



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

“Nothing about us, without us”

Response By Deakin University’s Faculty of Health to the Position Paper Questions

Deakin University’s Faculty of Health is pleased to provide the following submission to the Review of the 2016 Statement on Consumer and Community Involvement in Health and Medical Research.

Deakin’s Faculty of Health is one of the largest and fastest growing health faculties in Australia. The Faculty is comprised of five schools (School of Exercise and Nutrition Sciences; School of Health and Social Development; School of Medicine; School of Nursing and Midwifery; School of Psychology), three research institutes (The Institute for Health Transformation; The Institute for Physical Activity and Nutrition; The Institute for Mental and Physical Health and Clinical Treatments), two strategic research centres and numerous specialist units.

We conduct a broad range of multidisciplinary and translational research that addresses important individual and population health problems. Our research programs are supported by our collaboration with industry partners and governments to put findings into practice. Together, we tackle some of the most urgent and important clinical and public health problems of our time.

With input from members across the whole faculty, with their expertise in multiple disciplines and wide-ranging research methodologies, and their experience undertaking research into the vast array of health and medical research topics the NHMRC Consumer and Community Involvement Statement applies to, we hope our submission provides a balanced and holistic response that is of value to the NHMRC in its review of the Statement.

Below we provide some general comments, followed by responses to the questions from the survey.

Deakin’s Faculty of Health researchers have an acute awareness of the importance and value of consumer and community involvement (CCI) in all phases of our research, and we are dedicating significant resources towards growing our capabilities for meaningful engagement. The Faculty’s Community Research Engagement Network (CREN) works to support faculty staff and research students to facilitate, support, and enhance CCI across the Faculty, with a specific focus on health and medical research. It promotes inclusivity through engagement with a true cross-section of the broader population including Aboriginal and Torres Strait Islander peoples, people with a disability, culturally diverse populations, gender and sexually diverse communities, and socioeconomically disadvantaged communities. CREN has developed a framework and best practice guidelines with appropriate mechanisms for CCI at all stages of research and professional development. It has a multidisciplinary group of Advisors who support and guide faculty researchers on effective CCI. It identifies ‘best practice’ approaches and showcases exemplars through workshops for staff and students and makes tools and resources available on an internal SharePoint site.

The establishment of the [Community and Research Network](#) within The Institute for Mental and Physical Health and Clinical Treatments and the [Consumer Network](#) within The Institute for Physical Activity and Nutrition further demonstrate our commitment to CCI.

A new Centre for Excellence in Consumer Engagement in Health, [The Health Consumers Centre](#), is part of the Institute for Health Transformation and supports our whole organisation, and others, to undertake best practice CCI and build capabilities. The Centre builds on the legacy of Victoria’s peak health consumer body, the Health Issues Centre, leveraging its people, resources and the extensive community and consumer networks that were developed over the past 40 years. Examples of the Centre’s work in CCI in research includes:



- Facilitating consumer engagement activities in early stages of research to inform hypotheses, test and develop methods and inform grant submissions
- Chairing and supporting consumer review panels in grant making processes
- Recruiting consumers for research projects as participants, advisors, co-investigators and members of co-design teams
- Providing training to consumers and to researchers and leaders in Research Institutions around the development of consumer engagement strategies, structures and processes to support meaningful consumer engagement practice in research
- Supporting the implementation of consumer advisory and engagement mechanisms
- Advocating for and supporting CCI in an international conference by embedding requirements for engagement in abstracts and presentations to supporting a cohort of consumers to be active participants in the conference and running a workshop on meaningful engagement
- Leading projects where we have designed methods, recruited consumers and explored key questions through focus groups, workshops, interviews, surveys, community forums and codesign processes.

Our research teams recognise the unique expertise of community with lived experience and the value of meaningful CCI in all stages of research, from project inception and funding application through to dissemination. We have numerous examples of CCI at all stages of research from priority setting to policy recommendations with industry and government organisations, including:

- Working with community to conduct evidence reviews and develop consensus statements
- Identifying consumer’s needs and preferences and setting research priorities through truly consumer-led approaches
- Co-designing research projects, survey tools and interventions with consumers as investigators
- Consumers as members of decision-making committees
- Partnering with consumers in making policy recommendations
- Co-production of research with consumers as researchers from conceptualisation to policy recommendations.

