



# Towards systematic monitoring of the experiences of care of Aboriginal and Torres Strait Islander people with cancer

## Study team

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**TACTICS**  
Targeted Approaches to Improve Cancer Services  
for Aboriginal and Torres Strait Islander Australians



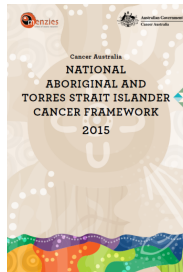
## Why?

- Poor cancer outcomes for Indigenous people
- Qualitative evidence of problems
- Recognised need for different methods to collect data
- Fragmented nature of cancer care
- Is person-centred care being delivered?
- Does a survey approach elicit crucial aspects of care?
- Implications of failure to detect and act on gaps/failures



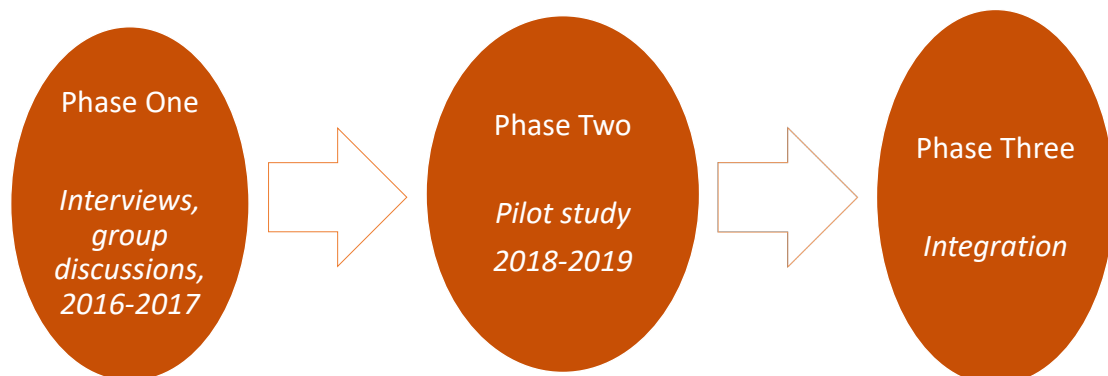
## Our approach

- Indigenous view of health
- Person-centred care principles
- Cancer Framework



## Overall picture

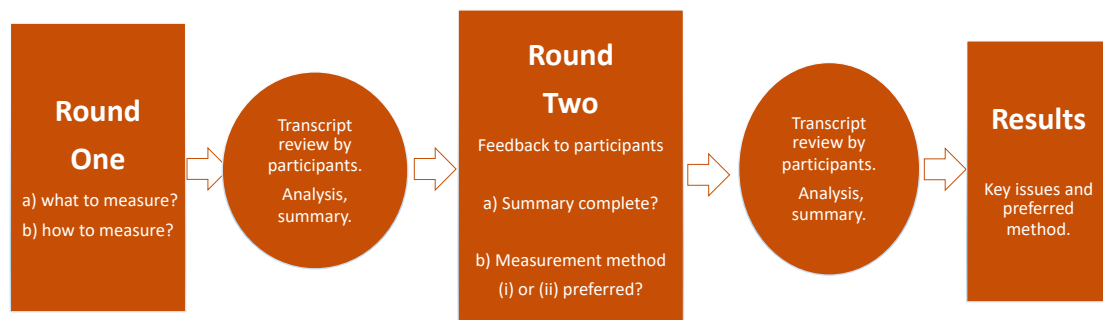
Aim: Work towards systematic, routinely collected, accurate, population-based data on the experiences of care of Indigenous people with cancer.



# Phase One outline

What to measure. How to measure it.

What is different.



## Participant demographic characteristics

	CaAff(a)	HP(b)	Both(c)	Total
	n=17	n=28	n=7	n=52
<b>Age (years)</b>				
20-39	2	3	1	6 (11%)
40-59	10	16	5	31 (60%)
≥60	5	9	1	15 (29%)
<b>Gender</b>				
Female	11	25	6	42 (81%)
Male	6	3	1	10 (19%)
<b>Recruitment source</b>				
Urban sites	2	15	1	18 (35%)
Regional site	7	10	3	20 (38%)
NICaN(d)	8	3	3	14 (27%)

(a) CaAff: An Indigenous person affected by cancer, either diagnosed or as a carer.

(b) HP: A health professional whose work relates to care of Indigenous people with cancer.

