Implementing the Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP) into routine cancer care

ASPOG Conference 2017

Presented by: Dr Sue Moore

Acknowledgements

I acknowledge the traditional owners and custodians of the land in which we are meeting today, the Turrbal people. I wish to pay respects to Elders past and present, and also to the Aboriginal and Torres Strait Islander people who are present here today.

Aims

- Overview of cancer epidemiology for Indigenous people,

- Discuss the unmet supportive care needs of Indigenous Australians affected by cancer,

- Inform about the Supportive Care Needs Assessment tool for Indigenous People (SCNAT-IP)

Brief Overview

- Overall cancer incidence is **higher** amongst Indigenous people but **particularly so for some cancers.** *(e.g. lung, liver, cervix and uterine)*

Overall Cancer Incidence 2008-2012

Ref: AIHW, Cancer in Australia 2017
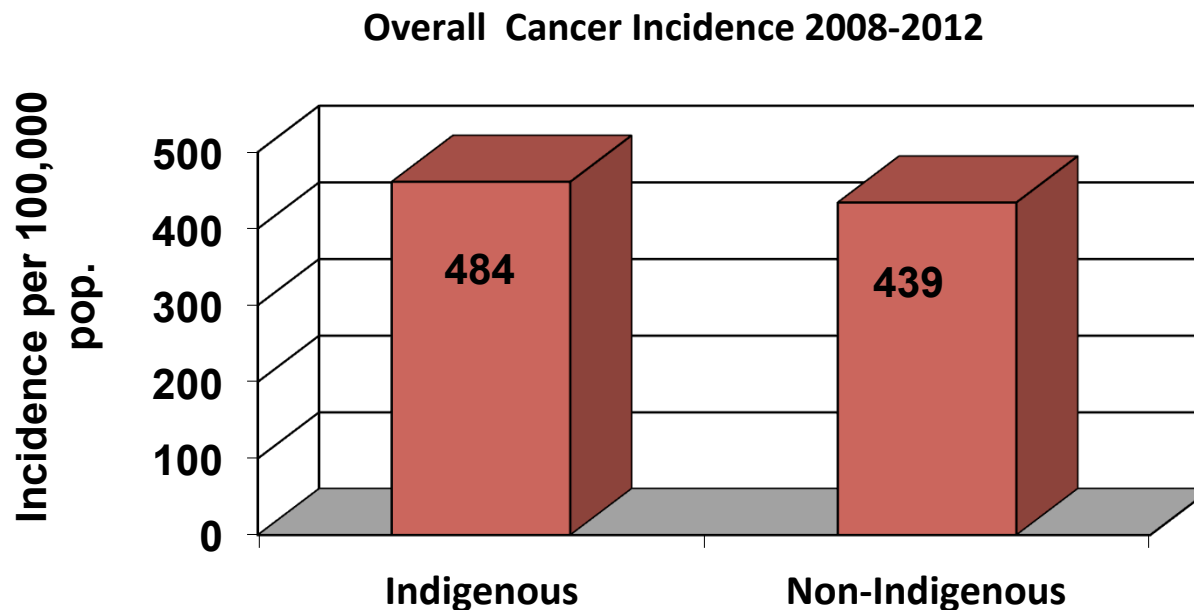
Most common

CANADA - Aboriginal (4.3%): First Nation, Inuit, Métis

CANADA, Alberta (FN 3.3%; Inuit 0.1%)

M	F
CRC	CRC
Lung	Lung
Prostate	Breast
Kidney	Cervix

UNITED STATES - Alaska Native / American Indian (1%)

(Contract Health Service Delivery Area (CHSDA))

USA, Alaska (15.6%)

M	F
Lung	Breast
CRC	CRC
Prostate	Lung
Stomach	Uterus
Kidney	Stomach

USA (Except Alaska) (1%)

M	F
Prostate	Breast
CRC	CRC
Lung	Lung
Kidney	Uterus
Liver	Kidney

NEW ZEALAND - Māori (15.5%)

New Zealand, Maori

M	F
Lung	Breast
Prostate	Lung
CRC	CRC
Stomach	Cervix
Liver	Stomach

AUSTRALIA - Aboriginal & Torres Strait Islander (2.7%)

