to support the Statement's review process.

The purpose of the scan is to review the relevant grey and academic literature to identify the principles underlying good practice in consumer and community involvement in health and medical research, along with the roles and responsibilities for funders, research institutions, researchers and consumers for consumer involvement in health and medical research. This enables NHMRC to situate the revised Statement within the context of global practice.

This summary paper is also a useful resource for researchers and institutions seeking guidance and further resources to support the implementation of consumer and community involvement in research projects. The international literature includes detailed frameworks and guidance documentation to support good practice in consumer and community involvement in research. These have been referenced in the analysis of Principles and Roles and Responsibilities sections of this paper and outlined in the Annotated Bibliography in the Reference and Resources section. The purpose of this is to introduce the existing quality resources to provide more detailed implementation support to research teams looking to improve consumer involvement.

This paper is a summary of the global literature and should not be read as NHMRC's position on consumer and community involvement in health and medical research. This paper can be read together with The Statement. NHMRC will publish a revised Statement following the completion of stakeholder engagement activities and additional consultation processes.

Methodology

The paper is not intended to be an academic analysis nor systematic review. It draws upon applied research methods but is not an academic research paper. The scan was conducted as a desktop review of relevant resources.

The resources reviewed in the scan have been identified using the 'snowball search' method. Using academic and applied resources provided by CSAC members, policies, frameworks and academic papers have been identified within the bibliographies of each of the resources reviewed.

This summary paper provides a succinct analysis of the global literature to be useful to consumers, research teams and research institutions involving consumers in research activities. The paper is structured in the following sections: Principles; Roles and Responsibilities; and References and Resources. The Principles section provides a thematic analysis of the key principles covered in the literature. The Roles and Responsibilities section outlines the possible roles and responsibilities for the different participants - consumers, researchers, research institutions, and funders. These roles have been mapped against the research lifecycle for each group of participants. The References and Resources section is an annotated bibliography which identifies the literature used in the review, with detail provided on each resource and how the resource might be useful for research teams planning consumer involvement activities.

Principles of Consumer and Community Involvement in Health and Medical Research

The scan of the literature identified the core principles that underlie guidance for consumer involvement in health and medical research. While some documents explicitly list principles for consumer involvement in health and medical research, other documents outline the factors that contribute to effective consumer engagement by research teams. In each case, the literature has been reviewed to identify the underlying principles articulated in the document. The principles that have emerged in this review are identified using **bolded text** and have been grouped thematically around 4 broad themes:

- Collaboration and Partnership
- Respect for Experience and Expertise
- Supporting Skills and Capacity
- Equity and Justice

Collaboration and Partnership

The theme of collaboration and partnership emphasises meaningful "involvement of consumers from the beginning" (McKenzie) of the research process and throughout the research lifecycle, with the understanding that "partnering with the community is necessary to create change and improve health" (*Principles of Community Engagement 2011*).

The principle of **meaningful involvement throughout the research life cycle** is outlined in Cancer Australia's National Framework for Consumer Involvement in Cancer Control which states that the "organisation is committed to meaningful consumer engagement by integrating consumer involvement in all aspects of organisational practice, processes and systems from governance structures through to service delivery, policy development, research and evaluation" (*Cancer Australia 2011*).

Similarly, the Autism CRC Participatory and Inclusive Autism Research Practice Guidelines states that "Our research will be conducted in partnership with autistic people and their supporters: Autistic people and their supporters will, wherever possible, be involved in the production of Autism CRC research. Where practical, this involvement will occur at the level of co-production or higher" *(den Huting J. 2021).*

Co-production emphasises research undertaken and produced in partnership with consumers, where consumers are involved in the production of the research itself, rather than as participants, subjects or external advisers. "In co-production, researchers and community members work together as equal partners from the beginning of the research process. Researchers and community members jointly agree on a research question to answer, and together they design and conduct the research project. Researchers and community members share power and control all throughout the research process". **Co-producing** research is an ideal avenue for consumers to be meaningfully involved in the research lifecycle, though may not be appropriate for all research projects.

