

Lotjpa Yapaneyepuk (Talk together) about cancer trials



Jasmine Howell-Saunders
 Healing hands, 2024
 Community/Language Group: Yorta Yorta and Dja Dja Wurrung.
 artbyjasminelyn on Instagram.

Artwork story

Representing the hardships and steps we need to take in coming together to better support for our mob dealing with cancer. This piece is a call to action - ensuring our voices are heard in the conversations leading to better pathways. The handprints represent “the future is in our hands” and the long journeys that come with dealing with cancer. Gathering circles represent places of healing and resilience, where our mob come together to share knowledge and experiences in a safe space. Coming together to shape a better future.

Participant Information and Consent Form

Short Name of Project	Lotjpa Yapaneyepuk (Talk together) about cancer trials.
Full Name of Project	Lotjpa Yapaneyepuk (Talk together) about cancer trials: Improving Aboriginal and Torres Strait Islander people’s access to cancer clinical trials in regional Victoria.
Principal Investigator	Monica Green
Associate Investigators	Leah Lindrea-Morrison, Javier Torres, Shannon Drake, Joan Cunningham, Craig Underhill, Damon Parker.
Project Sponsor	This study is part of the ReViTALISE project (Regional Victoria Trials Alliance: Linkages, Innovation, Special populations, Equity), which is funded by the Australian Government through the Medical Research Future Fund.

What am I being invited to do?

The research team invites you to take part in a project that aims to improve access to cancer clinical trials for Aboriginal and Torres Strait Islander people with cancer living in regional Victoria, which we hope will improve cancer survivorship. You have been invited to take part because we want health professionals working in the cancer clinical trial area to understand why it is important that Aboriginal and Torres Strait Islander people have access to clinical trials, and how to connect Aboriginal and Torres Strait Islander people to clinical trials.

Please read this information and ask us any questions.

What is the purpose of this project?

The project is about improving access to cancer clinical trials for Aboriginal and Torres Strait Islander people with cancer in regional areas, which we hope will improve cancer survivorship. Cancer is now the leading cause of death of Aboriginal and Torres Strait Islander people in Australia and little is known about participation of Aboriginal and Torres Strait Islander people in clinical trials, despite sound evidence of trials leading to improved cancer outcomes. This work seeks to increase knowledge and understanding of strategies that connect Aboriginal people living in regional areas to clinical trials, by working with health staff, and co-designing resource materials with community members. As community members learn more about clinical trials, it is imperative that health staff have the knowledge and skills to support patients to make informed decisions about participation in clinical trials. More information on the study is in the 'Project overview', attached as a resource during webinars or provided as background information at in-person training.

Do I have to take part and can I change my mind?

Taking part is up to you. You can say yes or no.

It is important that you read and understand what this study is about. The researcher/s can answer any questions you may have.

You can change your mind at any time

If you do take part, you can stop at any time. If you want to stop, please tell someone in the research team (contact details below). You do not have to tell us the reason.

The project might stop for other reasons

We might need to stop the project while you are taking part. If this happens, we will explain the reasons to you. We may also ask you to stop taking part in the project if it is no longer in your best interests. If this happens, we will discuss this with you.

What do I have to do if I take part?

The project runs from October 2024 until 30 April 2026. You may be invited to take part in a webinar or an in-person training session on the topic of improving cancer clinical trial access for Aboriginal and Torres Strait Islander people.

If you are a webinar participant, we ask that you complete the anonymous surveys via the link provided to participants.

If you participate in training sessions, we ask that you complete a demographics survey and contribute to a short Yarning session at the end of the training.

We want to understand how to improve the webinars and training sessions and ask for your feedback to help us do this. For more information, please ask a member of the study team.

What are the benefits of taking part?

The benefits are longer term and may not directly benefit you. By taking part in this project, the work will lead to improved training and information sessions about improving access to cancer clinical trials for Aboriginal and Torres Strait Islander people. In the longer term, we hope that Lotjpa Yapaneyepuk (Talk together) will improve cancer survivorship for Aboriginal and Torres Strait Islander people.

What are the risks and discomforts of taking part?

Risks are expected to be minimal, but may include inconvenience, discomfort, and chance of distress if discussing sensitive experiences. Research staff at in-person training sessions have a Distress Protocol to support you if this occurs. For webinar participants, as survey responses are anonymous, we will not be in a position to directly support you. Support is also available through

- 13YARN (Call 139276) 24hours x 7 days per week
- Lifeline (131114) 24hours x 7 days per week

How will my information be used for this project?

We are not collecting identifying information for this part of Lotjpa Yapaneyepuk, however we would like to collect demographic information to help us understand the information that participants give us. We want to understand how to improve the training and information sessions for future training.

Where will we collect information from	What kind of information we will collect
You	Aboriginal and Torres Strait Islander status; age; gender; whether diagnosed with cancer, family / friend of diagnosed person, carer. Professional role and workplace, years of experience. Pre and post training knowledge and confidence of the topic. Anticipated practice change following the training. Your opinions about clinical trial resource/s developed for community as part of this project.

Keeping your information safe

To keep your information safe, we will:

- follow all relevant privacy requirements
- All digital data for the project will be stored in a password-protected OneDrive folder, housed on the Border Medical Oncology Research Unit’s (BMORU) secure server
- All paper-based data will be stored in a locked cabinet in a locked room at Goulburn Valley Health until transfer to electronic form by scanning or photographing.

You can ask us to tell you what information we have collected about you as part of this project. If your information is not correct, you can also ask us to change it. If you have any complaints about how we are managing your personal information, you can contact the study team.

We will keep your information for 5 years. After this, the study information will be permanently removed. Only the published summaries and the resources will remain.

Sharing your information with others

Your implied consent is relevant for this study only. We will not share or use your information beyond the end of this study.

Publishing project information

We will share summary information from health professional’s responses to survey questions (in webinars) and evaluation of in-person training, so that others can understand the study findings and improve future training or information sessions. This might include articles in academic journals and presentations at conferences. It is highly unlikely that individuals will be identifiable in such summary information; as we are not collecting any

identifiable information in this component of the study, any quotes used will be attributed to a study code.

Who is running and paying for this project?

This project is being run by Border Medical Oncology Research Unit in Albury. Our main partners are Rumbalara Aboriginal Cooperative Ltd in Mooroopna and Goulburn Valley Health. The project is funded by the Australian Government through the Medical Research Future Fund.

Who has reviewed and approved this project?

The Aboriginal Health and Medical Research Council of New South Wales has approved this project (reference number 2324/24). This is an independent committee that makes sure that this project meets Australian ethical standards for research that involves Aboriginal and Torres Strait Islander people.

Comments or complaints about how this project is being run

If you have any comments or complaints about this project, please contact:

The Chairperson, AH&MRC Ethics Committee

Harvey Street Little Bay

NSW 2036 Australia

Email: ethics@ahmrc.org.au

Telephone: (02) 9212 4777

Where can I find more information?

Thank you for taking the time to read this information about our project. You can contact a member of the project team at any time to ask questions.

Monica Green Chief Investigator 0421 236 366

Leah Lindrea-Morrison Associate Investigator 0484 305 702.