AUSTRALIA, Western Australia (1.7%)

M	F
Lung	Breast
H&N	Lung
Prostate	CRC
Oesophagus	Cervix
CRC	H&N

AUSTRALIA, Northern Territory (31.6%)

M	F
Lung	Breast
H&N	Lung
CRC	Uterus
Prostate	Cervix
Liver	H&N

AUSTRALIA, Queensland (3.6%)

M	F
Lung	Breast
H&N	Lung
Prostate	Cervix
CRC	CRC
Oesophagus	H&N

Ref: Moore Lancet Onc 2015

menzies
school of health research

Cancer death rate increasing

Ref: Cancer Australia 2016

Factors affecting cancer outcomes

Indigenous Australians with cancer are more likely to….

- be diagnosed at later stages

- develop cancers with poor prognosis *(e.g. lung, head and neck, pancreas)*

- have a higher number of co-morbidities

- are less likely to receive optimal treatment

- **have a greater number of unmet supportive care needs**

Support Needs

- Cancer patients commonly report **physical, emotional, social, informational, practical and spiritual difficulties**.

- Occur across the cancer continuum- screening, diagnosis, treatment, survivorship.

- Across a wide range of services

- Many require **supportive care** to deal with these

Ref: Crooks et al., 2004

Defining Supportive Care

Definition:

"*Supportive care aims to prevent, reduce and alleviate the symptoms of treatment, enhance communication between patients and clinicians and assist patients and their family to manage needs associated with the diagnosis and treatment of cancer*"
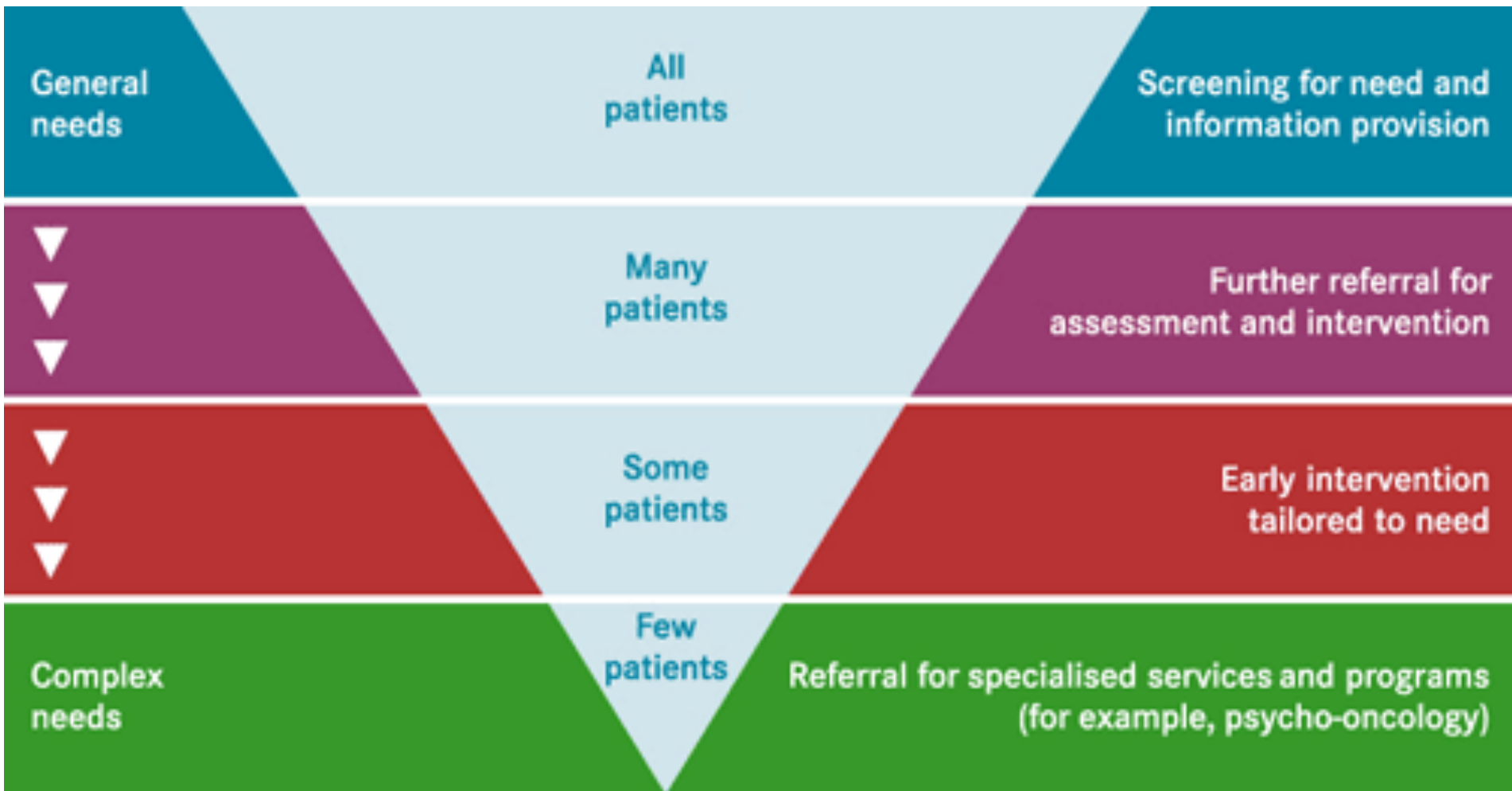
Ref: Surbone A, Baider L, Weitzman TS, et al . (2010)