However, consumers can still be involved in **co-deciding/shared decision making** in which "Meaningful community participation extends beyond physical involvement to include generation of ideas, contributions to decision making, and sharing of responsibility" *(Principles of Community Engagement Second Edition 2011).*

A key element of shared decision making is reciprocal relationships, a principle outlined in the PCORI Engagement Rubric produced by the US-based Patient-Centred Outcomes Research Institute, which considers the principle of reciprocal relationships to be met when "the roles and decision-making authority of all research partners, including the patient and other stakeholder partners are defined collaboratively and clearly stated" *(PCORI Engagement Rubric 2016).*

Effective community involvement and shared decision-making enables the research to produce **shared benefits** to researchers and communities. Shared benefits can be realised when consumers are involved throughout the research lifecycle. "The desired objectives are mutually agreed in these groups and used to monitor and sustain the effectiveness of consumer engagement. Consumers and professionals supported by systems, work together to act for mutual benefit. The purpose, goals and outcomes of the group are well described and understood by all participants. This element includes the development of performance measures to facilitate learning and build knowledge in areas where consumer involvement can make the greatest difference" *(Cancer Australia 2011).*

Shared benefits may include measurably improved patient outcomes as a result of the research intervention *(Syed et al 2010)*, though such clear and immediate improvements are not guaranteed or may not be immediately apparent. Shared benefits of the research may aim for improved support *(den Huting J. 2021)*, or the production of research evidence that is mutually beneficial *(The Statement of Principles for Consumer Involvement in Cochrane 2015).*

Respect for Experience and Expertise

The theme of respect for experience and expertise is observed in the global literature, covering respect for the lived experience and cultural expertise of consumers and community members and for community skills and assets, along with respect for research expertise and mutual trust. Effective collaboration and partnership is made possible where there is **respect for lived experience and community expertise** and acknowledgement of value that consumer involvement can offer the research process. "Obtaining meaningful community participation and having a successful, sustained initiative require that engagement leaders respect, listen to, and learn from community members" *(Principles of Community Engagement Second Edition 2011).* This recognises that "positive change is more likely to occur when community members are an integral part of a program's development and implementation. All partners must be actively respected from the start" *(Principles of Consumer Engagement Second Edition 2011).*

Respecting lived experience acknowledges that consumers can offer new insights into a research area that may not be identified without consumer involvement. "The contributions of patients can be extremely valuable, providing alternative views from those of the research team or NHS staff. Patients are able to make judgements based on their understanding of their condition and may have different aspirations and thoughts about health outcomes that health care professionals and researchers may not have considered" *(Patient and Public Involvement in Health and Social Care*

Research: A Handbook for Researchers 2014). This principle of respect for lived experience and community expertise includes cultural, linguistic, ethnic and geographic diversity, which will influence how consumer involvement is designed and managed. "Consumers from Aboriginal and Torres Strait Islander, culturally and linguistically diverse and regional, rural and remote communities are engaged in an appropriate and culturally safe manner" (Cancer Australia 2011).

The principle of **mutually respectful relationships** acknowledges that this respect is a reciprocal process that can lead to better research outcomes. This is outlined in the UK Standards for Public Involvement produced by the NHS, which includes the core principle "Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships. Public involvement in research is better when people work together towards a common purpose, and different perspectives are respected" *(UK Standards for Public Involvement n.d).*

Engaging in the research process with attention paid to mutually respectful relationships ensures that both the expertise of researchers, and the expertise that lived experience brings to the research, are valued and can be utilised to the benefit of the research. This may include the development of **equitable partnership** with consumers and communities. The Patient-Centred Outcomes Research Institute considers this principle to be demonstrated when "time and contributions of patient and other stakeholder partners are valued and demonstrated in fair financial compensation, as well as in reasonable and thoughtful requests for time commitment by patient and other stakeholder partners. When projects include priority populations, the research team is committed to diversity across all project activities and demonstrates cultural competency, including disability accommodations, when appropriate" *(PCORI Engagement Rubric 2016).*

Key to respectful relationships is the principle of **transparency and trust**, which ensures that all parties to the research project understand and can be included in decision-making and have the opportunity to influence the research process. "Transparency, Honesty and Trust: These principles are demonstrated when major decisions are made inclusively and information is shared readily with all research partners. Patients, other stakeholders and researchers are committed to open and honest communication with one another" *(PCORI Engagement Rubric 2016).*

Supporting Skills and Capacity

To build and sustain long term collaboration, research institutions, researchers and consumer advocates should pay attention to **support and learning** to build skills and capacity for consumer involvement. This includes supporting the skill development of consumers for engaging in the research process and skills for researchers in consumer and community involvement. Supporting learning and skills development for both consumer and researchers can ensure more effective consumer involvement in the research process. "Effective consumer engagement occurs in groups or teams and therefore education of those teams in the benefits of consumer engagement and how to engage, is important. Professionals who involve consumers benefit from education to prepare them to incorporate the consumer experience into team activities" *(Cancer Australia 2011).*