Through these types of activities we have benefited from CCI in many ways including by refining and sometimes completely reframing research questions; informing methods and ethics considerations; improving how research is communicated and promoted to the community; assisting in reaching recruitment goals and targeting recruitment to achieve diverse representation; having a consumer lens applied to how the results are interpreted, meaning derived and outcomes and value communicated to the field. We have also observed that genuine researcher-community collaboration increases the perceived (and real) credibility of our research by the broader community. This increased credibility and community ownership is invaluable in mobilising support and advocacy for research funding and project implementation.

Nonetheless, we need further support to understand the most appropriate ways to include consumers and community in all stages and types of research, particularly basic science and preclinical research, where the role of consumers is less clear.

The current Statement and importance of consumer and community involvement in research

What parts of the current Statement have or have not worked well?

The current Statement provides a useful framework for CCI. Many parts of Deakin University’s Faculty of Health have used the Statement to help develop our own policies and practices for consumer involvement.

However, the statement could be much stronger in relation to terms such as ‘should consider the benefits of’ CCI and be clear that it is an expectation and aligned with best practice. It is important that the language and intentions are clear, that this is essential practice and the examples should reflect all parts of the spectrum of participation. The options presented are much more at the involve and consult rather than

partnership and leadership end of the spectrum and there is a risk of tokenistic practice without additional and expanded examples. The Statement also needs to cater to best practice engagement approaches to diverse groups within the population.

The statement could also be braver and bolder in framing CCI as a core skill and the focus of continuous learning and evolving practice for every researcher throughout their career and the responsibility of every research institution and funding agency to enable.

It needs to reflect the importance of relationships and true partnerships, of navigating and overcoming power differentials, of recognising inherent biases, creating safe spaces for people to find their voice and agency, sitting with discomfort and finding the solutions together that is critical to effective practice.

The expertise that is derived from lived and living experience of ill health, harm and recovery or of well members of the community depending on the nature of the research and the intersectionality of experiences and identities across all parts of a person’s life are important to acknowledge. It needs to be clearly stated that there are risks of harm that need to be actively and skilfully managed and highlight the need for support, briefing, independent debriefing and remuneration to reduce barriers and enable diverse engagement, particularly of those who are most marginalised in our community but who often have the greatest needs and insights to offer.

The role of funding agencies needs to be clearly stipulated in assessing the value, meaning and effectiveness of engagement in the development of hypotheses and grant applications and the intended practice of CCI in the conduct of the research and its dissemination and translation into practice (as relevant). Consumers need to have an equal seat at the table where research funding decisions are made to bring their unique and valuable perspectives to bear. Their contributions should contribute to scoring and criteria around CCI should be scored and considered in the funding decision making process. Only when this occurs universally will there be true and widespread culture change across the research sector – accelerating the change that has occurred in the sector since the current statement was published.

Different sectors use different terminology so clarity around definitions is important. For instance, in health services ‘patients and families’ are most frequently used. In maternity services, the term ‘woman’ is used. In residential aged care settings, the term ‘residents’ is used. While ‘consumers’ may be the best term across health and medical research, a statement of recognition is needed regarding: the various terminology used to refer to ‘consumers’ throughout research; the positionality of the current framework in terminology choice and recommendation, as well as; the variable community preferences (within and between communities) on selected terms and the need to be responsive to community preference. For example, Australian guidance on communicating with and about people with diabetes recommends avoidance of the term ‘patient’ while community members report ‘consumer’ to be a passive term which does not reflect their real and active role in self-management (Diabetes Australia ‘Our Language Matters’; 2021).

