Consumers in Research

Submission on the DRAFT Statement on Consumer and Community Involvement (CCI) in Health and Medical Research

21 September 2025

Submission 1 of 2

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Submission prepared by:

Carrie Hayter
Dr. Anthony Brown
Julia Brockhausen

1. About Health Consumers NSW

Health Consumers NSW (HCNSW) is a membership-based, independent, charity with over 1,000 individual consumer and 60 Consumer Organisations members. We provide a voice for patients, their family members and carers, patient leaders and health consumer representatives in NSW. We represent health consumer organisations, who in turn, representing specific disease and population groups. Our purpose is to inspire and lead health consumers to drive genuine, positive change across health systems, policies, services and research.

2. Why this submission

Since 2016, HCNSW has been actively working with health consumers and people with living experience of health conditions to support their **capacity** and **capability** to be actively involved in health and medical research. HCNSW has contributed to building the evidence base of Consumer and Community Involvement (CCI) through collaborating in research projects, and partnering with research Institutes and universities to build their capacity to involve consumers and the community in research (see Appendix 1 and Appendix 2).

HCNSW has 186 individual consumers active on our online consumers in research community. Our members are involved in a diverse range of health research projects, are peer reviewers for grants, are consumer researchers on research projects and involved in fostering consumer and community involvement in clinical trials. They have a wealth of expertise and living experience of actual involvement in a range of health and medical research across Australia.

On 9 September 2025, HCNSW facilitated an online consultation with 18 consumers involved in health and medical research. Building on the consultation with consumers co-hosted by HCNSW in March 2023 the workshop explored four key questions:

- What is good about the draft statement?
- What is missing from the draft statement?
- What do participants think of the values and principles outlined in the draft statement?
- What is the role of Consumer Organisations in supporting you to be involved in health research?

This submission is based on the feedback from this workshop, and ongoing conversations with HCNSW members who are involved and collaborate in research.

3. Key Feedback

Introduction

Consumers involved in research welcomed the review of the Statement. Consumers recognise the impact the existing CCI Statement has had in strengthening collaboration between health consumers and researchers.

Consumers are, however, disappointed that the language used in the document to describe consumers is outdated and does not reflect current practice. Our members said the term “person with lived or living experience” is often used as well as the term “consumer” and “community”. HCNSW acknowledges that the terminology and language in CCI is evolving. We do, however, suggest the Statement include the following definition of people with lived and living experience.

> **People with lived and living experience[1] -** A person who uses their lived or living experience of disability, mental health or any other health condition to inform the planning, conduct and interpretation of research and health services.

Consumers would also like to see a **future focused** Statement, that is a call to action for the next decade across health and medical research in Australia. CCI should be **mandated** in all NHMRC funded research. Furthermore, there are many times that the document uses the term ‘may’ or ‘could’. The language needs to include **‘must’** and **‘should’** to reflect that CCI **should be mandatory** in all NHMRC funded research.

Consumers reported that the draft Statement felt like consumers and people with living experience were not at the centre of the research process, but rather “invited in” by researchers to play specific roles largely determined by the researchers. The Statement does not address the fundamental principle of co-design in health and medical research. Furthermore, the document does not acknowledge the leadership roles that consumers already play as Chief Investigators or lived experience researchers.

Consumers questioned who the audience for the draft Statement was and that it felt like it was written for a research audience. The strong recommendation from consumers is that the final Statement needs to be in a more consumer-friendly format. Consumers, consumer organisations and people with living experience should work with the NHMRC to co-author a consumer-friendly final Statement.

The draft Statement also uses the terms “consumer” and “community” somewhat interchangeably. More work is needed to define the differences between health consumers and community members and the different but complementary insights and perspectives each brings to research.

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[1] See the Language guide for Consumer and Community Involvement in Health Research at Sydney Health Partners, co-created by consumers, researchers and researcher/clinicians in partnership with Health Consumers NSW, available at https://sydneyhealthpartners.org.au/guiding-principles-framework-and-language-guide/

Specific feedback questions

1. Does the Statement set clear and suitable expectations that consumers and community will be involved in all stages of research?

Consumer and community involvement should be **mandatory,** and the draft Statement does **not** describe how consumers and community organisations can be involved in the evaluation of CCI throughout the research process.

The Statement segments and limits the role of consumers in research in that it does not identify that consumers and people with lived experience can be consumer researchers.

2. Does the Statement clearly explain the key values and principles that ensure effective consumer and community involvement?

