



HARRY PERKINS INSTITUTE  
OF MEDICAL RESEARCH

# ABORIGINAL CANCER COMMUNITY YARN

## COMMUNITY CONVERSATION REPORT



Prepared By

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19th of February 2025



Consumer and Community  
Involvement Program

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# ACKNOWLEDGEMENTS

## **Acknowledgement of Country**

We acknowledge the Aboriginal people of the many traditional lands and language groups of Western Australia. We acknowledge the wisdom of Aboriginal Elders both past and present and pay respect to Aboriginal communities of today.

## **Acknowledgement of Attendees**

Aboriginal and Torres Strait Islander communities are formally acknowledged and thanked for participating in this community yarn.

## **Acknowledgement of Lived Experience**

We acknowledge the importance and expertise of the lived experience voice of health consumers and carers. We recognise their involvement in making a difference in supporting health research and impacting the health and wellbeing of our communities.

# BACKGROUND

The Perkins team conducting research in Aboriginal people with cancer organised a Community Yarn to bring together members of the community with lived experience of cancer to discuss and capture feedback around their cancer journeys. The information obtained during the event will be used to inform future cancer research and ensure that work is guided and led by Aboriginal people in a way that is appropriate.



# ABOUT THE COMMUNITY YARN

The Community Yarn was held on the 19th of February, 2025, and was attended by 24 Aboriginal people with a lived experience of cancer

Leanne Pilkington facilitated the yarn together with co-facilitators Maria Maynard and Lionel Gregory.

Andrew Redfern, the cancer research team leader and Medical Oncologist, presented the team's research findings. Other cancer research team members attended to help answer questions and take notes to document the yarn.

Kerry Mace, Ingrid Laing and Caroline Jones from CCIPProgram also attended and helped with the yarn.

Doctors need to use simple terms with no medical jargon when talking to us about cancer.

We need an Aboriginal Cancer Advisory group that includes the regions.



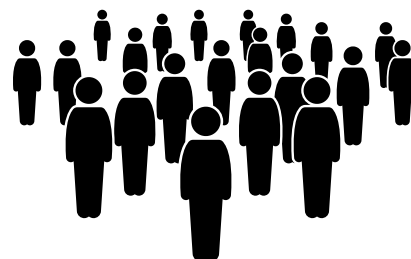
# KEY TAKEAWAYS OF THE COMMUNITY YARN

There are many ways that culturally sensitive healthcare can be delivered throughout WA:

- Ways to improve healthcare for Aboriginal people need to come from Aboriginal people;
- Provide simple, clear and appropriate information at diagnosis that includes support services and networks;
- Expand the number of Aboriginal health workers.

Aboriginal people with cancer want to be around other Aboriginal people to help:

- get through tough treatments with people who understand our culture;
- find services and support that are not immediately available to us (but should be);
- advocate for each other.

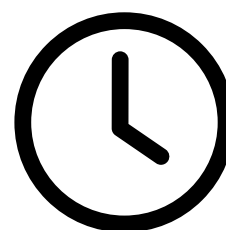


We need to create a central place for Aboriginal people with cancer to go and get information:

- There is a strong feeling of isolation and pain throughout cancer;
- An all-inclusive resource is needed for the different phases of the cancer journey;
- A culturally safe, easy-to-access telephone or interactive online system for Aboriginal people with cancer is needed.

## TIME FOR CHANGE

- Aboriginal people are over-researched and sick of talking;
- Not enough has changed and gaps in survival remain.



# COMMUNITY YARN QUESTIONS AND RESPONSES

## THEME 1: GUIDING RESEARCH

### QUESTIONS

HOW DO YOU THINK RESEARCH INTO ABORIGINAL CANCERS SHOULD BE CARRIED OUT?  
WHAT SAY/INPUT SHOULD ABORIGINAL PEOPLE HAVE INTO IT?

