



Welcome to the Australian Indigenous
Cancer Survivors Forum 2011

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Cancer Institute NSW



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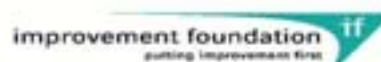
Forum Agenda, 19 May 2011

9:00	9:05	Welcome to the Country
9:05	9:15	Forum overview (Ms Malathi Kanagasabapathy)
9:15	9:25	2011 Forum - Where we are going? (Ms Catherine Jacka)
9:30	9:50	The Fog (Donna Meehan)
9:50	10:45	Sharing our Stories (Facilitated by Cancer Council NSW)
10:45	11:00	Morning Tea
11:00	12:45	Feedback and How we can help? (Facilitated by Cancer Council NSW)
12:00	1:00	Lunch (Provided by Cancer Council NSW)
1:00	1:45	Table Top Discussion <ul style="list-style-type: none">• Genetics (Ms Kim Orchard as facilitator)• Self Care (Ms Donna Meehan as facilitator)• Returning to work (Mr David Copley as facilitator)• Support Groups (Ms Veronica Saunders as facilitator)
1:45	1:55	Raffle Draw - Giveaway
1:55	2:20	Update on APOCC - CCNSW (Ms Veronica Saunders)
2:20	2:45	Closing the Divide in Cancers – QIMR (Ms Catherine Jacka)
2:45	2:55	Afternoon Tea
2:55	3:10	Summary and Evaluation
3:10	4:00	Networking and Close

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Where are we? Where to from here?

Catherine Jacka

Where are we now?

- We know we are diagnosed with cancers at a similar rate to other Australians
- We know we pass away more frequently (up to 45% more)
- We get more fatal cancers (lung, liver)
- It is fairly clear to me that because of our background, our cultural beliefs, our kinships that we have different support needs than other Australians
- I don't know if treatment is offered to us differently or our bodies react differently to treatment, but these are things we still need to look into.

Our aims

- To show you there are others who have shared an experience of cancer & survived
- To provide a safe place for you to share your story
- To discuss what may be important for you now (post treatment)
- To share what others are doing to inform the medical community
- Let others know that Cancer is a issue for us...but we do survive

Our aims

- Assist in bridging the gap between Cancer Councils and Indigenous people and communities...
- Provide an avenue to address issues you may think are important

Our commitment

- to hold Indigenous Cancer Survivors Forums
 - every year
 - in a different state (2010 QLD, 2011 NSW)
 - so that all Aboriginal and Torres Strait Islanders cancer survivors /carers have the opportunity to meet other survivors /carers and talk about their experience
 - talk about areas that could be improved
 - raise things that may be bothering you now
- host a National Indigenous Cancer Survivors Forum

In the future....

- Publish articles about why it was important to host the ICSF
talk about priorities for attendees
????????



APOCC UPDATE

Aboriginal Cancer Survivors Forum 19th May 2011
Veronica Saunders Aboriginal Liaison Officer Cancer Council NSW



Patterns of Cancer Care

- Patterns of Cancer care side of study is finished
- 58 Interviews with cancer patients, carers and health care workers
- Lots of themes came up
- Coding is next



Pathways to Diagnosis

- The aim of this part of the study is to do a phone interview of Aboriginal Cancer patient who has been recently diagnosed.
- The interview will be about the medical care received before being diagnosed with cancer
- The research has been approved by ethics committees of the AHMRC and RPA



- 200 phone interviews recruiting from AMS's Clinical cancer registries Hospital
Awaiting for ethics approval
Ethics approval for Hunter New England Area Health Service



Who will be in the study?

- We will be asking Aboriginal people in NSW diagnosed with cancer from 1st January 2010 onwards to participate and as we said your name could be obtained from a clinical cancer registry of an Area Health Service where your cancer was treated.



Information Will Be Kept Confidential

All the information cancer pt provides will remain strictly confidential and will be stored in accordance with strict privacy protection procedures.

Only authorised research staff will have access to the data and names will be removed from records and replaced with a code number.