Supporting skills and capability also recognises that there already exist skills and capacity within the community which can benefit the research process and research outcomes. Research teams can **utilise and develop the skills and expertise within the community** to better sustain consumer involvement in research. "Community engagement can only be sustained by identifying and mobilizing community assets and strengths and by developing the community's capacity and resources to make decisions and take action" *(Principles of Community Engagement Second Edition 2011).* For some research interests, this may lead to greater community control over research. For example, the Autism Research Centre for Research Collaboration Inclusive Participatory and Inclusive Research Practice Guide states this as an aim for their consumer involvement and support for autistic research capacity "We will continue to work with the autistic community in developing research skills and experience, to facilitate greater community control in autism research" *(den Huting J. 2021).*

Equity and Justice

The theme of equity and justice emphasises the possible role for consumer and community involvement to contribute to greater equity and justice in health outcomes. The principles identified in this thematic area speak to increasing accessibility for participation in health research, reducing the exclusion of marginalised community groups from participating in health research and addressing inequality through health research.

Health research can be used as a way of **addressing inequality** and improve health outcomes for diverse populations. "If health is socially determined, then health issues are best addressed by engaging community partners who can bring their own perspectives and understandings of community life and health issues to a project. And if health inequalities are rooted in larger socioeconomic inequalities, then approaches to health improvement must take into account the concerns of communities and be able to benefit diverse populations" *(Principles of Community Engagement Second Edition 2011).*

When undertaking consumer involvement activities, it should also be noted that inequalities can exclude marginalised groups from the process unless attention is paid to addressing inequality in process "Factors such as systemic racism, historical abuses, structural discrimination, and lack of knowledge on the benefits of research participation might preclude underrepresented groups from engaging in research. Researchers, healthcare providers who contribute to research recruitment, and research institutions might also inadvertently perpetuate these structural barriers to participation through implicit or unconscious biases, as well as the development of research infrastructure and practices that fail to promote broader engagement or inclusion. For this reason, efforts to broaden benefits [of research] must begin with meaningful engagement with historically and currently underrepresented communities" *(Lemke, A. et al 2022).*

Consumer involvement, when conducted with attention to addressing inequality, can also result in greater justice in research outcomes "Community-engagement practices can help identify community perspectives on how best to address justice concerns, including ensuring access to the downstream benefits of research within underserved communities and assessing the possible distribution of gains or profits" *(Lemke, A. et al 2022).*

Addressing inequality through consumer involvement in research requires research teams to pay attention to **accessibility, diversity and inclusion** in their activities. The UK Standards for Public Involvement highlights this principle "Offer public involvement opportunities that are accessible and that reach people and group according to research needs. Research to be informed by a diversity of public experience and insight, so that it leads to treatments and services which reflect these needs" *(UK Standards for Public Involvement n.d.).* Similarly, "Cochrane recognises and respects the diversity of its consumer contributors, values people's differences in the way they contribute, and acknowledges that promoting an inclusive approach to their involvement means that consumers can contribute to their full potential" *(The Statement of Principles for Consumer Involvement in Cochrane 2015).* The use of accessible communication and plain language is particularly noted as important to consumer involvement "Use plain language for well-timed and relevant communications as part of involvement plans and activities. Communicate with a wider audience about public involvement and research, using a board range of approaches that are accessible and appealing" *(UK Standards for Public Involvement n.d.).*

Roles and Responsibilities

The review of the literature identified a number of possible roles for consumers in health and medical research, to support the research process from identification and design through to dissemination and evaluation. The intention of these roles is to contribute to improved design and applicability research, and dissemination of research findings[1]. The various roles identified in the literature have been mapped against the research lifecycle in **Table 1**.

The roles that researchers and research institutions play in facilitating consumer involvement in health and medical research is also covered extensively by the literature reviewed. Roles for researchers lie in the development of mutually beneficial relationships between community and researchers to facilitate consumer involvement throughout the research lifecycle. The roles for researchers identified in the literature have been documented in **Table 2**. Roles for research institutions lie in research governance, policy and procedures and resourcing. These roles have been identified in **Table 3**.