### PROMPTS:

- Should there be an Advisory Group/Reference Group for all cancer research? Should it be Statewide?
- Who should be included – people with lived experience? Elders, Aboriginal Health professionals, carer's community members? How should they be selected?
- Should the panel meet in person or is online ok to facilitate remote and regional membership?

### ATTENDEE INSIGHTS

Summary of the responses and thoughts shared by attendees at the Community Yarn:

- There must be an Aboriginal Advisory Group that guides Aboriginal cancer research. This should involve the regions and ensure that Aboriginal protocols are considered.
- Include Aboriginal people with cancer or who have cared for someone with cancer. The group could include social workers and health officers, or there may be a need for a second, separate group to include perspectives from professional carers.
- Elders would add value to this group and could feed into the group.
- The group should ensure that mob benefits from all research and should approve of all research before it starts.
- The group should be truthful and transparent from the beginning; do not leave anyone in the dark.
- Ensure that all Aboriginal people are listened to. 'We have a lot to say and share'.
- Logistics will matter, especially considering up North. Everyone will need to be on the same page. 'We will need to work together to make progress'.
- Needs and desires will be different in different geographical areas. This will need to be managed carefully to ensure that everyone is included and heard.
- Researchers need to talk to Aboriginal people with cancer at the grassroots, get out and around the state. The needs of people in Bunbury will be different to those in Perth, which will be very different to those up North.
- Possible composition of the group: 2 representatives from East Kimberley and West Kimberley each and 1 representative from Karatha, Port Headland, Kununura, Kalgoorlie, Canarvan, Esperance, Albany, Bunbury.

- The group should meet twice a year, ideally in person.
- The role of the group would be to guide and promote the research (consider talks under a tree in a park, a BBQ in the community, or visit Aboriginal hostels and run information sessions). With the support of the researchers, the group will need to get out into the community to provide connection.
- The role of the researchers is to talk to Advisory group members about the research, openly share results in a way that is understandable and meaningful, and take on advice and suggestions in an authentic way.
- Run community 'cancer' days throughout WA: educate and promote, offer free checks/screens, talk about the research and understand what the community wants.
- The Advisory Group will represent WA (statewide) and will consider all cancers.
- This group will provide guidance and protection at a community level. WAAHEC does this at a professional level.
- Members of the advisory group should be invited, not nominated. This will ensure that people who are passionate are involved.
- This group will need a lot of support, there is a risk of burnout.
- The group should ensure that mob benefits from all research and should approve of all research before it starts.





# COMMUNITY YARN QUESTIONS AND RESPONSES

## THEME 2: DATA SOVEREIGNTY

### QUESTIONS

WHAT IS THE BEST WAY FOR RESEARCHERS TO SHARE INFORMATION ABOUT RESULTS AND ASSOCIATED DATA WITH THE ABORIGINAL COMMUNITY?

WHO SHOULD TAKE OWNERSHIP OF THE DATA? HOW SHOULD IT BE USED? WHERE SHOULD IT BE KEPT?

### PROMPTS:

- Collective resources suggest that Indigenous Data Sovereignty is the right of Aboriginal peoples, communities, and organisations to maintain, control, protect, develop, and use data as it relates to us.
- What does Data Sovereignty mean to you?

### ATTENDEE INSIGHTS

Summary of the responses and thoughts shared by attendees at the Community Yarn:

- Is 'data sovereignty' the best term? 'This is a very broad and white term. Can we assign an Aboriginal name to this that will mean something to us?'
- Clear communication and consistent language are crucial.
- If research and data are to benefit the community, we need to enable the process. How do we move barriers? And ensure that the research benefits the community?
- No more repetitive conversations; we need action.
- The importance of boodja and regional differences will need to be considered.
- 'Aboriginal people should own Aboriginal data. We should have the right to choose if we share our data.'
- 'Our data must be used for the right reasons. Researchers need to be clear about what our tissues and data will be used for and must be held accountable to ensure our data benefits us.'
- If Aboriginal status is a tick box on a form, make sure it is clear why this information is being asked.
- Can we look at how data sovereignty is managed in other states or by peak bodies?
- Rules and governance are important for the protection of our data.

