



Cervical Screening for Cancer Prevention Community and Consumer Advisory Panel Terms of Reference Draft 7 July 2022

Background

Having regular screening is one of the best ways to prevent cervical cancer. It finds cancers early so they can be treated. Some people are less likely to have a cervical screening test because they face challenges. This puts them at greater risk of getting cervical cancer (the cervix is the opening to the uterus or womb).

Groups who more often miss cervical screening tests include people with a cervix from Aboriginal and Torres Strait Islander communities, people from some different cultural backgrounds, people who speak languages other than English, people living with a disability, people from LGBTIQ+ communities (including lesbians, people born with a variation in sex characteristics, non-binary people and trans men) and people from rural and remote parts of Australia.

From 1 July 2022, people who are having a cervical screening test have the option to collect their own screening sample if they choose to. This is called 'self collection' or a 'self test'.

Self-collection is when a person takes their own sample for cervical screening. This is done under the supervision of a health professional (such as a nurse or doctor) where the health professional gives instructions on how to take the sample and offers the person a private place to do it¹.

This change to the national program has been made so that cervical screening is more accessible, including for people who are overdue, or who have never had a test before, because they face barriers to screening.

Purpose of the Community and Consumer Advisory Panel

The Evaluation and Implementation Science Unit (EISU) at The University of Melbourne want to make sure that everyone can access cervical screening. The Unit is working with research partners on research projects that will support the people who can have screening, and the health professionals who provide cervical screening tests.

The Community and Consumer Advisory Panel (CCAP) has been set up so that the people who could benefit from the cervical screening program can help guide the research that is being done, by sharing their knowledge and experience.

So that the research is done in the right way, and is relevant for the community, the CCAP provides a way for consumers and community members to share what they think will improve the quality of the research. 'Community members' and 'consumers' include people who have had a cervical screening test before, and people who haven't.

To start with, CCAP members will provide advice on two projects that aim to increase participation in cervical screening through self-collection.

¹ Cancer Council <https://www.cancer.org.au/cervicalscreening/i-am-over-25/do-i-need-the-test/self-collection-and-the-cervical-screening-test>

Participation in the panel

We understand that not everyone feels comfortable to be part of a formal group, and that there are other ways people can use their skills, knowledge, and experience.

CCAP members can choose to be part of the Panel in any or all the following ways:

1. joining formal meetings of the CCAP (online via Zoom/Teams).
2. in smaller groups or talking one-to-one with members of the research team (via video, in person or telephone); and/or
3. giving feedback in writing (such as in emails).

CCAP members will be asked to choose how they would like to be involved when they apply to join the panel.

Definition of 'consumer' and 'community member' (what we mean by 'consumer' and 'community member')

Consumers are people who have used cervical screening services. This includes people who have had a cervical screening test before - either through self-collection, or with a health professional.

A **community member** is a member of a community. **Community** means a group of people who share a common interest (e.g., cultural, social, political, health, economic interests) but don't necessarily live in the same area.²

The CCAP will aim to include a mix of people who have used cervical screening services and people who have not used these services and people from a range of communities.

Benefits of the Panel

The CCAP will benefit consumers, the community, and the research team by:

- making sure the research is relevant to the needs of consumers and members of the community, including for people who experience challenges and barriers to accessing screening
- making sure that consumers and community members know about the research that we are doing, and that they support this research
- helping to share what we learn from the research in ways that lead to improved health for people
- providing opportunities to improve the quality of the research that we do

Role of Panel

The role of the Panel is to provide advice and guidance on the research projects.

This can be done through discussion at meetings, small group, or one-to-one conversations, and/or by reviewing and commenting on research documents. Some panel members may also choose to be more involved the research, depending on their interest and skills.