(c) Both: An Indigenous person affected by cancer who is also a health professional whose work relates to care of Indigenous people with cancer.

(d) NICaN: the National Indigenous Cancer Network.



## Context (participants)

- Racism and discrimination
- Underlying patterns of illness
- Health system characteristics
- Varied life experiences
- Silence about cancer
- Aboriginal people are not all the same
- Life experiences and background



## Results – what to measure

- Feeling safe in the system
- The importance of Indigenous care providers
- Barriers to care, especially when receiving treatment away from Country
- The role of family and friends
- Effective communication and education
- Coordination of care, including the transition from hospital to home care
- Palliative care issues
- Carers' wellbeing



## Feeling safe in the system

*If you don't feel that you're safe in medical care and your treatment, then it's not going to be somewhere that you want to keep coming back to.*

(HP 205)

*When I walk ... into a hospital today, I'm very wary of who ...can I trust. Who can I talk to?*

(CaAff 512)



## The importance of Indigenous care providers

*(Aboriginal care provider)  
really understood where I was coming from being off Country. It was important to talk with an Aboriginal person – far more important than ...the social worker for me.*

(CaAff 303).

## Family and friends

*..they may be the decision-maker in the family ... while they're away having treatment, the family breaks down.*

(Both 504)

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## Communication


*... if we stop thinking we're just treating cancer. We're treating our patient, and what could we do that helps this patient through? ...that just comes with relationships and communication.*  
(HP 101)

## Barriers to care

*when I got to [hospital name], I hadn't been welcomed to Country. So I actually felt quite uncomfortable being a [e.g. Yaruwu] person on [e.g. Gadigal] land."*  
(CaAff 303).


## Carers


*.....the carer is the one that carries the load .. they're the ones that are looking after the sick person as well as trying to manage family.*  
(Both 103)

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## Results - how to measure

- With sensitivity!
- Face to face preferred
- Opportunity for yarning very important
- Ability to express your own story to trusted person
- Traditional survey could be acceptable with caveats – support available
- Little support for emailed or online surveys
- Touchscreen acceptance variable

➤ More yarning 

Less ticking 



## Key messages

*Many of the problems identified in this study are amenable to being measured and addressed if appropriate questions about patient experiences are asked and acted upon.*

*Although additional resources may be required, investment is necessary to elicit the care experiences that would facilitate meaningful change.*



## Phase Two 2018

Aims:	Examine acceptability of the survey; aspects of methodology and implementation
Participants:	Indigenous adults diagnosed with cancer
	Senior Health services staff
	Interviewer
Approach:	Interviewer guided
Funding:	NHMRC-funded Centre of Research Excellence in Targeted Approaches To Improve Cancer Services for Aboriginal and Torres Strait Islander Australians (TACTICS; #1153027) NHMRC-funded Centre of Research Excellence DISCOVER-TT (#1041111) Cancer Council NSW STREP Ca-CIndA (SRP 13-01; with supplementary funding from Cancer Council WA).





## Phase Two - Structured interview

**Indigenous People's Experiences of Cancer Care Survey**

**Instructions for interviewers**

In this document we report why we developed and tested this survey to understand the experiences of Indigenous people, acceptor-researcher to questions of diagnosis and treatment and to understand the experiences of Indigenous people with cancer during their cancer care, with a focus on where changes can be made to better meet the needs of Indigenous people with cancer in the future.

We would like the general public to use this survey in the community. The purpose of this survey is to understand the experiences of Indigenous people with cancer in the future.

The survey contains 10 questions and will take about 10 minutes to complete. Instructions on how to complete the form are below.

