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| Statement on Consumer Engagement in Cancer Research (the Statement) |
| Victorian Cancer Agency |

This Statement has been developed to support the implementation of best practice consumer and community engagement in research funded by the Victorian Cancer Agency (VCA). The VCA is committed to building sustainable long-term capacity and understanding of the wider Victorian cancer research sector in engaging consumers and the community in research. In developing this statement, the VCA has consolidated feedback, views, and insights collected over multiple years from people with a lived experience of cancer who have participated in the assessment of VCA funded research.

We wish to express our gratitude and thanks to the many individuals who have contributed to the VCA Funding Round Consumer Evaluation Panels. Their contributions have helped distil best practice consumer and community engagement in research, that will improve outcomes for people diagnosed with cancer, their families and carers, into the future. We learn from you every year and look forward to championing the benefits of consumer and community engagement in all aspects of cancer research.

## Benefits of consumer and community engagement in research

VCA considers consumer and community engagement integral to cancer research. This Statement provides practical guidance for researchers to actively and authentically engage consumers and the community in their proposed research. Those affected by research have a right to be involved in research[[1]](#footnote-2), particularly where research is publicly funded. Their input should be included throughout all stages and types of research.

Incorporating the lived experience of consumers improves the likelihood of achieving the goals and objectives of proposed research, including the impact and broader relevance of the research to consumers and the community. As noted on the Cancer Australia website, “Evidence suggests that involving consumers leads to improved health outcomes, improved safety, a more trusted health system and a more satisfied workforce”.[[2]](#footnote-3)

**Consumers and carers affected by cancer offer a unique perspective about research that is different to that of the researchers. This perspective is based on their lived experience of cancer and will be useful if it is to be incorporated in each one of the stages of the research cycle. Consumers and carers perspectives should also be included in the ideation stages of research and the formulation of research questions.**

*Manager of Training and Development Health Issues Centre and VCA Consumer Evaluation Panel Chair, Dr Tere Dawson.*

Embedding the unique personal experience of people with a lived experience in research will directly benefit outcomes in health and medical research. It is therefore crucial that research funded by the Victorian Government through VCA involves meaningful ‘two-way’ consumer engagement.

A “consumer” is any person who is or has been personally impacted by cancer, also known as “lived experience”, this could include a person diagnosed with cancer or a carer/family member of a person diagnosed with cancer.

**“My involvement as a consumer representative on a VCA Early Career Research Fellowship and VCA Consumer Evaluation Panels has given me the opportunity to contribute my lived experiences to cancer research in a meaningful way. It’s been rewarding to not only be able to influence projects but also see great research progress.”**

*VCA Consumer Evaluation Panel member, Mr George Kiossoglou.*

“Community” refers to a group of people sharing a common interest (e.g., cultural, social, political,

health or economic interests), but not necessarily a particular geographic association.[[3]](#footnote-4) In the context of health research this could also include community organisations, networks and support groups.

Collaboration between researchers and consumers is a partnership that is mutually beneficial. Researchers who engage consumers meaningfully in their research often report a rewarding connection with their consumers and a positive impact on their research.

**“I was not initially convinced that consumer and community involvement would significantly benefit my research and only began the process in order to meet with VCA requirements for the fellowship scheme. However, the relationships I have built with consumers and being able to embed their wisdom into my research project has been one of the most rewarding and worthwhile experiences of my fellowship. Research outcomes have been more meaningful, and consumers have shared ownership of this work.”**

*VCA Early Career Research Fellow, Dr Imran House.*

**A comprehensive, inclusive, safe, and equitable approach to consumer engagement**

VCA recognises that there is not a ‘one size fits all’ approach to consumer engagement in research. As outlined in the *Victorian cancer plan 2020-2024*, cancer affects people of all ages, genders, cultures, backgrounds, geographical locations and recognises that every person impacted by cancer has unique needs and experiences.