Values

Consumers were pleased to see the inclusion of key values that underpin the Statement. However, the values are disconnected from the principles and were poorly defined and integrated throughout the document. The values could be streamlined and grouped together. For example, diversity and inclusion could be paired; as could transparency, accountability, and integrity. To make the values more impactful, consumers suggested having a maximum of 5 key values with a clear definition of each value that is embedded and referred to throughout the Statement.

Principles

Consumers said that the principles provided a high-level overview of consumer and community involvement in health and medical research. However, they could be strengthened by providing practical examples of **what** the specific principle means in practice.

Regarding **principle 1**: the importance of involving consumers and the community **before** the research commences must be emphasised. Consumer involvement during planning can guide and advise on what health and medical research is undertaken and how to involve people with living experience in the research process. Experienced researchers have reported to HCNSW that involving consumers in the research planning leaders to different *and better* research questions.

Consumers should also be involved in research **after** it is completed to support the implementation and distribution of research findings.

Regarding **principle 3: working in partnership for mutual benefit**, this principle should include partnering with communities to undertake research.

In **principle 4: equitable inclusion of diverse consumers and communities,** this principle should explicitly include reference to marginalised communities. Consumers described the importance of involving underrepresented consumers in health and medical research to improve health outcomes. It would be useful to define what is meant by the term 'diversity'. Health Consumers NSW suggest the following definition of diversity[2]

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[2] See the Language guide for Consumer and Community Involvement in Health Research at Sydney Health Partners, co-created by consumers, researchers and researcher/clinicians in partnership with Health Consumers NSW, available at https://sydneyhealthpartners.org.au/guiding-principles-framework-and-language-guide/

> 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.

Providing practical examples of what inclusion means in practice for researchers and consumers would also be useful, to demonstrate how to translate the principle into research processes and practice. Involvement of people from diverse communities must also consider the issues of safety discussed below (in reference to principle 6).

The importance of building relationships between researchers and consumers is well made and welcome. This emphasis on building trusted relationships between people needs to be more embedded in the framework and explicitly linked back to the values of respect and partnership.

In **principle 5: Transparency, accountability and integrity in the conduct of research involving consumers and communities**, consumers asked how integrity is defined and for whom? What does integrity mean and look like in practice for researchers, consumers and communities? Additionally, there is no mention of the concept of data sovereignty for consumers and communities.

In **principle 6: safety of consumers and communities** there was significant support for the principle of safety, however, consumers wanted more detail about what this means in practice. Additionally, consumers described the importance of **consumer organisations** in providing support and mentoring to support consumers and communities to be safely involved in research.

Safety for consumer involvement must also include a focus on **strengths based** and **trauma informed** communication. When health consumers share their lived experience with researchers they are often being asked to speak and reflect on some their worst experiences, such as being diagnosed with a chronic or life-limiting condition or the death of child or other family member. Living with certain chronic conditions can mean experiencing stigma and discrimination (for example people with mental health issues, or people living with blood-borne viruses) and can challenge people's sense-of-self and their identities (for example members of families with a recent diagnosis of genetic illness). Not all consumers are aware of the prognosis of their conditions or the potential risks involved in treatment, and such discussions need to be handled with sensitivity by researchers.

> *One attendee described working with researchers on a project researching a new treatment for the serious health condition she was being treated for.*
> *She described being given something to read that was justifying the need for the research to a funding body. That justification included the statistics on poor success rates for current treatments of that condition and survival indications.*
> *She said, "My treating physician had not (and probably would never have) given me that information. It was very confronting."* [3]

Consumers, especially members of priority populations, are often in vulnerable circumstances. People with chronic ill health may be experiencing financial distress due to loss of income at not being able to work, and often have caring responsibilities for other family members with chronic conditions, as well as managing their own health. Working with consumers needs to take people's individual circumstances into account and be flexible in the ways people contribute to research.

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[3] *Research4Me, Health Consumers NSW, (2017)* Involving Health Consumers in Health and Medical Research: Enablers and Challenges from a Consumer Perspective, Health Consumers NSW and Research4Me, p.22.

Researchers need to not only reimburse people, which lowers financial barriers to involvement, but also be prepared to meet outside of work hours, and accommodate different needs around meeting requirements, such as some people's need to meet online (due to mobility issues, lack of access to transport, or inability to access respite care) while other's can only meet face-to-face because inability to access or use the necessary technology.