Thank You

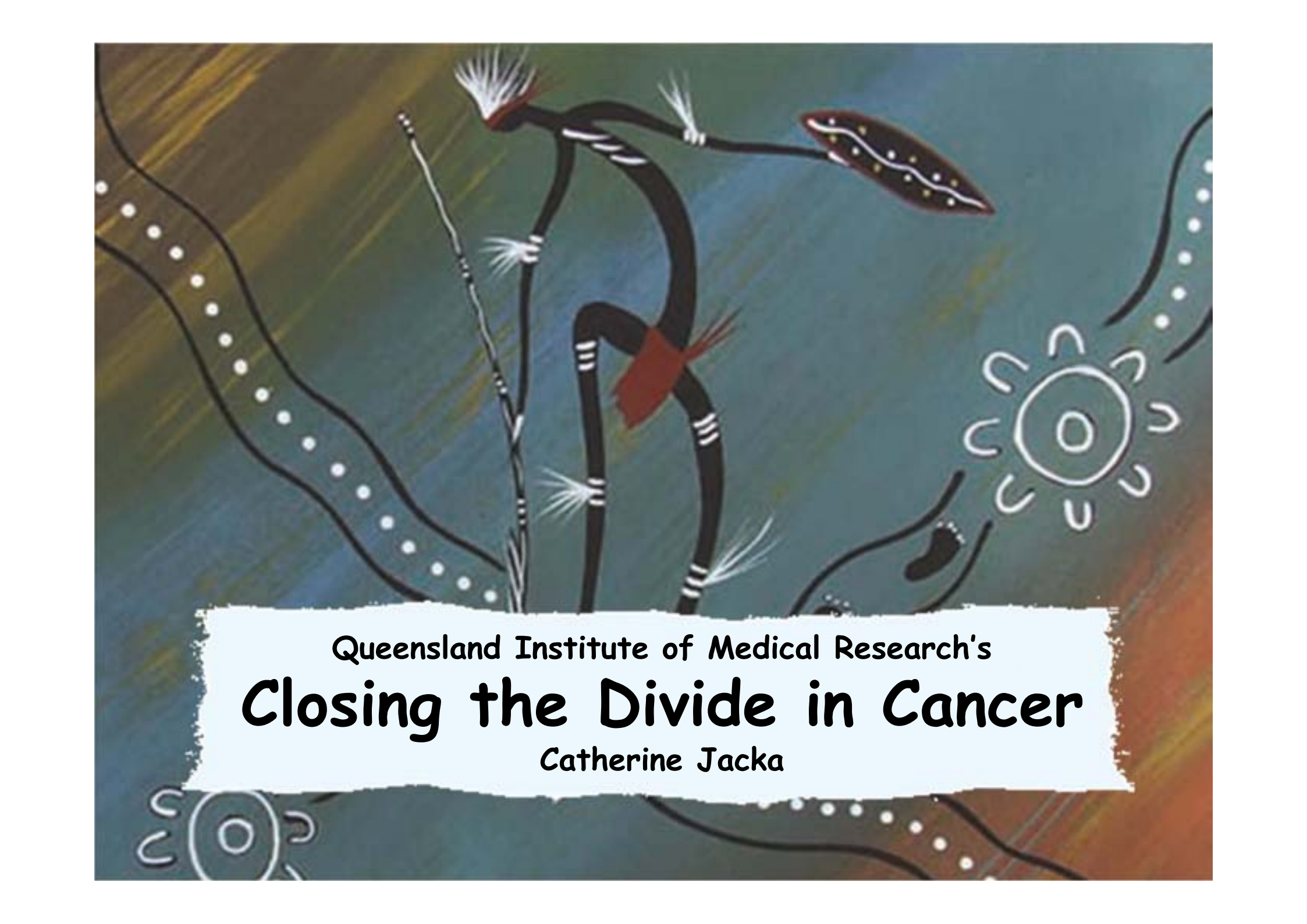
Veronica Saunders
Aboriginal Liaison Officer

APOCC Study

Cancer Council NSW

PH: 0293341488

EM: veronicas@nswcc.org.au

The background is a piece of Aboriginal art. It features a central figure in black with white and red accents, set against a dark blue and green background with white dots and lines. A white banner with a torn edge is overlaid on the bottom half of the image, containing the title and author's name.

