

LANGUAGE GUIDE
for Consumer and Community Involvement in Health Research at Sydney Health Partners

WHY THIS GUIDE?

This Language Guide is written for researchers, clinicians and consumers. Its purpose is to provide an explanation of terms that are commonly used when talking about consumer and community involvement (CCI) in health research.

This Guide was developed by researchers, clinicians and consumers as a companion document to the Consumer and Community Involvement in Health Research at Sydney Health Partners Guiding Framework and associated Guiding Principles. The principles include **respect**, **equality**, **inclusion** and **evidence**.

Language matters and is a great leveller; a shared understanding will support consumers, carers and community members to be equal partners in health research.

The language that has been used in this area is inconsistent and sometimes contested. For example, there is debate about the use of the term 'consumer' when referring to members of the wider community.

Additionally, there is confusion about when to use 'involvement' and when to use 'participation'. This guide aims to promote greater consistency and understanding around the use of such terms.

The term 'consumer and community involvement' or CCI is the terminology adopted and used by Australia's National Health and Medical Research Council in its *Statement on Consumer and Community Involvement in Health and Medical Research* (first issued in 2002) (1). As this is a primary guide for use in Australia, 'consumer' is used throughout.[1] A review of the Statement is currently underway and this Language Guide will be updated if any significant changes in terminology are made.

1 The term 'patient and public involvement' or PPI is more commonly used in the UK.



KEY TERMS

CARER
A person who provides care and support to a family member or friend with disability, an older person, a person who experiences mental health issues (2) or a person with a health condition.

CITIZEN SCIENCE
Citizen science is "scientific work undertaken by members of the general public, often in collaboration with or under the direction of scientists" (3, p3). Citizen science involves public participation and collaboration in scientific research with the aim to increase scientific knowledge, (4) including in health research.

CLINICIAN
A health professional, such as a doctor, nurse or allied health professional, who is directly involved in patient care or management of health services.

CLINICIAN RESEARCHER
A health professional, such as a doctor, nurse or allied health professional, who is directly involved in patient care and also undertakes research.

CO-DESIGN
Co-design is an approach to designing with, rather than for, people. Co-design in health research is poorly defined. It has been described as "the meaningful involvement of consumers in the planning phase of a research project where 'meaningful involvement' is taken to refer to [undertaking an] explicitly described, defined and auditable role or task necessary to the planning and/or conduct of health research" (5, p3). "Co-design works best when people with lived experience, communities and professionals work together to improve something they all care about. Overall, the primary role of co-design is elevating the voices and contributions of people with lived experience" (6, p14). There are four key principles for co-design: share power (with researchers, consumers and the community); prioritise relationships that build trust and connection; use participatory means (that facilitate self-discovery and move people from participants to active partners); and build capacity (to support people to teach and learn from each other) (6, p14-15).

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).

COMMUNITY MEMBER
A member of a community (see above).

CONSUMER
In this context, 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, 7).

CONSUMER RESEARCHER
A person who is actively involved in health research and brings their lived experience to the research process. For example, in mental health, consumer researchers refer 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" (8, 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.

CONSUMER AND COMMUNITY INVOLVEMENT (CCI)

Consumer and community involvement (CCI) in health and medical research is the active partnership between researchers and consumers and/or the community in the planning and conduct of research. Consumers, researchers and the community work as research collaborators (9).

CO-PRODUCTION

Co-production is a participatory approach to research where people with lived experience are co-researchers or employed as "lived experience researchers who share decision making power throughout all stages of the research process – including sharing the results of the study" (10, p4). "It is a way of doing research that is intentionally democratic and aspires to being emancipatory. It actively inverts traditional ways of working by centring the perspectives and wisdom of people and communities who are impacted by experience, event or circumstances rather than the perspectives of conventional researchers" (10, p6). The co-production research cycle includes co-planning (connecting and building relationships between lived experience researchers and conventional researchers), co-designing (co-defining problems and co-designing the study protocol), co-conducting (collaboratively preparing for and undertaking the research), and co-reflecting (dialogue, dissemination and next steps) (10, p6).

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 (11). 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 (12). It also includes research translation which incorporates research evidence into policy and practice to improve health outcomes for consumers and the delivery of health services (13).