“Putting the statement into practice” is a critical paper component which should support implementation. Indeed, there is currently a level of uncertainty within the research community around how to appropriately involve consumers in all types of research, particularly basic science or preclinical or greenfield research. There is a belief that consumers may be less interested in this type of research, that it doesn’t matter to them, that it is seen as opaque or arcane, and a concern that endorsement and priority setting driven by consumers may reduce the emphasis on this cutting edge research in favour of more applied research that may be the focus of consumers but may not necessarily contain unanswered questions. To really transform the culture of research and overcome these concerns, clear examples of different ways to involve consumers in all types of research and support to implement the statement are critical.

The provision of expectations for institutions, researchers and community members is useful but the current text is insufficient. With regard to institutions, current text includes a mix of concrete practice recommendations (e.g. “have a policy”) and abstract expectations (e.g. “minimise barriers to meaningful consumer and community involvement”) without indication of how institutions could achieve these expectations or the need for demonstrated mechanisms to achieve these expectations.



It is also not clear what role researchers have in achieving highly relevant expectations listed for institutions (e.g. researchers are not recognised as key stakeholders in “minimising barriers to meaningful consumer and community involvement”; “valuing” community members time and expertise, and “justifying the level of involvement”). Further missing elements of this section (both in practice expectations and implementation issues) are recognition of the role of health stigma and discrimination as potential barriers to effective CCI; the potential for negative impacts of CCI (e.g. burn out, distress) and the need for harm reduction practices; and the importance of sharing feedback and outcomes of involvement to consumers and community to foster trust (perhaps implied but not currently stated explicitly).

Why is consumer and community involvement in research valuable?

There are so many complex, wicked problems to be solved to achieve equity in health and wellbeing in our diverse communities. We have rising expenditure in health, a system and workforce in crisis and some of the gaps in experiences and outcomes across different parts of the community are widening. We need to be developing and testing solutions that are innovative and transformative and bring new ways of thinking and problem solving to bear. So often our work in health research is done with the best of intentions but without truly understanding or engaging with people who can bring insights from their lived experience as representative of the intended beneficiaries of the potential intervention that is being explored or tested. Without that grounding through every step in the research cycle, unconscious biases are not uncovered, assumptions remain untested and potential solutions may be missed. Essentially, we risk wasting efforts and resources or at the very least those resources not being optimised.

Genuine CCI offers multiple benefits for research conduct, outcomes and communities, helping to increase the relevance and quality of our research, and ensure it has maximum benefits to those who need it the most. Through safe and effective CCI, our research efforts are grounded in what matters most to those most affected. The unique perspectives and expertise of community or of people with specific lived and/or living experiences of ill health, harm or recovery including as a carer, family member or supporter can help to shape research and improve its applicability, acceptability, accessibility, appropriateness and effectiveness. CCI helps to identify potential barriers to access and participation in research and allows us to design research that is more inclusive and equitable, and more likely to have real impact. It can also support increased credibility and community ownership and uptake of research, enabling community-led support and advocacy for research funding and project implementation. Ultimately, this will result in better outcomes that are more likely to be translated into meaningful changes in systems, processes and practice.

As ethical research practitioners, the mantra in many disciplines is “Nothing about me, without me” or “Nothing about us, without us”. This mantra reflects a commitment to the rights and expertise of the beneficiaries of our research and their involvement in decision-making, and an awareness that they are often in the best place to understand and know about their needs and priorities and that their involvement is fundamental to improving health outcomes.

Why does consumer and community involvement in research matter to you?

Because it is a fundamental right and responsibility for us all and because it works. Because unmet health needs are so great and community members have the most at stake. Because we see the value and impacts of community-supported and community-led research. Because, as researchers, we have a responsibility to listen to and amplify the voices of the community we serve; be responsive to community needs and interests; and recognise the value of lived experience contributions.

CCI from all parts of the population helps our researchers to better understand the needs of consumers and communities. With a better understanding, researchers conduct research that has more meaningful impact and positive outcomes. Without lived experience of an issue/disease/condition, researchers cannot fully comprehend how appropriate and useful research design, methodologies and dissemination strategies will be. When done well and safely, the insights that are generated are fundamental to our success as researchers and lead to more meaningful, translatable outcomes.