Queensland Institute of Medical Research's
Closing the Divide in Cancer

Catherine Jacka

Queensland's Work

● Background

- Cancer in Indigenous Australians
- Assess the SCN-SF34 for use with Indigenous cancer patients
- Develop SCN-IP
- Assessing the Supportive Care Needs of 190 cancer patients in Qld
- Support Services to Indigenous cancer patients
- A comparative study: Patterns of care, co-morbidities and Quality of Life of Indigenous and Non-Indigenous people with Lung, Head & Neck, Breast & Gynaecological cancers

● Summary & Conclusions

Cancer in Indigenous people

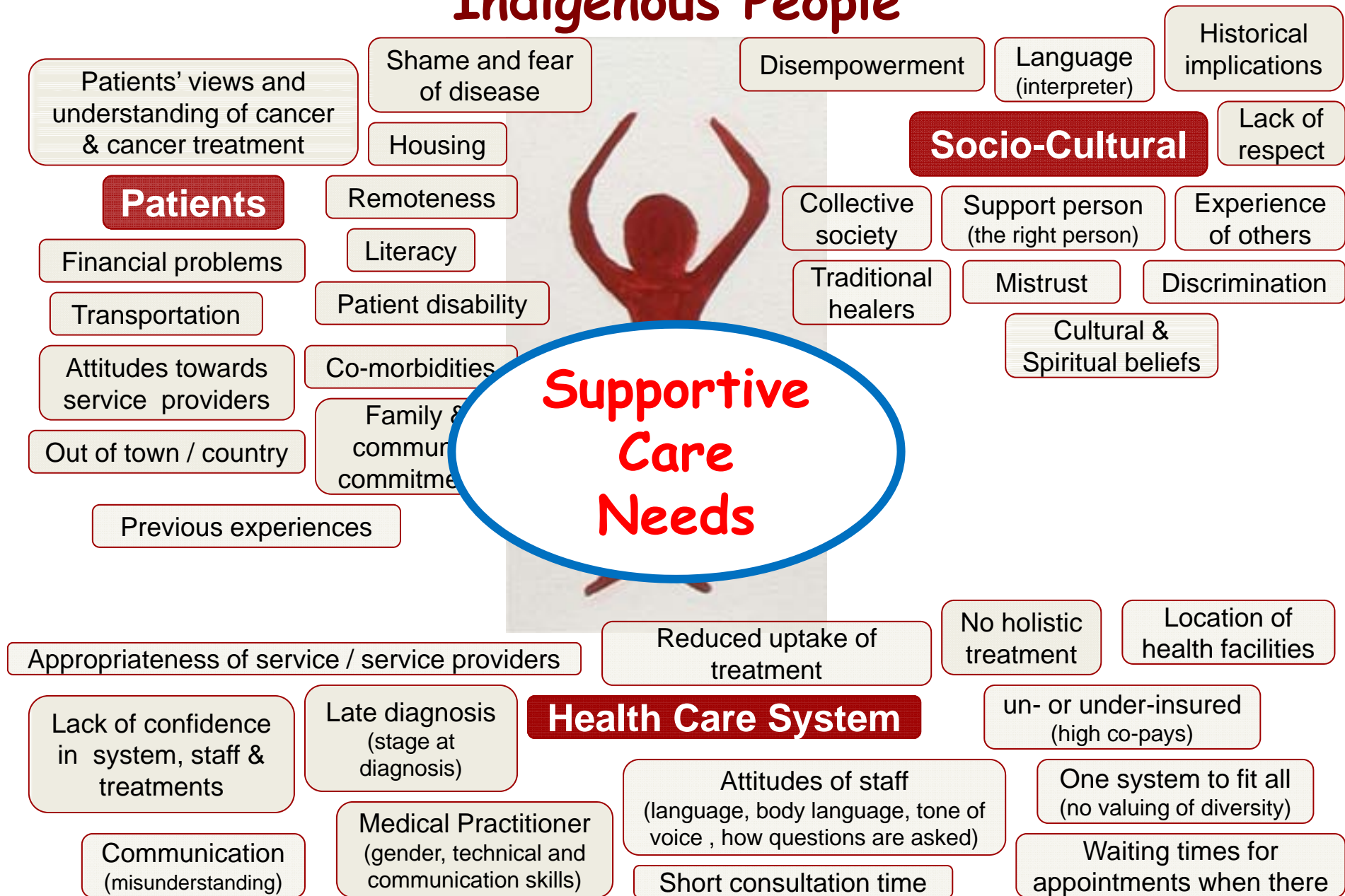
- Cancer is a leading cause of death
 - Indigenous Australians (17% of all deaths)
 - All Australians (30% of all deaths)
- No national data on cancer incidence
 - poor quality of identification of Indigenous people
- Reliable data is only available for the NT, WA, SA and more recently Qld