The role that funders play facilitating and encouraging consumer involvement in health and medical research is not covered in the same level of depth in the literature. Two of the papers specifically addressed the roles for funders. These roles lie at the level of setting expectations (such as through policy and guidelines), identification of research topics, funding decision-making and resourcing. The roles and responsibilities for funders are identified in **Table 4**.

Each table includes identifies reference documents that mention the roles and responsibilities, Refer to the numbered documents with the References and Resources section.

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[1] Shippee et al. Patient and Service User Engagement in Research: A Systematic Review and Synthesized Framework, Health Expectations 2013

Table 1: Roles and Responsibilities for Consumers

Research Phase[2]	Possible Roles for Consumers	References
Identifying and Prioritising	Inform research topics and priorities to ensure relevance to consumers	[4] [5] [14] [16]
	Identify topics for research	[4] [14] [17]
	Funding application review, prioritisation and decision making (in collaboration with research funders)	[14] [17]
Design	Clarify the research questions	[4]
	Identify patient appropriate research methods	[4]
	Assist in development of the recruitment strategy for study participants	[4] [17]
	Defining the characteristic of study participants to ensure relevance	[5]
	Designing study to minimise disruption to research participants and aid retention of study participants	[5]
	Provide feedback proposed questionnaires and data collection methods	[4]
Development of the Grant Proposal	Advise on research ethics from a consumer perspective	[4]
	Identify opportunities for consumer involvement in research activities	[4]
	Define outcome measures	[4] [16]
	Assist in the development the Lay Summary for consumers and the public	[4]
	Be named as co-applicants on the research project	[4]
Undertaking and Managing	Provide ongoing advice as a member of the research steering group	[4] [16] [17]
	Assist in writing consent forms for research participants	[4]
	Produce research updates in accessible language for consumers	[4]
	Assist in data collection by conducting interviews and surveys	[4] [5] [16] [17]
	Assist the research team in developing themes from the data	[4]

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[2] Research Phases adapted from NHS National Institute for Health Research Patient and Public Involvement in Health and Social Care Research: A Handbook for Researchers

Analysing and Interpreting	Be consulted to see if they understand and interpret the data in the same way as the research team	[4] [5]
	Assist with data analysis	[16]
Dissemination	Identify dissemination avenues to reach consumers and stakeholders	[4] [5] [16]
	Jointly present research findings with researchers	[4] [5]
	Write accessible research summaries for consumers and stakeholders	[4] [5]
Implementation	Develop consumer information for new services and interventions within health care services	[4]
Monitoring and Evaluation	Collaborate with researchers to evaluate the research process	[4] [16] [17]

Table 2: Roles and Responsibilities for Researchers

Research Phase	Possible Roles for Researchers	References
Identifying and Prioritising	Identify or self-select to act as Champions for consumer involvement in research	[3]
	Learn about the community and culture of the consumer group and identify key stakeholders and community leaders for consumer and community engagement	[12]
	Consider diversity when involving community members to ensure that the research will benefit diverse communities	[2]
	Develop mutually respectful relationships with consumers and stakeholders for research collaboration	[10] [12]
	Building and sustaining formal and informal networks for consumer involvement in research	[6]
Design	Plan and offer consumer involvement opportunities that are accessible according to research group needs	[10]
	Mobilise consumer communities for decision making	[6]
	Co-develop research plan in partnership with consumer community	[12]
	Co-develop community engagement evaluation metrics in partnership with consumer community[3]	[12]
	Co-design a communication plan to ensure effective engagement	[2]
Development of the Grant Proposal		
Undertaking and Managing	Clarify the roles that each consumer will play in the research project and who they represent (themselves as individuals or their community)	[2]
	Offer learning and support opportunities for researchers and consumers that can help remove barriers to consumer involvement in research activities[4]	[10] [12]
	Use plain language communication to ensure accessible communication for consumer involvement in research activities[5]	[10]
	Take a trauma-informed approach to consumer engagement to ensure that participation in research provides inclusive and appropriate support	[2]

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[3] Lemke et al. Addressing Underrepresentation in Genomic Research Through Community Engagement, The American Journal of Human Genetics 109, September 2022

[4] NIHR UK Standards for Public Involvement: Better Public Involvement for Better Health and Social Care Research; Cancer Australia National Framework for Consumer Involvement in Cancer Control; Lemke et al. Addressing Underrepresentation in Genomic Research Through Community Engagement, The American Journal of Human Genetics 109, September 2022

[5] NIHR UK Standards for Public Involvement: Better Public Involvement for Better Health and Social Care Research