Cancer Council definition

Cancer Council defines supportive care

- as all forms of care and support that aim to improve the quality of life of people living with cancer, cancer survivors and their loved ones, **particularly forms of care that supplement clinical treatment modalities**.

- can include allied health services, such as psychosocial support (often referred to as psycho-oncology); travel and accommodation support: financial assistance for people living with cancer and their families.

Ref: Cancer Council Aust 2017

Unmet Needs Assessment

- Needs assessment is the **patient perspective on concerns** and **degree to which they require help**

- Solution-focused

- Measures gap between **experience** and **expectations**

A Model of Supportive Care Needs assessment

General needs	**All patients**	**Screening for need and information provision**
▼ ▼ ▼	**Many patients**	**Further referral for assessment and intervention**
▼ ▼ ▼	**Some patients**	**Early intervention tailored to need**
Complex needs	**Few patients**	**Referral for specialised services and programs (for example, psycho-oncology)**

Adapted from Fitch, 2000

Why Assess Needs?

Routine screening for psychosocial problems may:

- lead to better patient outcomes (QOL, communication)

- improve quality of service delivery

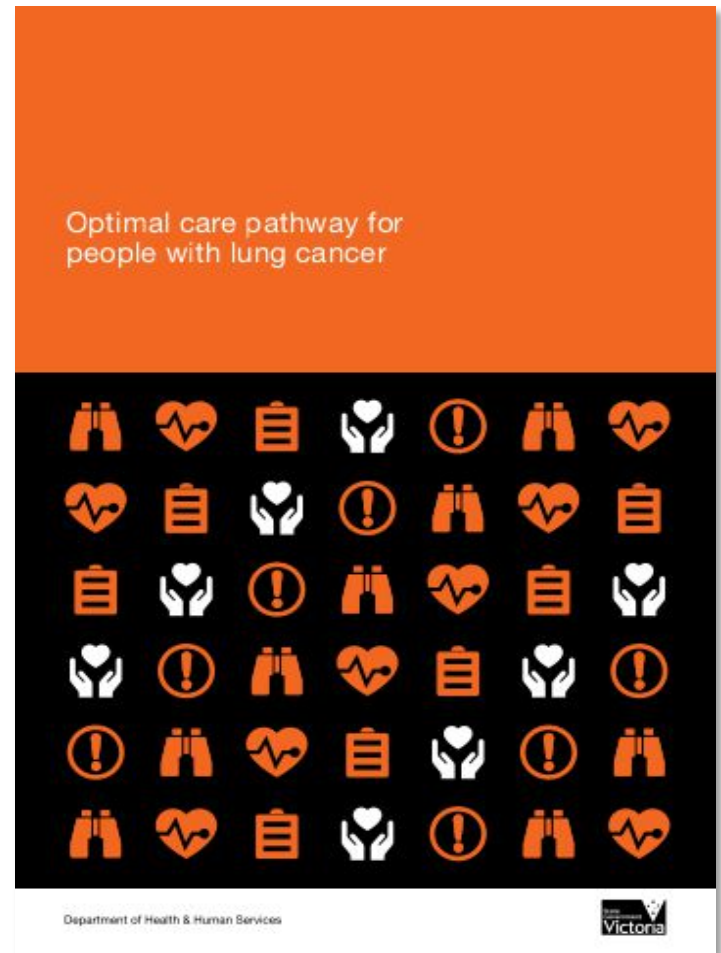- decrease health care costs

Ref: Carlson 2006

Screening is **BEST PRACTICE** recommended by:

- multiple groups and agencies

- more recently Cancer Australia Optimal Care Pathways (OCP)

Ref: Cancer Australia 2017

CA OCP Guidelines

3.5.2 Supportive care
Screening with a validated screening tool, and assessment and referral to appropriate health professionals or Organisations, is required to meet the identified needs of an individual, their carer and family.

Optimal care pathway for people with lung cancer

Department of Health & Human Services

Victoria

https://www.yumpu.com/en/document/view/48978969/providing-optimal-cancer-care-supportive-care-policy-for-victoria.

Why assess Indigenous patients needs?

- Indigenous cancer patients often present with **complex health and well-being issues,**

- Patients **don't often tell us** about their needs unless we ask them,

- There are often **cultural differences** in Indigenous people's perceptions of cancer, information needs, decision-making style and coping with illness,

Ref: Shahid S & Thompson S.C, (2009)