●

Compared to other Australians,

- **cancer incidence is similar or lower**
 - 172 per 100,000 Indigenous Queenslanders per year
 - (*~217 per 100,000 non-Indigenous Queenslanders*)
- **cancer mortality is higher**
 - **85 deaths** per 100,000 Indigenous Queenslanders per year
 - (*~62 per 100,000 non-Indigenous Queenslanders per year*)
- **cancer survival is poorer**
 - In Qld, the likelihood of **death** from cancer is about **30% higher** for Indigenous patients

Factors impacting on cancer outcomes of Indigenous People





Study Aim

- Evaluate the SCN-SF34 to see if it is appropriate for use with Aboriginal and Torres Strait Islander people, if not develop a culturally appropriate supportive care needs assessment tool

Methods

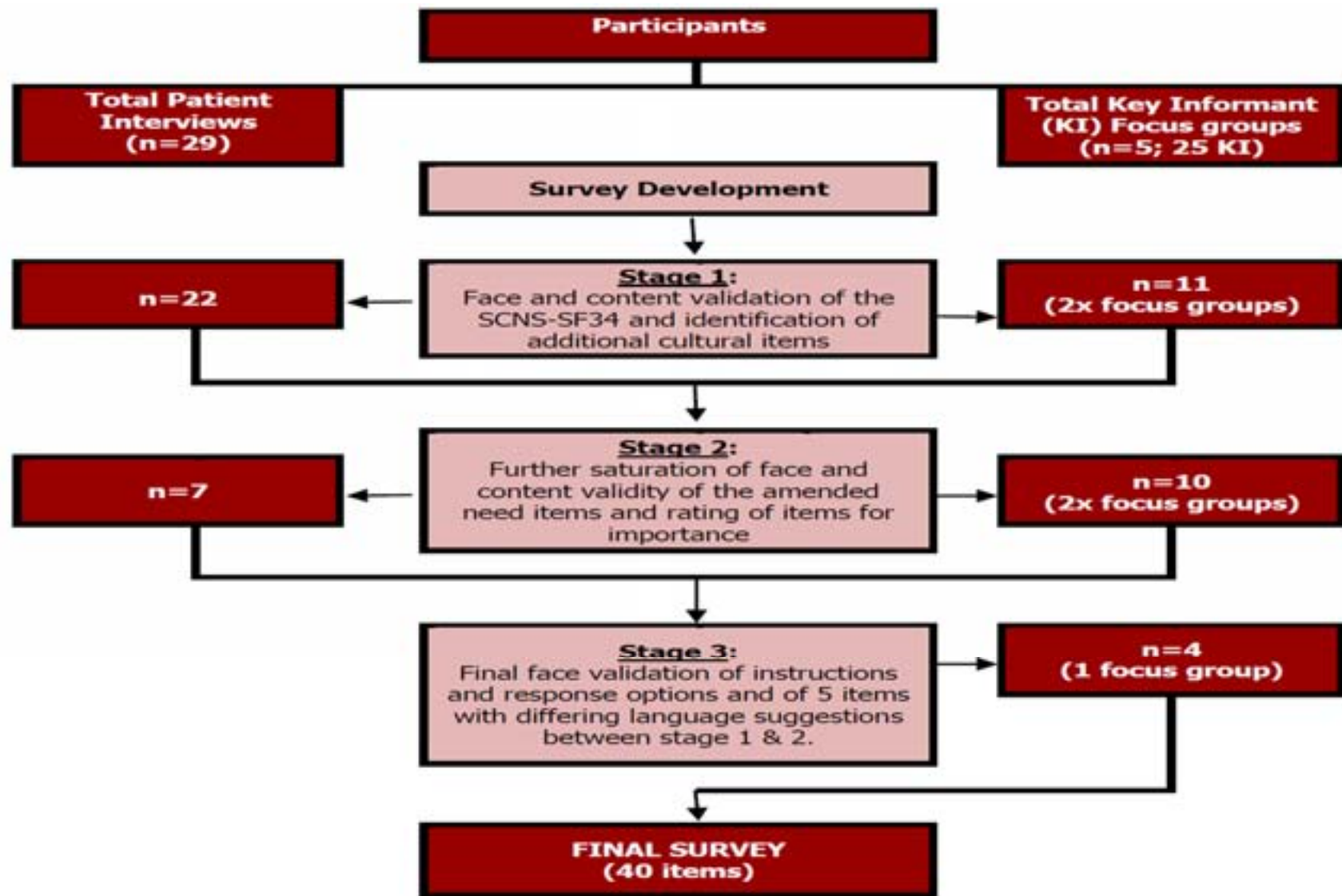


Figure 1 Overview of methods for the development and face and content validation of the Supportive Care Needs Survey-Indigenous Cancer Patients

Participants

54 participants were recruited into this study

Indigenous Cancer Patients (n=29)

- 19 women and 10 men
- average age of 53 yrs (29 -75)
- most lived in accessible or highly accessible areas (59%)
- all were receiving or starting a treatment for their cancer

gynaecological cancers (n=9)	lung (n=7)
breast (n=4)	thyroid cancer (n=1)
Lymphomas / leukemia's (n=3)	bowel (n=2)
brain (n=1)	prostate (n=1)

Indigenous Key Informants (n=25)

- 10 men and 15 women
- average age of 44 yrs (18-64)
- most lived in rural locations (56%)
- a range occupations

hospital liaison officer (n=5)	social worker (n=2)
health worker (n=5)	nurse (n=1)
non-health related occupation (e.g. drover, home duties) (n=12)	

Results

- All SCNS-SF34 items were rephrased
- Seven SCNS-SF34 items were dropped
 - items 8 (combined with 7), 11, 12, 14, 16, 18, 33
- The sexual items now have additional instructions
- Some items were re-ordered (e.g. sexual items together)

Table 1. Selected items from the original SCNS-SF34 and wording changes included in the SCNS-IP

Item no.	SCNS-SF 34 Original item	Final item in SCNS-IP	Reason given for change to item
1	Pain	Physical pain (e.g., hurt)	Culturally inappropriate
2	Lack of energy/tiredness	Feeling tired	Participants required more clarification of what this item meant