Value Statement

What overarching values are essential to include in the value statement of the revised Consumer Statement, and why?

Authenticity, partnership, equity and accountability – these are fundamental to effective CCI practice and building skills and practice that truly bringing these values into action will lead to better, safer, more meaningful and effective CCI. At their heart these are core to building trust, safety and enabling people to find their voice and agency and to ensuring that our practice is not guided by those who are easiest to engage but that we strive to be inclusive and to work with people whose voices are unheard or hardly heard (with the supports that are required for that to be effective).

We also advocate for the inclusion of respect. Respect acknowledges: community members autonomy in their own health decisions; lived experience as a form of expertise; community involvement in research as a choice and not a responsibility of people with lived experience. Respect is an essential component of effective partnerships and can assist in minimising stigma and discrimination.

The current values might be better framed within the purpose statement as they reflect the vehicles through which effective practice occurs and the vision is ultimately enabled.

The values that underpin the 2016 Statement are ‘shared understanding, respect and commitment.’ How might this be strengthened and improved in the revised Consumer Statement?

The current values imply that parties come together on an equal footing. Shared understanding, shared respect, and shared commitment may be more appropriately labelled as goals, rather than values. Respect and commitment are important values, but should be separated from the stem “i.e. shared”. It is imperative that researchers who seek to engage community do so with ‘respect’, however we cannot assume community members begin involvement in a position of ‘shared respect’ for research or researchers. Similarly, while commitment is shown across parties we should not assume this to be shared in nature.

Whilst shared understanding, shared respect, and shared commitment should grow from an effective partnership with consumers, the values that should guide our practice need to reflect the more fundamental foundations of practice that enable shared understanding, shared respect, and shared commitment – such as those suggested above.

Should values such as accountability, transparency, collaboration and partnership, equity, diversity and inclusiveness be included in the revised Consumer Statement?

These are all critical elements of consumer and community engagement and involvement, along with respect and authenticity.

Among these, there are some key guiding values, namely respect, accountability, partnership and equity. The other four reflect dimensions of each of those: transparency and authenticity as a part of demonstrating accountability and respect, and also as a means to build trusted relationships; collaboration as intrinsic to partnership and respect; and diversity and inclusion as fundamental to living a value of equity.

Better practice principles for consumer and community involvement in research

What do you regard as the most important principles that should be included in the revised Consumer Statement?

Principles included in the revised Statement should be those that clearly align with the Statement’s values. The examples of principles used in the Position Paper e.g., UK Standards for Public Involvement, the CDC and Australian Code, are clearly underpinned by values such as mutual respect, honesty etc.



While the MRFF principles are clearly tied to values such as partnership, diversity and equity, we would recommend that principles used in the revised Consumer Statement steer away from using wording such as “should” and use more inclusive languages such as “consumers are involved in all stages of research...” By re-framing these principles as ‘are involved’, ‘are partners’ etc., they become expectations, or at least aspirational, rather than nice-to-do but not essential.

Indeed, the language of ‘better practice principles’ could be strengthened. Concepts such as mutually respectful relationships, respect and honesty should be framed as essential to effective practice. Without these in play, the risks of tokenistic, ineffective and, potentially harmful practice are raised. It is important that there is awareness of these risks – psychologically safe and inclusive practice is everyone’s right and responsibility. Until we openly acknowledge the potential for harm, we risk naively engaging without the proper supports in place or inadvertently causing harm. This becomes even more important when we are talking about equity and engaging with people who are traditionally marginalised. The revision of this Statement in 2024 is an important opportunity to deepen understanding about the art and science of effective CCI practice.

There is also a need for inclusive language and statements which avoid placing undue responsibility on community (“e.g. Consumers and community members should...”, MRFF) or that assume an end-goal (e.g. “Mutually respectful relationships; UK standards) as a guiding principle. “Respect for lived experience and community expertise” (CDC US) is an important and well-worded principle. And as noted above, other principles could speak to the recognised benefits of CCI; the need for ethical conduct in CCI; the importance of harm-reduction approaches; and the need for transparency and accountability.