Consumers need training in safe and appropriate story telling (as has been developed by various mental health consumer groups). Researchers, in turn, require training that makes them aware of these issues, as well as giving them skills in trauma informed, strengths based, empathic communication. Both consumers and researchers also need to know how to respond to situations when people experience distress, triggered by their involvement in research.

3. Roles and Responsibilities for CCI

Does the Statement clearly explain the shared roles and responsibilities of all involved to ensure effective consumer and community involvement?

Table 1 in the Statement has started to describe the different roles and the level of involvement of researchers, consumers, consumer organisations, however, needs additional information. Table A provides key comments against each shared role.

Table A - Feedback on shared roles and responsibilities

Shared role	Feedback from consumers
Compliance	Consumers agree they have a role to play in compliance but are disappointed it is the first role identified. Consumers felt this emphasis on compliance reflects the priorities of research funders and not that of consumers.
Monitoring and evaluation	Consumers, consumer organisations and the community should be actively involved in monitoring and evaluating consumer and community involvement and provide feedback throughout the research process
Planning the research	Consumers told us how they are often brought into conversations too late to have meaningful input into developing research questions, methodology and study design. Consumers also told us of examples where they had been brought onboard AFTER the study protocol had been published, which effectively excluded them from being able to input into study design. Consumers also acknowledged that there are rarely resources available to researchers and consumer organisations to facilitate their involvement in planning, especially during writing research proposals.
Conducting the research	The is no acknowledgement in the draft Statement of the active role consumers play in conducting research, especially leadership roles as CIs or lived experience researchers. Consumers also reported that the role they play in data collection and data analysis is not acknowledged. There's a role for consumers **AFTER** the research that's missing - consumers can be champions **POST** research and involved in the distribution of research findings.

Shared role	**Feedback from consumers**
Research Governance	In addition to roles on boards and advisory committees of individual projects consumers need to be brought into the broader governance of research in Australia. This includes consumers as peer reviewers on grant applications with equal scoring to researchers. This currently occurs in grant review processes for cancer funding by the Cancer Institute of NSW. See also the guidelines developed by Sydney Health Partners: Describing and Assessing Consumer Involvement in Health Research funding applications.[4]
Resourcing, networking and recruitment	This can be supported with case studies and examples of how consumers and consumer organisations support networking and recruitment.
Capacity building, training and championing	Capacity building, training and championing should be a higher priority in this table as it is the key element to foster and support the involvement of consumers and the community in health and medical research. Programs need to be developed and resourced that support the planned capacity development of consumers. From recruitment right through the consumers leaders in research. Research funders **should** provide specific grants for training and capacity building of consumers, communities and researchers. Consumers play important roles in building the capacity of other consumers and researchers. Experienced consumers often act as informal mentors to both consumers new to research, and researchers new to consumer engagement. Opportunities for consumers and researchers to meet from different disciplines need to be encouraged.

4. Does the Statement clearly explain the roles and responsibilities of Consumers, Communities and Consumer Organisations that ensure effective consumer and community involvement?

The language used throughout the Statement is outdated, consumers and people with living experience can play much wider roles than currently described. For example, consumers and consumer organisations can lead and shape research. Consumer researchers can also lead research projects. Appendix 3 offers some suggestions for improving the contested and inconsistent language in consumer involvement in research.

5. Does the Statement clearly explain the roles and responsibilities of stakeholders to ensure effective consumer and community involvement?

The statement maintains a clear distinction between the roles of consumers and research. This is a false dichotomy, as the division of responsibilities exists on a continuum between projects with little consumer involvement where the roles are clearly divided, to projects with well-established and

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[4] Sydney Health Partners – Guide: Describing and Assessment Consumer Involvement in Health Research Funding Applications
https://sydneyhealthpartners.org.au/guiding-principles-framework-and-language-guide/

mature consumer involvement where consumer leaders and/or lived experience researchers plan, conduct and lead the work.

6. **Does the Statement clearly explain the roles and responsibilities of research Institutions that ensure effective consumer and community involvement?**

Consumers said that more information was needed on creating a safe environment for consumer and consumer organisations in research. Consumer Organisations should play a key role in supporting and empowering consumers to be safely involved in the research process that incorporates trauma-informed practices and processes in research institutes and research projects.