**Instructions**

- 1. Read all text and if you are happy to do the interview in English, if an interpreter is needed please arrange the form with the interpreter.
- 2. If you are not happy to do the interview in English, please let us know so we can arrange an interpreter for you. The survey is available in other languages and we can provide an interpreter if needed.
- 3. Please enter the person's study identification code (Study ID) on each page of the survey.
- 4. Please read the survey questions and answer them as best as you can. If you are unsure of the answer, please skip the question and move on to the next question. You can return to the question later if you wish.
- 5. Question 10 asks how the person is feeling on the interview day, using a number between 1 and 10. 1 is 'feeling fine' and 10 is 'feeling very bad'. Please read the question and answer it as best as you can. If you are unsure of the answer, please skip the question and move on to the next question. You can return to the question later if you wish.
- 6. Question 11 asks how the person is feeling on the interview day, using a number between 1 and 10. 1 is 'feeling fine' and 10 is 'feeling very bad'. Please read the question and answer it as best as you can. If you are unsure of the answer, please skip the question and move on to the next question. You can return to the question later if you wish.
- 7. Question 12 asks how the person is feeling on the interview day, using a number between 1 and 10. 1 is 'feeling fine' and 10 is 'feeling very bad'. Please read the question and answer it as best as you can. If you are unsure of the answer, please skip the question and move on to the next question. You can return to the question later if you wish.
- 8. Question 13 asks how the person is feeling on the interview day, using a number between 1 and 10. 1 is 'feeling fine' and 10 is 'feeling very bad'. Please read the question and answer it as best as you can. If you are unsure of the answer, please skip the question and move on to the next question. You can return to the question later if you wish.
- 9. Question 14 asks how the person is feeling on the interview day, using a number between 1 and 10. 1 is 'feeling fine' and 10 is 'feeling very bad'. Please read the question and answer it as best as you can. If you are unsure of the answer, please skip the question and move on to the next question. You can return to the question later if you wish.
- 10. Question 15 asks how the person is feeling on the interview day, using a number between 1 and 10. 1 is 'feeling fine' and 10 is 'feeling very bad'. Please read the question and answer it as best as you can. If you are unsure of the answer, please skip the question and move on to the next question. You can return to the question later if you wish.
- 11. Question 16 asks how the person is feeling on the interview day, using a number between 1 and 10. 1 is 'feeling fine' and 10 is 'feeling very bad'. Please read the question and answer it as best as you can. If you are unsure of the answer, please skip the question and move on to the next question. You can return to the question later if you wish.
- 12. Question 17 asks how the person is feeling on the interview day, using a number between 1 and 10. 1 is 'feeling fine' and 10 is 'feeling very bad'. Please read the question and answer it as best as you can. If you are unsure of the answer, please skip the question and move on to the next question. You can return to the question later if you wish.
- 13. Question 18 asks how the person is feeling on the interview day, using a number between 1 and 10. 1 is 'feeling fine' and 10 is 'feeling very bad'. Please read the question and answer it as best as you can. If you are unsure of the answer, please skip the question and move on to the next question. You can return to the question later if you wish.
- 14. Question 19 asks how the person is feeling on the interview day, using a number between 1 and 10. 1 is 'feeling fine' and 10 is 'feeling very bad'. Please read the question and answer it as best as you can. If you are unsure of the answer, please skip the question and move on to the next question. You can return to the question later if you wish.
- 15. Question 20 asks how the person is feeling on the interview day, using a number between 1 and 10. 1 is 'feeling fine' and 10 is 'feeling very bad'. Please read the question and answer it as best as you can. If you are unsure of the answer, please skip the question and move on to the next question. You can return to the question later if you wish.

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For each aspect of cancer care:

a) Tell us about it (*problem or no problem*)

b) Where did problem occur

c) How could problem have been improved

**About your experiences of cancer care**

Thinking about your most recent diagnosis, we would like to know about your experiences of cancer care, and if you have any problems to discuss, how you would like to discuss them.

41. Your diagnosis of cancer:  No problem ☐ Problem ☐

a) Tell us about it:

b) Which service or services?

c) What would have made it better?

42. Accessing or leaving the cancer care:  No problem ☐ Problem ☐

a) Tell us about it:

b) Which service or services?

c) What would have made it better?

43. Culture, needs and cultural safety:  No problem ☐ Problem ☐

a) Tell us about it:

b) Which service or services?

c) What would have made it better?

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## Considerations

- Acceptance of process – involve community
- Time!
  - Planning and testing
  - At time of measurement- what really drives patient experience
- Separation from service
- Timing of measurement
- Location of measurement
- Support from carer/s
- Confidentiality
- Addressing issues that emerge during measurement



# Challenges

Many methods, possibly no single 'best' strategy.

## Measurement

- Indigenous approach
- honours patient voice
  - evidence based
  - well designed
- simple to implement
- easy for patient to take part
  - existing methods

## Feedback / process

- Org infrastructure
  - private/public
  - staff involvement
- action taken – evidence of change
- evidence of feedback to patients
- translation into improved outcomes
- Larger scale – PREMs & PROMS



## Partners



## Study team





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