Analysing and Interpreting	Discuss data with consumers and seek input	[12]
Dissemination	Return and report back data to consumer community	[12]
	Facilitate community engagement to ensure effective dissemination of research findings	[12]
Implementation	Draw upon lived experience of community to inform research translation and ensure more effective research translation activities to directly benefit the community	[2]
Monitoring and Evaluation	Evaluation the consumer engagement process and outcomes	[2] [12]

Table 3: Roles and Responsibilities for Research Institutions

Research Phase	Possible Roles for Research Institutions	References
Identifying and Prioritising	Create governance structures, such as steering committees, to oversee consumer engagement activities to guide research priorities	[3]
Design	Design policies and procedures to guide consumer engagement in research[6]	[3]
	Plan and commit resourcing to the consumer and community engagement throughout the research lifecycle, including human resources, information resources (data and scientific knowledge), organisational resources (i.e. admin and IT systems), physical resources (i.e. consultation rooms) and fiscal resources (i.e. sitting fees, out-of-pocket expenses, travel and accommodation)	[3] [6]
Development of the Grant Proposal		
Undertaking and Managing	Offer accessible opportunities for consumer involvement according to their needs, experiences, skills and abilities, language, and availability. Be flexible and responsive to encourage a wide variety of levels and types of involvement of consumers	[9]
	Provide shared learning and development training for researchers and consumers to build capacity for consumer engagement in research	[3] [9]
Analysing and Interpreting		
Dissemination		
Implementation		
Monitoring and Evaluation	Evaluate the consumer and community engagement activities for their impact on the public, the researchers, and the research itself	[9]

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[6] Cancer Australia National Framework for Consumer Involvement in Cancer Control

Table 4: Roles and Responsibilities for Research Funders

Research Phase	Possible Roles for Research Funders	
Identifying and Prioritising	Setting expectations for consumer involvement and integration in the research life cycle	[17]
	Involving consumers in the identification of research topics	[17]
	Involving consumers in reviewing applications	[17]
	Involving consumers in funding decisions (in practice this does not happen systematically, but there are exceptions)	[17]
Design		
Development of the Grant Proposal		
Undertaking and Managing	Compensating consumers for their contribution to the research process	[17]
Analysing and Interpreting		
Dissemination		
Implementation		
Monitoring and Evaluation		

UNESCO Recommendations on Open Science

The United National Educational, Scientific and Cultural Organisation (UNESCO) adopted the Recommendation on Open Science in 2021 (the Recommendation). This provides an internationally agreed definition of open science, and a shared set of values and principles that underpin international efforts to open and democratise scientific endeavour. While the applications of the UNESCO Recommendation are not limited to community involvement in research, these principles and values are relevant to research teams looking to better engage consumers and community in health and medical research.

Core Values for Open Science[7]

a. ***Quality and integrity:*** open science should respect academic freedom and human rights and support high-quality research by bringing together multiple sources of knowledge and making research methods and outputs widely available for rigorous review and scrutiny, and transparent evaluation processes.
b. ***Collective benefit:*** as a global public good, open science should belong to humanity in common and benefit humanity as a whole. To this end, scientific knowledge should be openly available and its benefits universally shared. The practice of science should be inclusive, sustainable and equitable, also in opportunities for scientific education and capacity development.
c. ***Equity and fairness:*** open science should play a significant role in ensuring equity among researchers from developed and developing countries, enabling fair and reciprocal sharing of scientific inputs and outputs and equal access to scientific knowledge to both producers and consumers of knowledge regardless of location, nationality, race, age, gender, income, socio-economic circumstances, career stage, discipline, language, religion, disability, ethnicity or migratory status, or any other grounds.
d. ***Diversity and Inclusiveness:*** open science should embrace a diversity of knowledge, practices, workflows, languages, research outputs and research topics that support the needs and epistemic pluralism of the scientific community as a whole, diverse research communities and scholars, as well as the wider public and knowledge holders beyond the traditional scientific community, including indigenous peoples and local communities, and social actors from different countries and regions, as appropriate.

Guiding Principles for Open Science[8]

a. ***Transparency, scrutiny, critique and reproducibility:*** increased openness should be promoted in all stages of the scientific endeavour, with the view to reinforcing the strength and rigour of scientific results, enhancing the societal impact of science and increasing the capacity of society as a whole to solve complex interconnected problems. Increased openness leads to increased transparency and trust in scientific information and reinforces the fundamental feature of science as a distinct form of knowledge based on evidence and tested against reality, logic and the scrutiny of scientific peers.