7. **Does the Statement clearly explain the roles and responsibilities of research funders?**

The Statement needs to include consumers and Consumer Organisations being involved in the setting of health and medical research priorities in collaboration with research funders. Additionally, funders **should** appoint consumers and community members to participate in peer review, priority setting and designing funding schemes.

Consumers should be peer reviewers on grant applications with equal scoring to researchers, currently consumer peer reviewers provide feedback on MRFF grants but there is no scoring which is outdated practice. The cancer research grant review for the Cancer Institute of NSW has equal scoring for consumers and research peer reviewers reflecting collaboration in practice.

Other issues

Evidence for CCI

The draft Statement does not present any of the evidence for why CCI improves research outcomes. Some of this evidence should be included in the statement. The NHMRC could support a comprehensive literature review of CCI in research, that could be published as a supplement to the final Statement.

Building and Sharing the Evidence

The Statement should explicitly encourage consumers and researchers to build and add to the evidence around CCI. This could include publishing peer-reviewed methodological articles on CCI, reflective reports on the experience of CCI, and practical advice and guidelines for researchers and consumers.

Real World Examples

The Statement would be strengthened considerably by using practical examples and case studies. The draft *National Health Medical Research Strategy* provides a good template on how this could be achieved.

The NHMRC should resist calls to develop new high level CCI frameworks, guidelines and toolkits. HCNSW does not believe that the creation of such resources is the most effective investment, as there are already many excellent resources available. NHMRC should support investment in reviewing, consolidating and refining existing tools into capacity and capability building tools that people can easily access and use (such as training, resource hubs, and creation of simple tools, such as checklists and factsheets). The curating of existing resources into tools that people can easily use would be the most prudent and efficient investment.

Implementing the Statement

Consumers were concerned about how to operationalise the values, principles and practices in the Statement. Without adequate funding to support and sustain Consumer Organisations to actively support consumers to be involved in research, the Statement will not be effectively implemented. This is a lost opportunity for the involvement of consumers and the community and consumer organisations in health and medical research in Australia.

Resourcing implementation of the Statement

Consumers said that the NHMRC should fund Consumer Organisations across Australia to support the implementation of the Statement working directly with consumers to build their **capability** and **capacity** to be research ready.

HCNSW's submission *Consumer Organisations in Research* (the companion piece to this submission) outlines the role consumers organisations can play in more detail.

Recognising Consumer Investigators

The NHMRC could create a Consumer Investigator category for research applications. This position is a Consumer Researcher who leads or is part of an NHMRC funded research team. In recognition of the inequity faced by Consumer Researchers the NHMRC could set a target for a percentage of consumer researchers or living experience researchers involved in NHMRC grants. This principle is like the targets currently in place by the NHMRC for First Nations people being Primary Investigators.

SAPPHIRE

Concern was expressed about the current NHMRC systems and structures that inadvertently impede effective involvement. The structure mentioned most often is the SAPPHIRE system. All consumers find the SAPPHIRE system difficult to use, the interface is not intuitive or user-friendly. Furthermore, people living with sensory or physical disabilities report that SAPPHIRE is inaccessible to the point of being unusable.

The current SAPPHIRE system was built prior to the increased importance of consumer engagement, and currently, if those with lived experience are invited to be grant applicants (whether a Chief Investigator or Associated Investigator), they need a profile. The system is both difficult to use and does not record the expertise that consumers are bring to the table, such as relevant lived experiences and connections to various diagnostic and other communities. The physical requirements of obtaining a SAPPHIRE login, the login process itself and building a SAPPHIRE profile are not fit for purpose for those with lived experience.

We have been informed that SAPPHIRE will be discontinued and a new in-house process developed, for launch in 2027. Health Consumers NSW supports the submission from the *NHMRC Centre of Research Excellence for Stroke Trial Innovation and Translation*, namely:

> That the NHMRC co-design, with relevant people of lived experience, an appropriate, accessible and equitable process for those with lived experience to register their involvement in future grant applications. These discussions will be useful to decide whether you keep the current nomenclature ("Chief" or "Associate Investigator"), or whether you would want to introduce a new category [such as Consumer Investigator] that recognises the skills and experience of those with lived experience.
>
> A human centred design process with appropriate user testing will then be required.

Appendix 1 HCNSW involvement in research

Includes capacity and capability building activities for consumers and people with lived experience, partnering with researchers and research projects, and awards.