3	Feeling unwell a lot of the time	Not feeling well (e.g., feeling rotten, crook or sick) a lot of the time	Participants required more clarification of what this item meant
7	Feeling down or depressed	Feeling down or sad	Participants reported item 7 & 8 SCNS-SF34 had the same meaning so they were combined
11	Uncertainty about the future	Dropped item	Culturally inappropriate
12	Learning to feel in control of your situation	Dropped item	Not relevant to Indigenous people
15	Changes in sexual feelings	Changes in sexual feelings	As optional questions (sex items grouped together)

Indigenous specific items were added

Table 2. Selected items from the Indigenous-specific sub-scale (SCNS-IP)

1. Money worries (e.g., cost of accommodation, travel)
2. Having an Indigenous person to talk to and support you, someone who understands your culture
3. Having an Indigenous person to interpret and help with communication with health professionals
4. Ensuring family members were able to be present when talking or seeing health professionals
5. Directions to get to and around the hospital
6. Getting care items such as dressings, pads or colostomy bags
7. Getting information about your illness for your family and friends

Instructions for the SCNS-SF34 were changed

SUPPORTIVE CARE NEEDS SURVEY SHORT FORM 34

To help us plan better services for people diagnosed with cancer, we are interested in whether or not needs which you may have faced as a result of having cancer have been met. For every item on the following pages, indicate whether you have needed help with this issue within the last month as a result of having cancer. Put a circle around the number which best describes whether you have needed help with this in the last month. There are 5 possible answers to choose from:

NO NEED	1	Not applicable – This was not a problem for me as a result of having cancer.
	2	Satisfied - I did need help with this, but my need for help was satisfied at the time.
SOME NEED	3	Low need - This item caused me little concern or discomfort. I had little need for additional help.
	4	Moderate need – This item caused me some concern or discomfort. I had some need for additional help.
	5	High need - This item caused me a lot of concern or discomfort. I had a strong need for additional help.