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[7] As stated in the UNESCO Recommendations on Open Science Article 13

[8] As stated in the UNESCO Recommendations on Open Science Article 14

b. *Equality of opportunities:* all scientists and other open science actors and stakeholders, regardless of location, nationality, race, age, gender, income, socio-economic circumstances, career stage, discipline, language, religion, disability, ethnicity or migratory status, or any other grounds, have an equal opportunity to access, and contribute to and benefit from open science.
c. *Responsibility, respect and accountability:* with greater openness comes greater responsibility for all open science actors, which, together with public accountability, sensitivity to conflicts of interest, vigilance as to possible social and ecological consequences of research activities, intellectual integrity and respect for ethical principles and implications pertaining to research, should form the basis for good governance of open science.
d. *Collaboration, participation and inclusion:* collaborations at all levels of the scientific process, beyond the boundaries of geography, language, generations and resources, should become the norm, and collaboration between disciplines should be promoted, together with the full and effective participation of societal actors and inclusion of knowledge from marginalized communities in solving problems of social importance.
e. *Flexibility:* due to the diversity of science systems, actors and capacities across the world, as well as the evolving nature of supporting information and communication technologies, there is no one-size-fits-all way of practicing open science. Different pathways of transition to and practice of open science need to be encouraged while upholding the above-mentioned core values and maximizing adherence to the other principles hereby presented.
f. *Sustainability:* to be as efficient and impactful as possible, open science should build on long-term practices, services, infrastructures and funding models that ensure the equal participation of scientific producers from less privileged institutions and countries. Open science infrastructures should be organized and financed upon an essentially not-for-profit and long-term vision, which enhance open science practices and guarantee permanent and unrestricted access to all, to the largest extent possible.

References and Resources

The following section provides a reference list of the publications that were included in the scan of the literature. Globally there are quality guides, toolkits and publications that can provide implementation guidance to research institutes and researcher teams involving consumers throughout the research lifecycle. There are also published academic papers and environmental scans which this NHMRC paper does not aim to replicate. This reference list is written in the style of an annotated bibliography to assist the reader in identifying materials that can further support their consumer involvement activities.

Following the Annotated Bibliography, relevant United Nations Declarations and Recommendations which have been included as supplementary material for research teams promoting open science through consumer involvement in health and medical research.

Annotated Bibliography

[1]

Core Values for Public Participation (2017), International Association for Public Participation

https://cdn.ymaws.com/www.iap2.org/resource/resmgr/pillars/2017_core_values-24x36_iap2_.pdf

This resource is a single page reference document that outlines 7 core values that underpin public participation. The International Association for Public Participation Federation is a global not-for-profit focused on advancing the practice of public participation in all aspects of public decision making. The values are broadly applicable to public participation in any policy sector, including health and medical research. Organisations can apply to use or adapt the copyright materials produced by the association, and research organisations or teams may find the framework provided by the Core Values for Public Participation to be useful in developing values frameworks to guide their own consumer engagement activities.

[2]

Guidelines for Community Involvement in Genomics Research (2023), Involve Australia (Led by Community, Coordinated by Genomics Australia)

https://www.australiangenomics.org.au/wp-content/uploads/2021/06/Involve-Australia-Guidelines_April-2023.pdf

This document provides comprehensive guidance to researchers on the involvement of community members in genomics research. The principles outlined in the document are broadly applicable to health and medical research and provide a model for researchers in other disciplines or research topics to consider when approaching community engagement. This document is the only resource in this review which is written from the perspective of community members giving guidance to researchers.

[3]

National Framework for Consumer Engagement in Cancer Control (2011), Cancer Australia

https://www.canceraustralia.gov.au/sites/default/files/publications/national_consumer_framework_web_504af020f2184.pdf

This Australian publication is a comprehensive guideline for community engagement in cancer clinical research, covering values and principles, roles and responsibilities for researchers and community participants. The publication is a quality example from the Australia context of how to engage consumers and community in health and medical research.

[4]

Patient and Public Involvement in Health and Social Care Research: A Handbook for Researchers (2014), NHS National Institute for Health Research

https://www.rds-yh.nihr.ac.uk/wp-content/uploads/2015/01/RDS_PPI-Handbook_2014-v8-FINAL-11.pdf

This UK publication provides guidance and implementation support for researchers on involving consumers and the community in all stages of the research cycle.