2016

- co-hosted a Consumers in Research roundtable with AccessCR and co-authored a report entitled *Involving health consumers in health and medical research : enablers and challenges from a consumer perspective* Involving_health_consumers_in_health_and_medical_research_online_print.pdf (hcnsw.org.au)
- Partners on research projects with universities in NSW on a range of research projects in health and medical research
- Undertook one-off research and project work with researchers and research institutions and research on consumer engagement projects across Local Health Districts.

2017

- Co-presented findings on consumer representatives' experiences of partnering with researcher at *NSW Patient Experience Symposium.*

2019

- Initial partnership agreement with Sydney Health Partners to undertake a needs analysis of Consumer and Community Involvement and develop joint training for researchers and consumers.
- Initial partnership with Australian Centre for Australian Centre for Health Engagement, Evidence and Values (ACHEEV) at University of Wollongong. HCNSW partners with research investigating community attitudes to sharing health data using participatory methodologies (citizens' juries). Dr. Brown, HCNSW CEO, invited to become a Visiting Fellow at ACHEEV.

2020

- Needs analysis report for Sydney Health Partners published and joint training for researchers and consumers for Sydney Health Partners developed.

2021

- HCNSW Consumer Engagement Manager appointed, dedicated to support and build relationships with universities and research institutes and to work with HCNSW consumer members and organisations to support and foster consumer and community involvement in research

2022

- Publication of research and report on people with intersectional need's experience of healthcare. https://www.hcnsw.org.au/intersections/resources/
- Creation of statewide network of Consumer Voices in Clinical Trials (ConViCTioN) funded through a small grant from the NSW Office of Health and Medical Research. ConViCTioN co-created and developed information for consumers about clinical trials including a Checklist, Infographic and Video. https://clinicaltrials-consumervoices.com.au/home/
- HCNSW awarded Consumer Award by NSW Research Centre for Primary Health Care and Equity at University of NSW. For contributions to consumer and community involvement.

2023

- SHP and HCNSW Consumer and Community Involvement Framework, Principles and Language Guide released – co-created by consumers, researchers and clinicians. https://sydneyhealthpartners.org.au/guiding-principles-framework-and-language-guide/
- Developed remuneration and reimbursement guidelines for consumers in research that was adopted by all Health Translation Centres across NSW https://hcnsw.org.au/training-resources/resources/remuneration-and-reimbursement-of-health-consumers/
- Free online training for researchers and consumers – Consumer and Community Involvement in Health Research co-created by Health Consumers NSW and Sydney Health Partners.
- Development of Intermediate training on how to involve consumers in research with Sydney Health Partners bringing researchers and communities together. https://hcnsw.org.au/training-resources/training-courses/training-researchers-and-consumers-in-research/
- Memorandum of Understanding between HCNSW and The University of Sydney to work collaboratively to support Consumer and Community Involvement in research and education.

2024

- Updated website and information on consumers in clinical trials through collaboration with ConViCTioN from a small grant from the NSW Ministry of Health. https://clinicaltrials-consumervoices.com.au/home/
- Facilitated workshops with UNSW, Charles Sturt University and the University of Wollongong to involve consumers in research

2025

- HCNSW are consumer partners in two successful grants with The University of Sydney and The University of NSW (funded by NHMRC and MRFF).
- Designed and delivered a train the trainer program with Sydney Health Partners to deliver consumer and researcher training for consumer and researcher facilitators across Sydney Health Partners. SHP is providing training across their network for researchers and consumers, led by consumer and researcher facilitators.

Appendix 2 Key peer reviewed publications co-authored by HCNSW (names bolded) in CCI in health and medical research

Miller, E., **Hayter, C.**, & Manchester, H. (2025). Facilitating co-design in healthcare: a collaborative autoethnography of personalities, power, and competing priorities. *CoDesign*, 1–15. https://doi.org/10.1080/15710882.2025.2460037

Cheek, C., N. Hayba, L. Richardson, E. E. Austin, E. Francis Auton, M. Safi, N. Ransolin, M. Vukasovic, A. De Los Santos, M. Murphy, R. Harrison, K. Churruca, J. C. Long, P. D. Hibbert, A. Carrigan, B. Newman, K. Hutchinson, R. Mitchell, H. Cutler, L. Holt, J. Braithwaite, D. Gillies, P. M. Salmon, R. L. Walpola, Y. Zurynski, L. A. Ellis, K. Smith**, A. Brown**, R. Ali, K. Gwynne and R. Clay-Williams (2023). "Experience-based codesign approach to improve care in Australian emergency departments for complex consumer cohorts: the MyED project protocol, Stages 1.1-1.3." BMJ Open **13**(7): e072908.

