



Aboriginal and Torres Strait Islander People with Cancer – Clinical Trial Access Initiative



(summary of Consultancy Report)

What is this project about?

The *Aboriginal and Torres Strait Islander people with Cancer – Clinical Trial Access Initiative* is about making it easier for Aboriginal and Torres Strait Islander people living in **regional areas** to take part in **cancer clinical trials**, if that’s what the person wants.

This initiative is part of a larger program of work - the **ReViTALISE** project - which is aimed at improving access to cancer clinical trials, for people living in regional areas. ReViTALISE stands for:

**Regional Victorian Trials Alliance Linkages, Innovation,
Special populations, Equity Project.**

People with cancer who take part in clinical trials often do better than those who don’t. Research has shown that there are **barriers** to taking part in clinical trials for Aboriginal and Torres Strait Islander people with cancer, especially those who live in regional areas. Some of the most important barriers are shown on the right.

Border Medical Oncology Research Unit (Albury Wodonga), and Goulburn Valley Health will co-lead the work. It will be important **for Aboriginal and Torres Strait Islander people and community organisations** to be involved from the beginning and to help guide the work. This is likely to include local Aboriginal Community Controlled Health Organisations, the Victorian Aboriginal Community Controlled Health Organisation (VACCHO) and other community organisations.

Who is the project for?

Aboriginal and Torres Strait Islander people with cancer who live in regional areas, plus their families, their carers and friends.

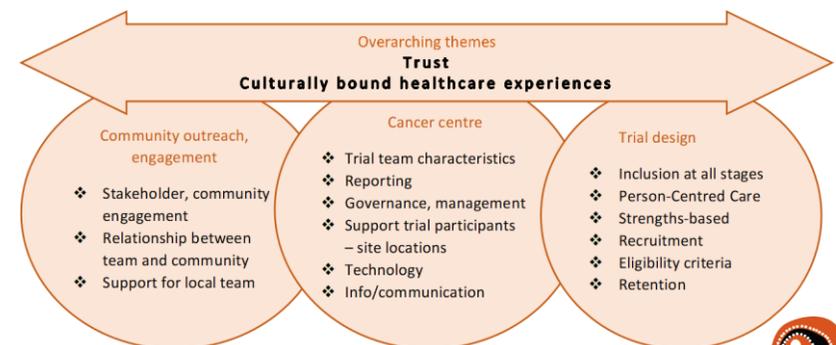


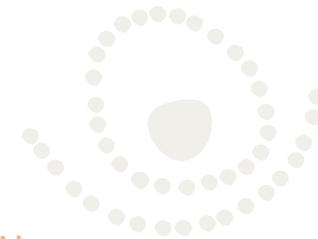
What are the barriers to being enrolled in cancer clinical trials for Aboriginal and Torres Strait Islander people?

- * Mistrust or fear of research
- * No consideration of cultural aspects of life in the trial designs
- * Taking part in a trial is not even discussed with a patient
- * Implicit or explicit bias
- * Strict inclusion criteria in trials
- * Length of trials and where they happen – many are in cities
- * Not enough trials for the cancers that are common in Aboriginal people
- * Language and communication problems – too much complex language
- * Patients not knowing about trials
- * Few Aboriginal and Torres Strait Islander people in research teams
- * Trial information is often in medical language that is difficult to understand
- * Demands or costs of taking part in trials – not enough support for patients

What can be done to change things?

A Consultancy Report by Menzies School of Health Research outlined many strategies that are likely to help Aboriginal and Torres Strait Islander people in regional areas enrol in cancer clinical trials, if they want to. **Trust** in health services / research, and recognising that healthcare experiences for many Aboriginal and Torres Strait Islander people are **culturally bound**, are very important factors that need to be recognised in this work. The figure below shows areas that need to be considered.





What will happen next?

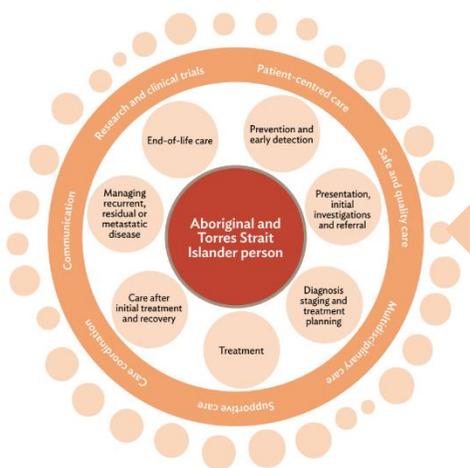
The Steering Committee will consider all the information in the Consultancy Report and make decisions about how to ensure the work is guided by Aboriginal and Torres Strait Islander people, that it benefits Aboriginal people, and that it meets the aims of the initiative. Part of this will be making sure the right people and organisations are included in a meaningful way. Respectful relationships will need to be built and maintained. Baseline information about what currently happens in regional Victoria about the participation of Aboriginal and Torres Strait Islander people in clinical trials will inform the process. All of this will need to be written into a detailed Implementation Plan.

Some options that the Steering Committee could consider

- * Education campaign for clinicians, patients, community;
- * Develop ways to connect Aboriginal and Torres Strait Islander people to clinical trials, such as those shown below;
- * Improve design of clinical trials, such as making sure the team includes Aboriginal and Torres Strait Islander people **at all levels**, that the trial paperwork is understandable, and that data sovereignty is respected

Critical issues

- * Involvement of Aboriginal and Torres Strait Islander people at all stages
- * Reporting of Indigenous status in health services
- * Overcoming gatekeeping and improving trial designs



Possibilities to connect Aboriginal people to clinical trials

- * Patient navigation;
- * Community Based Participatory Research, which makes community and researchers equal partners;
- * Teletrials;
- * Link with other ReViTALISE streams – Regional Research Teaching Hub, Registry Trials, Teletrials
- * Use the Optimal Care Pathway for Aboriginal and Torres Strait Islander people with cancer
- * Promote more flexible trial design
- * Advocacy to make sure that Aboriginal and Torres Strait Islander people have equal access to pharmaceutical trials

The principles and concepts in the *Optimal Care Pathway for Aboriginal and Torres Strait Islander people with cancer*

For further information contact the Border Medical Oncology Research Unit dlong@bordermedonc.com.au

This is a brief summary of the Menzies School of Health Research Consultancy Report. Click the link below for the full report:

[https://www.menzies.edu.au/page/Resources/Aboriginal and Torres Strait Islander People with Cancer Clinical Trial Access Initiative Consultancy Report for ReViTALISE Project/](https://www.menzies.edu.au/page/Resources/Aboriginal_and_Torres_Strait_Islander_People_with_Cancer_Clinical_Trial_Access_Initiative_Consultancy_Report_for_ReViTALISE_Project/)