Why assess Indigenous patients needs?

- Accurate measurement is important to provide a clear picture of the components and extent of **unmet needs**

- Early intervention can **reduce disparities** of cancer care

- **Until recently no culturally appropriate tool available...**

Ref: Shahid S & Thompson S.C, (2009)

SCNAT-IP Development

Stage 1
Face and content validation of the SCNS-SF34 and identification of additional cultural items

Outcomes: SCNS-SF34 did not adequately address some of the language, culture and specific needs of Indigenous people with cancer. First version SCNAT-IP developed consisting of 39 items + 1 open-ended item

Stage 2
Psychometric testing of the SCNAT-IP
(39 items + 1 open-ended item)

Outcomes: Initial support for the SCNAT-IP, as a measure of multiple supportive care needs domains specific to Indigenous Australians with cancer undergoing treatment. Final SCNAT-IP (Four domains containing 26 items + 1 open-ended item.

SCNAT-IP QUESTIONS

In the last month, did you need any help with:

If you answered YES,
How much help did you need?

		Satisfied with help received	Needed a little more help	Needed some more help	Needed a lot more help
1 Physical pain (e.g., hurt)	No $\square_1$ Yes $\square$	2 $\square$	3 $\square$	4 $\square$	5 $\square$
2 Feeling tired (e.g., sleeping OK)	No $\square_1$ Yes $\square$	2 $\square$	3 $\square$	4 $\square$	5 $\square$
3 Not feeling well (e.g., feeling rotten, crook or sick) a lot of the time	No $\square_1$ Yes $\square$	2 $\square$	3 $\square$	4 $\square$	5 $\square$
4 Work around the home (e.g., washing, cooking, raking the yard, sweeping the floor)	No $\square_1$ Yes $\square$	2 $\square$	3 $\square$	4 $\square$	5 $\square$
5 Doing the things you used to do (e.g., fishing, walking, seeing family)	No $\square_1$ Yes $\square$	2 $\square$	3 $\square$	4 $\square$	5 $\square$

Most frequent unmet needs

Prevalence of unmet needs vary by jurisdiction

Queensland study

➤ 248 Indigenous Ca pts

➤ 71% reported at least one unmet need.

➤ Domains
  • Mostly Physical/psychological

Items

• Money worries (22%)

• Concerns about the worries of those close to you (15%)

• Worrying about the illness spreading or getting worse (14%)

• Feeling down or sad (13%)

• Anxiety (12%)

• Worry about results of treatment (12%)

• Work around the home (11%)

Semi-National Study

➤ 148 Indigenous Ca pts

➤ 64.8% reported at least one unmet need.