Dahm, M. R., **A. Brown**, D. Martin, M. Williams, B. Osborne, J. Basseal, M. Potter, R.-A. Hardie, J. Li, J. Thomas and A. Georgiou (2019). "Interaction and innovation: practical strategies for inclusive consumer-driven research in health services." BMJ Open **9**(12): e031555.

Dahm, M. R., A. Georgiou, J. I. Westbrook, D. Greenfield, A. R. Horvath, D. Wakefield, L. Li, K. Hillman, P. Bolton**, A. Brown**, G. Jones, R. Herkes, R. Lindeman, M. Legg, M. Makeham, D. Moses, D. Badmus, C. Campbell, R.-A. Hardie, J. Li, E. McCaughey, G. Sezgin, J. Thomas and N. Wabe (2018). "Delivering safe and effective test-result communication, management and follow-up: a mixed-methods study protocol." BMJ Open **8**(2).

HCNSW Staff and members are also co-authors of other peer reviewed papers, and co-presenters at conferences, that the present the findings of various research collaborations.

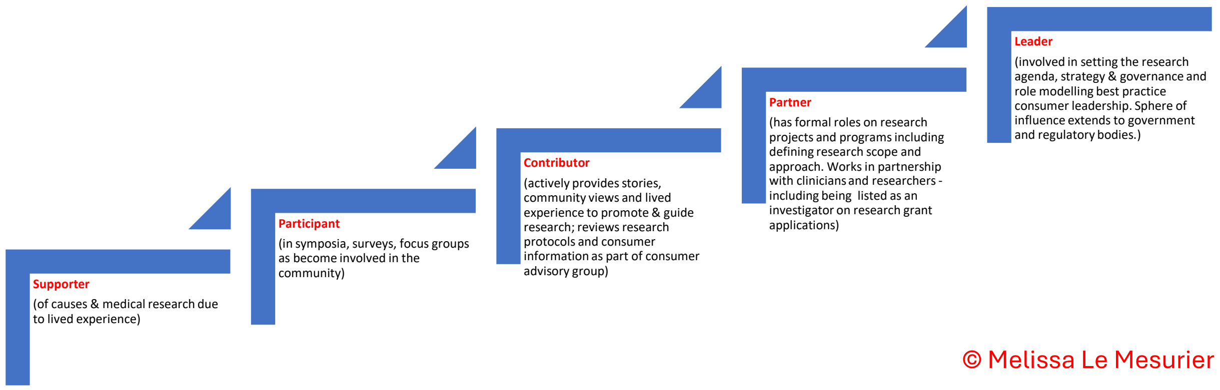
Appendix 3 Language Use and Definitions

The language used to describe consumer involvement in research is contested and evolving. ‘Involvement’, ‘partnership’, ‘participation’ and ‘engagement’ are all used. In some contexts, these words are used interchangeably to mean the same thing, while at other times they are used to refer to specific ways or level of involvement, and differently depending on the discipline.

Consumers, and other stakeholders, continue to debate the relative merits of the terms ‘patient’, ‘lived experience’, and ‘health consumer’. These terms are also used inconsistently in health research, health services, and health policy. Often the same term, usually ‘health consumer’, is used to describe a variety of people. A ‘health consumers’ can be someone who is actively receiving healthcare (i.e. a patient), a research participant, a consumer representative, a member of a research project advisory committee, and a consumer leader or lived-experience researcher Many documents, including the draft Statement, use the term in this way.

Consumer leader, Melissa Le Mesurier has produced a typology of *Supporter*, *Participant*, *Contributor, Partner*, and *Leader* (Figure 2) to describe the different roles and responsibilities health consumers and people with lived experience have in research. The typology is an important first step in consumers creating the terms we want to use to define our differing roles and contributions.

Figure 1: Stepped model of consumer involvement in research [5]



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We recognise it is beyond the scope of the next CCI Statement to resolve these language issues. The new Statement can, however:

- acknowledge the different roles consumers currently play, including leading research,
- acknowledge that the language is contested, evolving and used inconsistently,
- provide definitions to help promote consistency and shared understandings, and
- support the development of a consumer-led typology and definitions that reflect the different levels of involvement and collaboration, noting that language already varies between different disciplines and conditions.

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[5] Developed by Melissa Le Mesuier and used with permission, do not reproduce without permission.