1. **Providing advice, guidance, and perspectives on the way the research is designed and how it is done, including:**
 - how to best reach priority groups to be part of projects (including suitable language and ways to communicate)
 - how to run workshops, focus groups and interviews in ways that support people from under-screened groups

² Adapted from Victorian CCC Consumer Engagement Toolkit available at <https://vccalliance.org.au/our-work/consumer-engagement/toolkit/>

- helping the researchers make sense of and understand data (information) from different perspectives and experiences
 - how to share what is learnt from the research, in ways that will help change policy and the way things are done, and will reach the priority population groups
 - what to research next, including research priorities that come out of project findings
2. **Reviewing (reading) and commenting on research documentation including:**
 - information sheets, recruitment materials, and interview/focus group guides or surveys that will be used for the research projects
 - materials (such as articles) developed for sharing of research findings
 3. **CCAP members who are interested can also talk to the researchers about being more involved in:**
 - writing reports and developing policy recommendations
 - sharing findings and results with community and consumers (e.g., writing articles for consumer newsletters or journals, presenting at community events)
 - sharing findings through co-authoring papers, co-presenting at conferences
 - being part of education/training for health professionals to share their experiences and knowledge

Responsibilities

It is important that people feel safe and supported to be part of the CCAP. All panel members will be responsible for:

- Acting in a respectful way with the researchers and with other members of the Panel
- Providing advice and feedback within timeframes that are agreed
- Maintaining confidentiality (respecting privacy and not sharing things that are discussed, read or heard outside of the group)
- Letting the researchers and others know about any conflicts of interest that might come up
- Acting in accordance with [The University of Melbourne Appropriate Workplace Behaviour Policy \(MPF1328\)](#)

Members who act in a way that is outside the agreed Terms of Reference (TOR) may be asked to leave the panel.

Either the researchers, or other panel members, can raise issues with the Chair or the University of Melbourne key contact if they feel that someone is acting in a way that is outside the TOR.

Membership

- The CCAP will include people who are eligible for cervical screening (even if they have not personally had a screening test before). This includes people with a cervix aged between 25 and 74 years.
- Membership will include representation from people in under-screened priority groups.
- Representation will be sought from different states and territories; urban, rural and remote settings, different age groups and people from different backgrounds
- Members will be asked to join for one year. After one year, membership will be reviewed
- Members of the CCAP can participate in one or more ways

Skills and experience of CCAP members

- People who are eligible for cervical screening. That is, people who have a cervix, who are aged between 25-74 years, regardless of whether they have personally had a cervical screening test before
- Ability to engage respectfully with people from different social and cultural backgrounds

- Good communication skills and willingness to contribute to discussions
- Willingness to join training that is available through partner organisations, or previous experience as a member of a community/consumer advisory group
- Access and ability to use Zoom/ Teams to participate in Advisory Group meetings (or be willing to have training prior to the first meeting) – this may be provided/supported by a consumer-organisation

Meeting frequency and format (how often meetings will be held and in what ways)

- Group meetings will be held online, 3-4 times per year using Zoom or Teams
- Group meetings will run for 2 hours and be held at a time that suits most participants
- The Group will decide on how the meetings will be chaired (following the first meeting)
- The University of Melbourne will prepare meeting papers, take notes, support the Chair and members
- CCAP members who would rather talk with a member of the research team outside of formal meetings can do this using Zoom/ Teams or telephone. This would be for around 45 minutes, up to 4 times over the year, and can be arranged with the key contact.
- Smaller group meetings can also be organised for people who prefer to meet in that way. This will be worked out with CCAP members and the research team.

Support and remuneration (payment)

- Remuneration (payment) can be made either through a casual contract with The University of Melbourne, or through gift cards (vouchers) (see rates below)
- CCAP members will be offered training through partner organisation’s existing consumer representative training (if they haven’t had training before)
- A researcher is available to offer support with accessing IT, project information etc
 - The contact is Dr Tessa Saunders e: Tessa.Saunders@unimelb.edu.au

Rates of payment

Participation in Formal Group meetings	Participation in Individual Consultations	Participation in Document review
\$100 per meeting	\$50 per hour	\$40 per hour
This includes reading/preparation time and follow-up	This includes reading/preparation time and follow-up	For reviewing documents that are not part of meetings

Term of review

These TOR will be reviewed within 12 months after they have been approved to make sure they are appropriate. Confirmation of the TOR will be sought after the first meeting of the group.

Contact

Dr Tessa Saunders
 Evaluation and Implementation Science Unity
 Melbourne School of Population & Global Health,
 The University of Melbourne,
 Level 4, 207 Bouverie Street, Carlton, Victoria 3053 Australia
 E: Tessa.Saunders@unimelb.edu.au
 W: <http://mbspgh.unimelb.edu.au/research-groups/centre-for-health-policy/evaluation-and-implementation-science>