HEALTH LITERACY

Health literacy describes how people access, understand, appraise and apply health information in order to make decisions about their health (14, 15). Partnering with patients, families and carers to ensure understanding of their



health can reduce personal, community and economic costs of care (15). Health literacy has both organisational and individual components (15).

INVOLVEMENT
Involvement refers to a partnership between consumers and researchers, where consumers are actively involved in the research process (1, 16). It has been described as doing research 'with' or 'by' people who use health services, rather than 'to', 'about' or 'for' them (17). Consumers may be involved in a range of ways, including as a consumer representative on a research committee, as a co-researcher doing the actual research, or co-writing research reports and presenting at conferences and seminars.

LIVED EXPERIENCE RESEARCH
Research that illuminates the perspectives and experiences of people with lived experience. It includes a wide range of diagnoses and conditions. For example, in mental health, lived experience research is research that examines the perspectives and experiences of people who live with mental health issues (18).

LIVED EXPERIENCE RESEARCHER
A person who uses their lived experience of disability, mental health or any other health condition to inform the planning, conduct and interpretation of their research.

PARTICIPATION
Participation is where patients, consumers or the community have been recruited to provide data for a research study. For example, researchers may ask participants to undergo tests or procedures, complete a survey or take part in an interview or focus group discussion.

PARTNERSHIP
A relationship between one or more organisations or groups around a project in which there are well-defined common objectives and shared benefits, where each partner makes continuing contributions in one or more strategic areas, such as technical expertise, experience, financial contribution, etc. (modified from 19).

PATIENT
Any person who receives a health service and to whom, as a result, a health practitioner owes a duty of care. It also includes consumers, clients and the relevant substitute decision-maker where the patient does not have capacity to consent (20, p6).

PATIENT ENGAGEMENT
Patients, families, their representatives and health professionals working in active partnership at various levels across the health system to improve health and healthcare (21). Patient engagement is an integral part of healthcare and safe people-centred services. Engaged patients are better able to make informed care decisions that align with their priorities. Increasingly, patients expect health professionals to engage them in the decision-making process, although individual patients may vary in their preferences for such involvement (22).

PATIENT EXPERIENCE
Patient experience is defined as "...the sum of all interactions, shaped by our culture, that influence patient perceptions across the continuum of care" (23, p8). Patient experience encompasses the range of interactions that patients have with the healthcare system, including the care described in health plans, and the care



provided by doctors, nurses, and other staff in hospitals, medical practices, community centres and other healthcare facilities. As an integral component of healthcare quality, patient experience includes several aspects of healthcare delivery that patients value highly when they seek and receive care, such as getting timely appointments and easy access to information, and having good communication with healthcare providers (23).

RESEARCH
The creation of new knowledge and/or the use of existing knowledge in a new and creative way to generate new concepts, methodologies, inventions and understandings (1, 24). It can also include the translation of research evidence into policy and practice in clinical treatments and health services (1, 13).

RESEARCHER
Any person who conducts research. This includes consumer researchers, lived experience researchers and clinician researchers.

STAKEHOLDER
An individual or group with a key interest in research and research outcomes. Stakeholders might include government agencies, non-government organisations, health organisations, industry or research funders, as well as consumers, community members, clinicians and researchers (1). Collectively, consumers and community members may be referred to as 'the public' (12).

GOOD PRACTICE IN LANGUAGE USAGE

We recognise that different groups and communities may have different understandings about language, and that language changes over time. It is important to have shared meanings and understandings about language used in research projects.

Providing information in accessible formats, for example, in plain language (25) (translated as necessary) or large-print or audio versions, is important to foster consumer and community involvement in health research.

When writing research reports, journal articles or conference presentations, it is important to be explicit about the language that is used, ensuring that it reflects the perspectives of consumers, researchers and the community.

EVOLVING NATURE OF CONSUMER AND COMMUNITY INVOLVEMENT LANGUAGE

The language used in the area of consumer and community involvement in health research is changing and evolving. If you have any feedback or comments on the definitions in this Guide, please email Sydney Health Partners: sydneyhealthpartners.ea@sydney.edu.au or Health Consumers NSW: info@hcnsw.org.au.



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