

Overview: Increasing participation of people from CALD backgrounds in research

Aim: Develop strategies to improve research participation for people from culturally and linguistically diverse (CALD) backgrounds affected by cancer

Method: Co-design workshop

Outcome: An agenda for enhancing participation for people from CALD diverse backgrounds in cancer research in NSW

Guiding principles identified

- Coordination and collaboration
- Build on previous work and achievements
- Integrate CALD people into mainstream research initiatives
- Use technology and communication platforms to enhance reach

Co-designed strategies



1.

Map existing initiatives, resources and technologies



2.

Increase representation of people from CALD backgrounds in consumer networks, ethics committees and funding bodies



3.

Advocate for funding to enable participation of people from CALD backgrounds in research



4.

Promote research participation to people from CALD backgrounds using storytelling



5.

Pilot a streamlined research consent process for people from CALD backgrounds and their families



6.

Build the knowledge and skills of health professionals and researchers



7.

Pilot navigator roles to support people from CALD backgrounds participating in research

The workshop focused on cancer research but the strategies are relevant to health research generally.

High level of endorsement of strategies by participants – average rating

8.3 /10

45 people

participated, including researchers, clinicians, policy makers, funders, community leaders and consumers.

We designed strategies that are

- Feasible
- Potentially effective
- Complement existing initiatives

What's next?

Participating organisations and groups are identifying strategies to lead. We want to complement ongoing work and minimise duplication. We want to collaborate with others.

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Summary of workshop findings: Increasing participation of people from CALD backgrounds in research

Key Findings:

The outcomes of this workshop, held in March 2020 with a diverse range of participants, were seven co-designed strategies to improve research participation for people from culturally and linguistically diverse (CALD) backgrounds affected by cancer. The emphasis of the discussion was on cancer research but it was noted that the co-designed strategies may apply across a broad spectrum of health research.

The seven co-designed strategies were:

1. Map existing initiatives, resources and technologies being utilised to increase participation of people from CALD backgrounds in research that can be readily shared within the sector
2. Increase representation of people from CALD backgrounds in existing consumer research networks, human research ethics committees and funding/grant bodies
3. Advocate for identified funding to enable participation of people from CALD backgrounds in research
4. Promote the importance of research and participation to people from CALD communities using storytelling
5. Pilot a streamlined consent process for people from CALD backgrounds and their families
6. Build the knowledge and skills of health professionals and researchers to increase participation of people from CALD backgrounds in research
7. Provide navigators to support people from CALD backgrounds participating in research

Common themes across co-designed strategies included the importance and value of:

- coordination and collaboration at local, state and national levels;
- building on current work and what has already been achieved
- integration into mainstream initiatives to increase research participation
- technology and multi-media communication to enhance the reach of initiatives.

All seven co-designed strategies were seen to be feasible, potentially effective and complementary in increasing participation of people from CALD backgrounds in research. The strategies were endorsed by the majority of stakeholders and can be applied and evaluated in future practice and research.

Background:

The purpose of the workshop was to develop a shortlist of co-designed strategies to improve research participation for people from CALD backgrounds affected by cancer.

The primary focus of the workshop was on participation (where people take part in a research study); as opposed to involvement (where members of the public are actively involved in research projects and in research organisations) or engagement (where information and knowledge about research is provided and disseminated).¹

The half day workshop was held on Friday 6 March 2020 with forty five (45) participants comprising representatives from the following groups:

- Researchers and clinicians working in cancer research
- Researchers and clinicians with an interest in research with people from CALD backgrounds
- Research Offices, Human Research Ethics Committees and Local Health District research development roles
- Multicultural Health, Interpreter and Translation Services
- Policy agencies/funding bodies
- Community leaders and representatives

The workshop comprised:

- 1) a pre-workshop briefing on the stages and processes in designing and conducting cancer research;
- 2) an overview of the current situation regarding participation of people from CALD backgrounds in research;
- 3) a consumer perspective on participating in research; and
- 4) strategy development - small and large group work to explore and prioritise strategies, including ratings of feasibility and potential effectiveness in increasing participation.

¹ <https://www.invo.org.uk/posttypereource/what-is-public-involvement-in-research/>

Following the workshop, two surveys were conducted, one to assess participants' satisfaction with the workshop and the second to further refine and prioritise the strategies.

- 1) Respondents to the online evaluation survey indicated a high level of satisfaction with the workshop. They particularly valued the collaborative nature of the workshop, and interactive discussions amongst the wide range of stakeholders. The workshop was seen to be well structured and focused on solutions. Respondents valued engaging with community and consumer representatives and the opportunity to network.

"Good mix of participants, good facilitation ... good presentations. It was great to have people affected by cancer from diverse backgrounds involved in the) workshop. (It) was very interactive and there was a lot of experience, energy and engagement from participants." (Workshop participant)

- 2) Respondents provided advice on further refinement and prioritisation of the strategies. This feedback has been incorporated into the findings below. Respondents also indicated their interest in working with others to progress the strategies.

Participants in the workshop expressed interest in collaboratively working to advance one or more of the co-designed strategies.

Findings:

There were a number of common themes identified across the co-designed strategies. Participants emphasised the importance of:

- Collaborating at a local, state and national level; and ensuring efforts are coordinated and resources are shared.
- Building on existing initiatives; embedding strategies related to people from CALD backgrounds into general/ mainstream initiatives to increase research participation
- Using technology, multi-media communication to support reach of initiatives
- Integrating participation in clinical trials and other research as part of health care.