# COMMUNITY YARN QUESTIONS AND RESPONSES

## THEME 3: GAPS IN CANCER CARE AND RESEARCH

### QUESTIONS

WHAT WAS YOUR CANCER EXPERIENCE LIKE? AS A PERSON WITH LIVED EXPERIENCE/CARER/FAMILY MEMBER?

WHAT COULD HAVE MADE IT EASIER? WHAT EXTRA SUPPORT DID YOU NEED/WANT? DID YOU FEEL CULTURALLY SUPPORTED?

WHERE DID YOU GET YOUR INFORMATION?

### PROMPTS:

- Diagnosis
- Communication
- Treatment Plan
- Care during treatment.
- After treatment care
- How was your family treated, were they included?
- Costs

### ATTENDEE INSIGHTS

Summary of the responses and thoughts shared by attendees at the Community Yarn:

- Simple terms and language are needed; too much medical jargon is confusing and unclear. This leads to a breakdown in communication with doctors.
- Pictures and drawings should be used more in education and health promotion.
- Consider other languages and interpreters in areas like the Kimberley and Pilbara.
- Extend family support to attend around a new diagnosis.
- At first diagnosis, doctors should get feedback early on from patients and family together. This will build the relationship and trust; will improve the patient journey.
- 'There is a need for more support groups to help us be with other people with cancer.'
- Expand the Aboriginal workforce and provide more opportunities for Aboriginal people in cancer and research. Can the McGrath Foundation hire more Aboriginal cancer nurses?
- Establish an Aboriginal Palliative Care Service; Aboriginal stream within Carer's WA.
- Dedicated cancer education information and sessions for Aboriginal people; better promotion of services and health care available.
- General health checks don't focus on cancer, we need a dedicated person for this.
- Health information is not passed on to Aboriginal patients.
- Tertiary health systems have poor communication with rural providers.
- Cultural insensitivities are prolific, even from professional medical and nursing staff.

There needs to be support with finances that is unjudged and automatic.

# WHAT'S NEXT?

We will use the information from the Community Yarn to establish an Aboriginal Cancer Advisory Panel, continue to strengthen the data sovereignty mechanisms that are in place, and advocate for better information, support and resources for Aboriginal people with cancer.

We have a large body of breast cancer research that we have been working on for a long time. A phase of this work is now complete. We plan to disseminate this information widely across the state so that Aboriginal people can decide what should be done with this information and what we should do next. We anticipate that similar research in head and neck and lung cancer will be ready to share soon as well.

We will pass on feedback to BreastScreen WA that the group felt it should capture more information and facilitate access to health services, especially for people living in remote areas who may need to fly and travel long distances.



# FUTURE RESEARCH QUESTIONS FROM ATTENDEES AT THE COMMUNITY YARN?

- If we create a visual map of cancers by region, are there clusters of certain types of cancers in areas? Are these associated with any environmental exposures? e.g. waterways.
- Can we do focused genetic screening that is open to all Aboriginal people with cancers that may run in their families? 'A lot of us don't know our history because screening and detailed diagnoses or causes of death are not available for our parents.'
- Certain families are riddled with cancer. Why is this? Is it the environment or is there something in our make-up? 'This can be a really hard thing to talk about with family members. There is a lot of shame and fear.'

## DO YOU HAVE A QUESTION OR A COMMENT FOR THE RESEARCH TEAM?

## DO YOU WANT TO BE INVOLVED IN ABORIGINAL CANCER RESEARCH OR KNOW WHAT IS GOING ON?



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### WEBSITE

[Aboriginal Cancer Research at Perkins](https://perkins.org.au/research/labs/cancer-program/translational-oncology-aboriginal-cancer-overview/)

<https://perkins.org.au/research/labs/cancer-program/translational-oncology-aboriginal-cancer-overview/>

**We are keen hear from Aboriginal students interested in working with us in Aboriginal Cancer research.**