Roles and responsibilities

What roles and responsibilities for consumers and community members should be included in the revised Consumer Statement?

The roles and responsibilities outlined in the current Statement are still very relevant and should be considered for inclusion in the revised Statement. However, we suggest moving away from “Consumers and community members should” language. Where there exists an imbalance in power (i.e. power held by researchers), it is not the responsibility of community to “advise” but rather their right to choose to do so. Relatedly, consideration of “rights” under CCI roles, expectations, and responsibilities would be useful.

Rights could include: 1) right of autonomy in disclosure, involvement, and sharing of and lived experience; 2) right to participate in CCI in a safe and respectful environment free from harm; 3) right to acknowledgement and / or remuneration* for time and expertise in a way that does not disadvantage them (for example, restricting payments only via vouchers); 4) right to transparency in research conduct, outcomes and implementation of CCI contributions; 5) right to be informed of the findings of the research to which they contributed.

* Regarding remuneration, it is important to respond to individuals' preference as some do not wish to receive remuneration and prefer acknowledgement, and some wish to stay in the background.

A key responsibility for consumer and community members is: Acknowledgement of their scope of lived experience and personal biases. This is of increasing importance as we, researchers, build and lean on existing strong CCI partnerships which may not best speak to the research population nor recognise diversity within the population of interest.

It is important to acknowledge that roles of consumer and community members and the intensity of their involvement may vary in response to the types of research, as well as specific research needs. For example, consumer and community member roles may look quite different in basic science, preclinical or greenfield research compared to applied research such as designing and testing an intervention. Articulating the roles consumers and community members may play across these different types of research will be of value to consumers and community members themselves by clarifying and managing

expectations, but will also be of great use to researchers who may not always be clear on the most appropriate ways to include consumers and community members in these varying types of research.

It is also important to strengthen recruitment practices around screening, matching consumers to roles, supporting, briefing and offering debriefing support to enable effective practice. An approach to learning and improving practice together as partners should be baked into this Statement. This is essential for meaningful participation, true influence and for consumers and community members to be valued and respected as equal partners in research.

What roles and responsibilities for researchers should be included in the revised Consumer Statement?

The roles and responsibilities outlined in the current Statement are still very relevant and should be considered for inclusion in the revised Statement.

We would also recommend highlighting that a role and responsibility for researchers is to plan for CCI as early as possible and that CCI must be meaningful and add value to the research; it should never be tokenistic.

In addition, we recommend the following responsibilities are also considered:

- 1) ensure diversity in numbers and perspectives in CCI
- 2) respect CCI members, and ensure that it is the people with lived experience who make the decision to disclose and share their story if they choose to
- 3) clearly and consistently communicate expectations and outcomes of CCI
- 4) acknowledge the value of lived experience by providing appropriate remuneration, credit, and support
- 5) take steps to foster a safe environment for CCI; reducing potential for harms and dismantle stigma
- 6) seek development / training opportunities to build skills that are required for effective participation – its planning, implementation, evaluation and improvement. This would include formal training as well as iterative practice and a commitment to continuously improving their craft as a CCI practitioner.

We support the inclusion of researchers as championing CCI as outlined in the position paper. But to make this role effective, we recommend an added responsibility for researchers to ensure that there are adequate resources included in their research budgets to bring that to life. Examples of budget items include:

- Consumer payments and reimbursement to enable participation, including allocations for time to contribute to publications arising from the research as a co-author
- Inclusion of consumer engagement expertise in the research team or time for the core team to incorporate this practice effectively into the research
- Allocations for external support if there needs to be additional work or outsourcing to enable meaningful participation e.g.:
 - Inclusion of funding that would support a community leader to co-facilitate an engagement that might be in a language other than English and, most importantly, create a safe space for those community members to participate
 - Funding to support advertising and targeted recruitment of consumers
 - Access to independent debriefing support or evaluation services to embed continuous learning and assessments of the effectiveness and impact of engagement into the program of work
 - Learning and coaching support to build skills and evolve practice – learning by doing.