[5]

PCORI Engagement Rubric (2016), Patient-Centred Outcomes Research Institute

https://www.pcori.org/resources/engagement-rubric

This resource is a brief guideline document published by PCORI, a research funding institute. The Engagement Rubric provides guidance to research teams looking to engage in patient-centred research, and identifies key principles that underlie good practice in consumer engagement and identifies possible roles for consumers throughout the research lifecycle.

[6]

Principles of Community Engagement Second Edition (2011), Clinical and Translational Science Awards Consortium Community Engagement Key Function Committee Task Force on the Principles of Community Engagement, Centre for Disease Control, National Institute of Health Publication No. 11-7782

https://www.atsdr.cdc.gov/communityengagement/pdf/PCE_Report_508_FINAL.pdf

This publication provides a detailed understanding of best practice in community engagement and participation in research. At 197 pages in length this publication is the most comprehensive document referenced here. The publication includes a literature review, outlines 9 principles of community engagement, and gives case studies of the principles in action in research project. The publication also provides implementation support through covering the structural requirements to support effective community engagement efforts by a research organisation, identifying challenges to effective community engagement in research, outlining the value of social networking for community engaged research, and guidance on program evaluation and evaluation of community engagement. Readers looking to develop a detailed understanding of community engagement practice may find this publication a useful reference.

[7]

Principles for Consumer Involvement in Research Funded by the Medical Research Future Fund (2023), Consumer Reference Panel of the Medical Research Future Fund, Department of Health

https://www.health.gov.au/sites/default/files/2023-03/principles-for-consumer-involvement-in-research-funded-by-the-medical-research-future-fund.pdf

This concise document is advice produced by the MRFF Consumer Reference Panel. It identified the principles underlying good practice in consumer engagement and brief implementation guidance for researchers applying for MRFF research funding.

[8]

Spectrum of Public Participation (2018), International Association for Public Participation

https://cdn.ymaws.com/www.iap2.org/resource/resmgr/pillars/Spectrum_8.5x11_Print.pdf

This resource is a single page reference document that outlines 5 levels of public engagement practice, from the lowest level of public influence on decision making. The International Association for Public Participation Federation is a global not-for-profit focused on advancing the practice of public participation in all aspects of public decision making. The spectrum of public participation is broadly applicable to public participation in any policy sector, including health and medical research. Organisations can apply to use or adapt the copyright materials produced by the association, and research organisations or teams may find the framework provided by the Spectrum of Public Participation to be useful in identifying the appropriate level of engagement to guide research in their institution or team.

[9]

The Statement of Principles for Consumer Involvement in Cochrane (2015), Cochrane Consumer Network

https://consumers.cochrane.org/sites/consumers.cochrane.org/files/uploads/statement_of_principles_for_consumer_involvement_in_cochrane_july_2017.pdf

This brief document produced by the Cochrane Consumer Network outlines the 3 key principles that guide Cochrane's community engagement, and the 7 key commitments to community contributors to Cochrane's research processes.

[10]

UK Standards for Public Involvement (n.d.), National Institute of Health Research

https://www.invo.org.uk/wp-content/uploads/2019/11/UK-standards-for-public-involvement-v6.pdf

This concise publication outlines 6 standards to guide good practice in consumer and community engagement in health and social policy research. These standards provide similar guidance to research teams as NHMRC's Statement on Consumer and Community Involvement in Research.

[11]

den Huting, J. (2021), *Participatory and Inclusive Autism Practice Research Practice Guidelines*, Autism Research CRC

https://www.autismcrc.com.au/access/inclusive-research-guides

This document provides implementation guidance for producing participatory research projects with the autistic community. It identifies principles of inclusive research, outlines participatory research processes and provides a comparison between traditional community engagement practice to participatory research practice and how these differ at each stage of the research life cycle.

[12]

Lemke, Amy A., Edward D. Esplin, Aaron J. Goldenberg, Claudia Gonzaga-Jauregui, Neil A. Hanchard, Julie Harris-Wai, Justin E. Ideozu, Rosario Isasi, Andrew P. Landstrom, Anya E. R. Prince, Erin Turbitt, Maya Sabatello, Samantha A. Schrier Vergano, Matthew R. G. Taylor, Joon-Ho Yu, Kyle B. Brothers, Nanibaa' A. Garrison, (2022) *Addressing Underrepresentation in Genomics Research Through Community Engagement*, ASHG Guidance, Volume 109, Issue 9, p1563-1571

https://www.cell.com/ajhg/fulltext/S0002-9297(22)00357-3

This publication is an academic paper which outlines the ethical considerations and rationale for achieving more diverse and equitable engagement of community members in genomics research.