Often consumers experience barriers to access and care across the cancer continuum and system. VCA considers diversity and equity as key principles of consumer engagement. While research questions ‘at first glance’ might not appear to impact diverse communities, applicants are encouraged to engage consumers with wide-ranging experiences and backgrounds representing the community that we live in, including:

* people living in rural and regional Victoria
* Aboriginal and Torres Strait Islander people
* culturally and linguistically diverse people
* young people
* people with complex and chronic conditions
* people with disability
* LGBTIQ+ people

Culturally inclusive practices are essential to ensure diversity of consumers is considered and a culturally safe research environment is established.

For further guidance refer to the National Health and Medical Research Council (NHMRC) [`*Ethical guidelines for research with Aboriginal and Torres Strait Islander Peoples’*](https://www.nhmrc.gov.au/research-policy/ethics/ethical-guidelines-research-aboriginal-and-torres-strait-islander-peoples)and *`*[*AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research’*](aiatsis-code-ethics-jan22.pdf) and *`*[*A Guide to applying The AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research’*](aiatsis-guide-code-ethics-jan22.pdf).

The Victorian Aboriginal Community Controlled Health Organisation is leading the development of a Victorian Aboriginal Research Accord[[4]](#footnote-5). The core purpose of the Accord is to embed Victorian Aboriginal community’s self-determination, regarding research that impacts Communities within a draft Accord which is Aboriginal led, informed by Aboriginal literature and is culturally appropriate. It is anticipated the Accord will provide additional guidance for Victorian researchers to ensure all research is undertaken in a culturally appropriate manner.

**Minimum requirements for consumer engagement in cancer research**

The VCA expects that all applications involve at least two individual consumers with a lived experience of cancer. These consumers can be engaged as patients in their own right and/or be members of cancer related groups such as peer support groups or cancer-specific associations. Their names should be included on the application (with their written consent), their role and how they have participated in the research project are clearly articulated, and they should be listed as part of the research team, preferably as an Associate Investigator.

Including community organisations, networks and support groups can further bolster the collective consumer voice however this should be in addition to rather instead of engaging individual named consumers.

**Advice to strengthen consumer engagement in cancer research**

The guidance provided below is a summary of several years of VCA consumer panel comments and feedback about what constitutes an application with strong evidence of consumer engagement. This is not intended to be a mandated list, rather general advice that may strengthen applications. This includes:

* Evidence that consumers are an integral part of the team and involved in all stages of research e.g., planning, development of the research question, project development, grant applications, governance, data collection and analysis, reporting and dissemination and communication of results, and translation of research into practice.
* Established long-term relationships with consumers and details on how this developed and is/will be sustained.
* Describe the consumer role clearly. Provide evidence of the depth of consumer and community involvement. Be clear about what the plan is for consumers and community engagement over the life of the project.
* Consumer component is clear, well written, easy to understand and in lay terms. Clearly evident that consumer/s have read the grant and provided advice on how to convey technical terminology. Use of clear diagrams and figures to explain technical concepts.
* Applicants include a budget allocation for consumer and community engagement, e.g., reimbursement for travel, parking and other costs; training and conference attendance; and renumeration for an individual’s time.
* A clear explanation on how equity and diversity have been considered thoroughly for rural/regional and diverse populations. Consideration of equity of impact on rural/regional areas.
* Clear explanation of how research will specifically impact the community and individuals in both short- and long-term timeframes. Outline the benefits to the community if the research is successful.
* Name of community organisations, networks and support groups who have been engaged and details on their specific involvement.
* Consumers engaged represent a breadth and depth of experience and knowledge that enhances the research project. Provision of rationale for the choice of consumers, describing the consumer/s knowledge, experience and background that informs the research.
* Inclusion of consumers in meetings and on committees, including setting up a specific meeting schedule to allow for consumer feedback, review and update (at least quarterly); research/project meetings; clinical trial committees; planning meetings and advisory groups.
* Consumers involved in communication of results, e.g., invited to present at lab meetings, launch events, fundraising opportunities or conferences, and/or present to cancer related support groups they are affiliated with.
* Clear description of the current impact of the cancer on the Australian/Victorian population and provision of cancer statistics specifically relevant to Victoria/Australia.
* Details on how consumer/s have influenced the project to date with specific examples included in the application of how the project has evolved.
* Laboratory-based and pre-clinical research can demonstrate effective consumer engagement through factoring in toxicity issues with combination therapy and/or dosage, consideration of impact on quality of life on the people receiving the intervention, using repurposed drugs to accelerate access to treatments, and applicability of research to other cancer types.
* Low‑survival cancer researchers describe the diverse options they have used to engage with low survival cancer support and advocacy groups, carers and family members with lived experience.
* Collaborations with peak bodies and/or philanthropic organisations coupled with consumer engagement add strength to applications, including but not limited to, Cancer Council Victoria, Rare Cancers Australia, Lung Foundation, Ovarian Cancer Australia, LiverWELL, Pancare Foundation, Breast Cancer Network Australia, Leukaemia Foundation, Health Issues Centre and the Consumers Health Forum of Australia.
* Engaging both individual consumers and community organisations, networks and support groups is likely to strengthen applications/research plans.
* Consumers (as patients or carers) involved in clinical settings or clinical trials or from consumer-related organisations or peer support groups can also be recruited. They don’t necessarily have to represent these groups. Note please consider providing them with training in advocacy and consumer engagement in research.