Where there are references to person or persons, it is important to reflect that more than one consumer is standard practice for representation and, ideally, there would be multiple people in multiple roles that are implemented in any research endeavour. There might be a single consumer advisor for example as a critical

friend who works with the researcher and provides insights from a consumer perspective. If setting up an advisory committee to oversee the research, there should be two or more consumers with a seat at the table. Additional consumers might then be recruited for a Consumer Reference Group or to participate in consultation workshops to inform the research methodology or deepen understanding of the problem, needs and preferences. A selection of those consumers might then join a team to work with health professionals and other stakeholders in a codesign process.

The concept of equality should be extended to equity reflecting that there are barriers to participation that will need to be overcome for people to truly participate as partners.

It is important that there are different levels and methods of engagement that are fit for purpose as there are different levels of activity and roles for consumers, as outlined in above sections. It is important to be clear in language and intentions around community, consumer, lived and living experience perspectives and that part of the craft of CCI is in developing methods and roles that are fit for purpose rather than a one size fits all approach. This is as important as the design of the research methods themselves.

Should involvement of consumers and community members be an expectation of research?

Please answer Yes/No/Not sure and provide a reason for your response.

Yes. To improve applicability, acceptability, accessibility, appropriateness and effectiveness of research and its dissemination and translation into meaningful impact in the community leading to a greater positive impact for those who need it the most.

As discussed above, the nature of this participation or partnership may vary based on the type of research, and this should be clearly articulated through the Statement to ensure awareness of how to involve consumers in all types of research in an appropriate way.

Is there an ethical imperative to involve consumers and community representatives in research?

Please answer Yes/No/Not sure and provide a reason for your response.

Yes. "No research about us, without us."

Involving consumers and the community in research is ethically important, as it ensures that their voices are heard and respected throughout the research process. This helps to build on values such as trust, transparency and accountability between researchers and the community. It also maximises the likelihood that research outcomes can be translated to meaningful improvements in the health and healthcare of the community. It is a right and a responsibility of all and, at a minimum, an essential accountability for the use of public funds. The national statement on ethical conduct in human research states the following values: "respect, research merit and integrity, justice, and beneficence". CCI pays respect to the persons/populations in research and can support the demonstration and determination of all listed values. Of course, the value and utility of the practice runs much deeper than that.

What roles and responsibilities for research institutions should be included in the revised Consumer Statement?

The institution must create a culture that enables meaningful CCI. This requires leadership/executive support and commitment, and to demonstrate that leadership in action through providing practical supports for CCI. This includes:

- setting the standards and expectations and upholding those standards within the organisation
- demonstrating values in action through the development of a CCI strategy for the organisation

- establishment of formal mechanisms for CCI that are embedded into the organisation's governance structure and that provide insight and oversight of CCI practice across the institution – truly walk the talk
- establishing consistent systems, policies and processes within the institution to support researchers to embed CCI into their practice and to support consumers to meaningfully and safely participate
- establishing consumer feedback processes to support ongoing quality improvement
- provide access to training and support for skill development of researchers as CCI practitioners
- provide seeding funding that enables meaningful engagement to occur that informs research priorities, planning and the preparation of grant applications
- a commitment to the measurement and reporting of impact of CCI to showcase best practice examples, contribute to the evidence base around effective involvement and to inform continuous improvement and strategic priorities in this critical area.

The examples listed in the Position Paper do not meet the community nor researcher needs from research institutions. The suggestions provided above provide clear direction for institution action.

What roles and responsibilities for research funders should be included in the revised Consumer Statement?

Research funders have a responsibility to practice and respond to CCI in making funding allocation decisions (i.e. not only in peer-review of applications, but to inform funding calls which explicitly address a community-identified priority area). This responsibility is disappointingly absent from the current and new suggested statement content. Research priority setting exercises have been extremely popular over the last decade, but without research funder support, community priorities remain under funded and under researched and thus opportunity for CCI benefits go unmet.