Co-designed strategies, ranked by participants for priority action, were:

1) Map existing initiatives, resources and technologies being utilised to increase participation of people from CALD backgrounds in research that can be readily shared within the sector

This strategy was seen to be an important precursor to future work that was both feasible and effective in increasing participation of people from CALD backgrounds in research. Mapping existing initiatives, resources (toolkits, translated materials) and technologies was seen to be useful in relation to sharing current information and resources, identifying gaps and developing recommendations for coordination of future work.

Suggestions for the mapping included identifying resources relevant to different stakeholder groups (consumers, researchers, clinicians, funders)

Suggestions for resource development included:

- 1) toolkits on how to work with interpreters in research settings;
- 2) how to start a conversation about research participation with consumers from CALD backgrounds (e.g. work being undertaken by Clinical Oncology Society of Australia (COSA)²); and
- 3) enhancing existing resources for research planning (e.g. National Health and Medical Research Council (NHMRC) Consumer Engagement Toolkit³) to include CALD engagement strategies/contacts etc.

2) Increase representation of people from CALD backgrounds in existing consumer research networks, human research ethics committees and funding/grant bodies

This strategy promotes a systemic approach to ensuring the involvement of people from CALD backgrounds in current consultation and decision making structures.

Suggestions for implementing this strategy include: funding/grant bodies, human research ethics committees and consumer research networks to mandate representation of people from CALD backgrounds in their own structures; embedding best practice examples and resources for increasing representation of people from CALD backgrounds in existing toolkits and training for researchers; development of CALD community panels to be available to research teams to inform research design and support interpretation of results.

3) Advocate for identified funding to enable participation of people from CALD backgrounds in research

This strategy highlights the role of both consumers and researchers in advocating to key funding bodies (such as Cancer Council Australia, state-based Cancer Councils, Cancer Institute NSW, NSW Office of Health and Medical Research and Cancer Australia⁴), peak bodies (such as COSA, Federation of Ethnic Communities Council Australia (FECCA)⁵, and Australian Clinical Trials Alliance (ACTA)⁶) and industry representatives.

Recommendations for the focus of advocacy efforts included:

- 1) budget templates to include mandatory items covering participation of people from CALD backgrounds in research (such as interpreter and/or translation costs; consultation with CALD communities, multi-media cross-cultural communication);

² <https://www.cosa.org.au/> ³ <https://www.nhmrc.gov.au/about-us/consumer-and-community-engagement#download> ⁴ <https://cancer australia.gov.au/>

⁵ <http://fecca.org.au/> ⁶ <https://clinicaltrialsalliance.org.au/>

- 2) target participation rates of people from CALD backgrounds in research;
- 3) identified funds to incentivise/support researchers to enable participation; and
- 4) a requirement for researchers to present and justify their plans for inclusivity.

4) Promote the importance of research and participation to people from CALD communities using storytelling

Storytelling was seen to be a powerful way of engaging people from CALD communities around research participation. Peer champions (patients from CALD backgrounds that have participated in research) were ideally placed to tell their stories.

Suggestions for content included:

- 1) communicate benefits of clinical trial/research participation;
- 2) address known barriers to participation, myths and misconceptions. Education/promotional packages could be co-designed with communities and NGOs to support the delivery of key messages through education sessions and multi-media campaigns. Journalists and community leaders could be identified to support the campaigns.

It was noted that it was important to build community trust in research and to simultaneously communicate with the research sector/health services.

5) Pilot a streamlined consent process for people from CALD backgrounds and their families

This strategy highlighted the need for a more meaningful and accessible consent process. It recognised the current work being undertaken by ACTA, CT-IQ Clinical Trials⁷, and others to address the complexity of the current consent processes.

A key recommendation was for consent documentation to be divided into two sections. Section 1 to be generic, common to all research studies. This could be translated into multiple languages and be a resource for all researchers. This section could also contain links to existing support materials e.g. multilingual videos. Section 2 would be specific to the research and translation would be the responsibility of the specific research team.

There was support for this to be undertaken as a partnership project and be piloted across NSW and Victoria. It was noted that early consultation with legal representatives was essential to ensure that simplified consent processes met current requirements.

It was noted that challenges included engaging international pharmaceutical companies to assess their acceptance and potential funding for the project.

6) Build the knowledge and skills of health professionals and researchers to increase participation of people from CALD backgrounds in research

A broad approach was recommended to implementing this strategy across workforce including researchers, clinicians, general practitioners, and interpreters.

Suggestions for where to embed education and training included:

- 1) existing research skills training;
- 2) clinical education sessions;
- 3) clinical ethics forums;
- 4) communication skills and working with interpreters training modules. It was also suggested that interpreters could be provided with training in relation to clinical trials terminology and processes.

An additional suggestion was to develop online learning modules in partnership with established organisations, such as the Federation of Ethnic Communities Council Australia (FECCA).

7) Provide navigators to support people from CALD backgrounds participating in research

There was broad support for the role of culturally responsive “research” navigators to work with people from CALD backgrounds in raising awareness of specific research studies and in providing practical and emotional support during research participation. A key role of the navigator would be to build trust with potential research participants and provide in language information. This was proposed as an extension of existing roles of “health service navigator”, patient advocate and peer support initiatives.

This could be achieved by establishing local pools of volunteers who have experience as research participants.

These strategies were endorsed by the majority of stakeholders and can be applied and evaluated in future practice and research.

⁷ <https://ctiq.com.au/>