**Additional resources**

There are excellent existing resources available through other organisations that VCA recommend you should review in preparing your application and conducting research.

* *The NHMRC* [Consumer and Community Engagement Toolkit and Associated Resources](https://www.nhmrc.gov.au/about-us/consumer-and-community-engagement) (Particularly helpful are the downloadable forms at the bottom of this webpage).
* *Cancer Council NSW* [Consumer Review Guidelines for research grant applications](https://www.cancercouncil.com.au/wp-content/uploads/2020/05/CCNSW-Consumer-Review-Guidelines-2020.pdf)
* *The Consumer and Community Involvement Program* [CCI Program](https://cciprogram.org/)
* *Cancer Australia* [Consumer engagement | Cancer Australia](https://www.canceraustralia.gov.au/about-us/who-we-work/consumer-engagement)
* *Victorian Cancer Agency* [*VCA funding rules*](http://www.victoriancanceragency.vic.gov.au/)
* *Victorian Comprehensive Cancer Centre Alliance* [Consumer Engagement Toolkit](https://www.viccompcancerctr.org/about-vccc/consumer-engagement/toolkit)

To receive this publication in an accessible format [email the Victorian Cancer Agency](mailto:%20victorian.canceragency@dhhs.vic.gov.au) <victorian.canceragency@dhhs.vic.gov.au>

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Available at: [Victorian Cancer Agency](http://www.victoriancanceragency.vic.gov.au) <www.victoriancanceragency.vic.gov.au

1. South Australian Health and Medical Research Institute, Position Statement Community and Consumer Engagement in Research at SAHMRI <https://sahmri.blob.core.windows.net/communications/sahmri.org/SAHMRI_CCE_Position_Statement_February_2021_final1.pdf> [↑](#footnote-ref-2)
2. Cancer Australia, <https://canceraustralia.gov.au/about-us/who-we-work/consumer-engagement> [↑](#footnote-ref-3)
3. Cancer Institute NSW, Consumer and Community Engagement Framework <https://www.cancer.nsw.gov.au/getmedia/3109d65f-6135-4df5-82a5-59fc4408159b/Consumer-Community-Engagement-Framework.pdf> [↑](#footnote-ref-4)
4. Victorian Aboriginal Community Controlled Health Organisation, <https://www.vaccho.org.au/research-resources/varap/> [↑](#footnote-ref-5)