For example

In the <u>last month</u> , what was your level of need for help with:	No need		Some need		
	Not applicable	Satisfied	Low need	Moderate need	High need
1. Being informed about things you can do to help yourself to get well	1	2	3	4	5

If you put the circle where we have, it means that you did not receive as much information as you wanted about things you could do to help yourself get well, and therefore needed some more information.

NO NEED	1	Not applicable – This was not a problem for me as a result of having cancer.
	2	Satisfied - I did need help with this, but my need for help was satisfied at the time.
SOME NEED	3	Low need - This item caused me little concern or discomfort. I had little need for additional help.
	4	Moderate need – This item caused me some concern or discomfort. I had some need for additional help.
	5	High need - This item caused me a lot of concern or discomfort. I had a strong need for additional help.

The final SCNS-IP: 39 need items & 1 open ended question
The SCNS-IP takes approx. 15 minutes to complete

Conclusions

- The language used in existing SCN tools was not suited to Indigenous people
- Some items and concepts in existing SCN tools were culturally inappropriate
- Additional cultural-specific items were also identified
- Developed a supportive care needs tool that is culturally appropriate for use with Indigenous cancer patients (SCNS-IP)
- Psychometric testing of this tool is being done

ASSESSING THE SUPPORTIVE CARE NEEDS OF ABORIGINAL & TORRES STRAIT ISLANDER PEOPLE DIAGNOSED WITH CANCER

- 4 major hospitals in Qld
- Asking Aust Indigenous cancer patients to become involved in this study
- Interviews at baseline, 3 months, 6 months
- Done face-to-face

- To date, 77 patients involved
- Estimate 190 participants
- Study ongoing for another 12 months

SUPPORT SERVICES FOR INDIGENOUS CANCER PATIENTS IN QUEENSLAND

To the best of our knowledge, this study is the first in Queensland to identify and describe the available support services for Indigenous cancer patients

Innovative internet survey used for organisational ease in responding

Assisted by CCQ in access to services in Qld

April 2009, Lisa Whop (MAE student, ANU)

FINDINGS

- No specific Indigenous specific service provision
- A paucity in the distribution of services to areas where a high proportion of Indigenous people reside,
- Less than adequate cultural training of staff and little strategies incorporated in mainstream service to encourage Indigenous patients to utilise their service.
- The study also indicated use of Aboriginal Community Controlled Health Services (ACCHS) was high amongst a convenient sample of Indigenous patients interviewed (30 patients interviewed).

Please note: These findings are unpublished at present.

A COMPARITIVE STUDY: PATTERNS OF CARE, CO-MORBIDITIES AND QUALITY OF LIFE OF INDIGENOUS AND NON-INDIGENOUS PEOPLE WITH LUNG, HEAD & NECK, BREAST & GYNAECOLOGICAL CANCERS

- **Medical chart review:**
 - to investigate patterns of care of a large number of Indigenous and non-indigenous cancer patients
 - to compare diagnostic, treatment and follow up practices.

It will look closely at variations in treatment and compare against clinical practice guidelines.
- **Patient and health professional interviews:**
 - it will describe the Quality of life of a small number of Indigenous and non Indigenous cancer patients
 - determine services used by patients
 - explore patients perspectives about their cancer treatment
 - explore health care professionals perspectives about their Indigenous cancer patients

National Roundtable on Cancer Research

- Held on 3rd December 2010
- Reps from the national, State and Territory cancer initiatives, major cancer treating hospitals, cancer survivors and representatives from the Aboriginal community controlled primary health care sector attended;

OUTCOME

- Centre of Research Excellence proposal to NHMRC that would enable a concerted and combined effort on Aboriginal and Torres Strait Islander cancer research.
- A proposal has been written, the next stage of assessment is June/July 2011

Thank you