The costs of and time it takes to undertake meaningful CCI must also be factored into Research Funder expectations about project outcomes, timeframes and budgets.

Funders also have the levers to help drive the leadership and culture change that is needed at both the researcher level and the Institution level.

In their grant application guidelines, research funders should clearly state their requirements for CCI. This includes and is not limited to guidance on budgeting for CCI. Funders can strengthen application templates by including a line item for CCI within budget templates. Providing a costing guide to support consumer remuneration would help to promote greater consistency and equity within the sector.

Application templates should also include questions that drill down into the specific mechanism or mechanisms for CCI in the specific research proposal. It is important that CCI is a criterion that is scored and influences decision making and that there is clear guidance provided to applicants, to peer reviewers and consumer reviewers as to how that is valued and scored.

Research funders could also consider providing some funding support to researchers to engage consumers to help inform their research planning and with research application preparation (i.e., before an application is submitted for grant consideration). If a researcher is looking to involve consumers in helping to set research priorities, identify research topics, review grant applications prior to submission, they need funding to remunerate consumers.

To assist with researcher capacity building, research funders could promote best practice examples of CCI. This would be particularly helpful for research in basic science and preclinical research where it can be more difficult to define how best to involve consumers and the community.

Research funders could also play a pivotal role in supporting institutions and avoid reinvention of the wheel (see dot points in the previous question). Funders could also require Institutions to demonstrate that they have a CCI strategy and supporting systems, policies and processes that enable CCI in the organisation and

in research. Embedding this as a standard question would be of value. Practical examples and thought leadership in this space are also important to support meaningful change.

Should funders of research mandate the involvement of consumer and community representatives in the research they fund?

Please answer Yes/No/Not sure and provide a reason for your response.

Yes, but... the additional measures as described above need to be in place to support meaningful CCI.

If a mandate for CCI was the only measure in place, is unlikely to be an effective driver of meaningful and widespread change and could easily lead to tokenistic approaches that do more harm than good. CCI in research must be undertaken as a genuine process and not for the sake of compliance.

It is important to acknowledge that tokenism is a longstanding issue in CCI practice. If we are to truly move away from pockets of excellence to meaningful CCI that is baked into learning and practice, requirements for engagement and targets, incentives and supports that enable change need to be considered together. Mandates are a part of the solution, but cannot be the only enabler.

Implementing the revised Statement

How should researchers involve consumers and community representatives in their research?

This question is covered in earlier responses.

However, the implementation question is actually the key to the Statement having the greatest impact in practical terms. It is important that there are accompanying mechanisms for support and guidance for each player in this system and practice of CCI and opportunities to share best practice examples and to resource the advancement of this field of practice. For many people and institutions, it is not due to a lack of passion or willingness that this practice is not more advanced but a lack of guidance and support to bring this all to life in a systematic way amid competing priorities.

Indeed, it is disappointing that the statement “does not focus on issues related to implementation of consumer and community involvement in health and medical research” given it is precisely the implementation of the statement which we have observed to be of most challenge to all parties. Implementation support requires considerable investment by NHMRC on how to actually do it.

What issues should be considered once the revised Consumer Statement has been finalised and published?

There needs to be a dissemination plan for the revised Consumer Statement once it is finalised and published to ensure researchers, organisations and consumers know that the Statement has been updated. We recommend that a monitoring/evaluation plan for the revised Consumer Statement is also developed, so its effectiveness can be measured.

It could be useful for research institutions to be aware of what training programs are endorsed by funders, to ensure that they are aligning their consumer and researcher capacity/skill development with best practice and not duplicating the development of such resources. This would be helpful in terms of implementation of the plan itself i.e. bringing the content to life.

Investment that progresses this area of practice is also important, such as requirements for successful grant recipients to participate in independent evaluations of CCI practice and outcomes. This would result in significant contributions to advancing the field of practice through capturing the actual mechanisms that are implemented and building a body of knowledge across all types of research of models of CCI, enablers and barriers to effectiveness and tangible examples of practice, value and impact.