[13]

McKenzie, Anne (2023), *Principles for Consumer Involvement in Health and Medical Research*, Respirology 2023 Volume 28, Issue 5, p423-4

https://onlinelibrary.wiley.com/doi/epdf/10.1111/resp.14467

This is a brief commentary article that covers the Australian context for consumer and community engagement in health and medical research and outlines core principles that for good practice in consumer engagement.

[14]

Oudendammer, Willemijn M. den, Jaquelien Noordhoek, Rebecca y. Abma-Schouten, Lieke van Houtem, Jacqueline E. W. Broerse, and Christine W. M. Dedding (2019), *Patient Participation in Research Funding: An Overview of When, Why and How Amongst Dutch Health Funds*, Research Involvement and Engagement 5, Article 3

https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-019-0163-1

This paper identifies the ways that Dutch research funding agencies involve consumers and community in the research funding process. It is one of the few papers that examines how research funders conduct consumer engagement in research funding.

[15]

Syed, M. Ahmed, and Ann-Gel S. Palermo (2010), *Community Engagement in Research: Frameworks for Education and Peer Review*, American Journal of Public Health, Volume 100, No. 8, pp. 1380-1387

https://ajph.aphapublications.org/doi/full/10.2105/AJPH.2009.178137

This paper outlines the principles of community engagement in public health research to give guidance for research investigators aiming to include engage community in their research design and implementation.

[16]

Shippee, Nathan B., Juan Pablo Domecq Garces, Gabriela J. Prutsky Lopez, Zhen Wang, Tarig A. Elraiyah, Mohammed Nabhan, Juan P. Brito, Kasey Boehmer, Rim Hasan, Belal Firwana, Patricia J. Erwin, Victor M. Montori, and M Hassan Murad (2013), *Patient and Service User Engagement in Research: A Systematic Review and Synthesised Framework*, Health Expectations, Volume 18, p1151-1166

https://onlinelibrary.wiley.com/doi/pdf/10.1111/hex.12090

This publication is an academic paper that provides a systematic review of the global academic literature related to consumer and community engagement in health and medical research. While it was published in 2013 and does not capture the developments in literature from 2014 to present day, it provides the most comprehensive academic analysis of the global literature.

[17]

White, Rory, Monique van den Eijnden, Anne-Laure Donskoy, Vijay Rajkumar, Danielle Kemmer, Raliza S. Stoyanova (2023), ***Lived Experience Involvement in Research Funding: Taking a More Systematic Approach*****, Nature Mental Health, Volume 1, p157-159**

https://www.nature.com/articles/s44220-023-00029-9

This journal paper outlines the results of a survey from the International Alliance of Mental Health Research Funders, which explores the ways that funders engage consumers and community in mental health research funding. The paper outlines the roles and responsibilities for funders to involve people with lived experience to be involved in mental health research funding and identifies the current prevalence of lived experience incorporation into these roles. The paper also identifies opportunities for change to improve engagement.

Relevant United Nations Declarations and Recommendations

It is beyond the scope of this environmental scan to explore the United Nations instruments in detail. However, the links to the instruments that are relevant to consumer involvement in health and medical research have been included below.

UNESCO Recommendation on Open Science

https://doi.org/10.54677/MNMH8546

United Nations Convention on the Rights of Persons with Disabilities

https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html

United Nations Declaration on the Rights of Indigenous Peoples

https://www.un.org/development/desa/indigenouspeoples/wp-content/uploads/sites/19/2018/11/UNDRIP_E_web.pdf

Aboriginal and Torres Strait Islander Consumer Involvement

NHMRC has a commitment to improving the health of Aboriginal and Torres Strait Islander peoples through the support of health research and its translation. Consumer and community involvement at all stages of research is central to this strategic priority. The NHMRC publication Roadmap 3: A strategic framework for improving Torres Strait Islander health was developed through a comprehensive community consultation process. It identifies pathways for community involvement in the research process, including actively engaging Aboriginal and Torres Strait Islander communities to identify research priorities, supporting researcher to effectively engage community throughout the project lifecycle and supporting community-based researchers to develop research expertise through non-traditional pathways.

https://www.nhmrc.gov.au/about-us/publications/road-map-3-strategic-framework