➤ Domains
  • Physical/psychological -47%
  • Practical/cultural – 34%

➤ NT and WA more unmet needs in the practical/cultural domain

• 'money worries'

• 'costs of accommodation'

• 'having an Indigenous person to talk to and support you, someone who understands your culture"

SCNAT-IP Development

Stage 3
Clinical implementation and pilot testing of the SCNAT-IP
(26 items + 1 open-ended item)

Outcomes: Empirical support for the feasibility and acceptability of use of the SCNAT-IP in routine cancer care with Indigenous Australians. Staff and patients found the SCNAT-IP to be an acceptable tool and supported universal screening for Indigenous cancer patients.
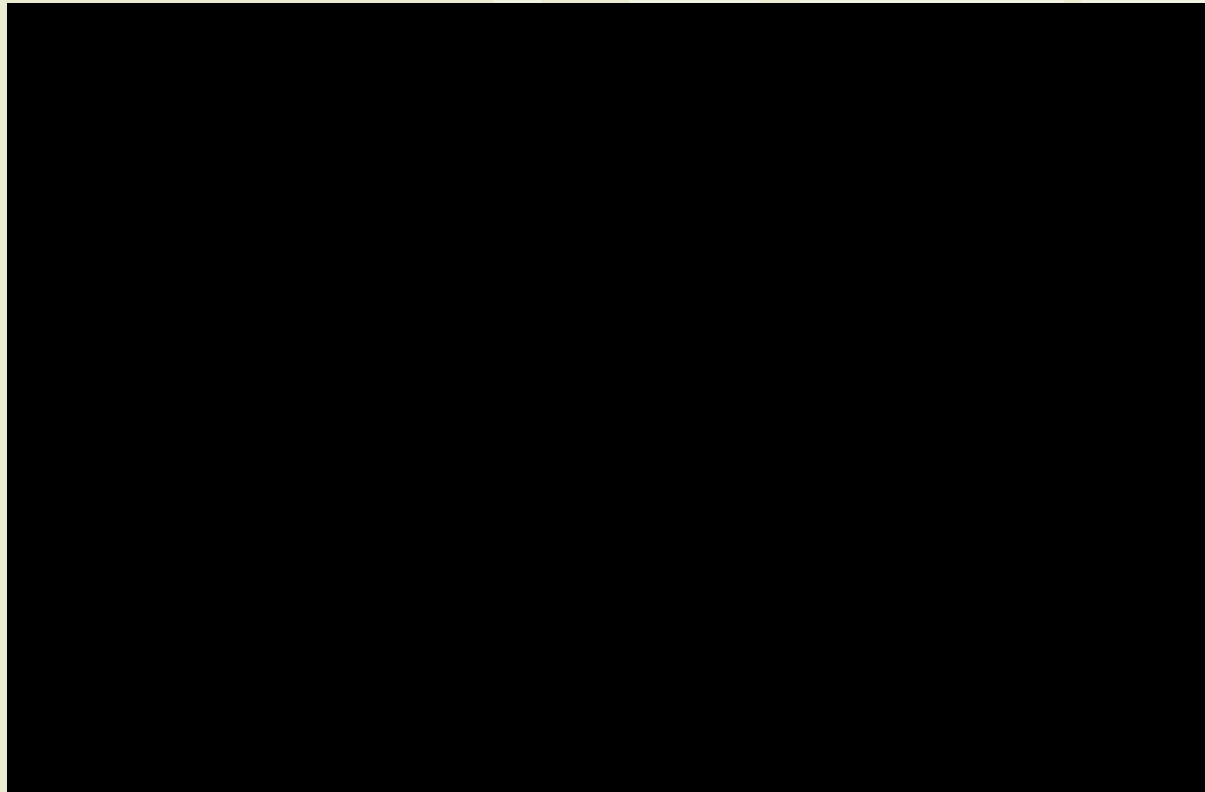
Stage 4
National implementation of the SCNAT-IP
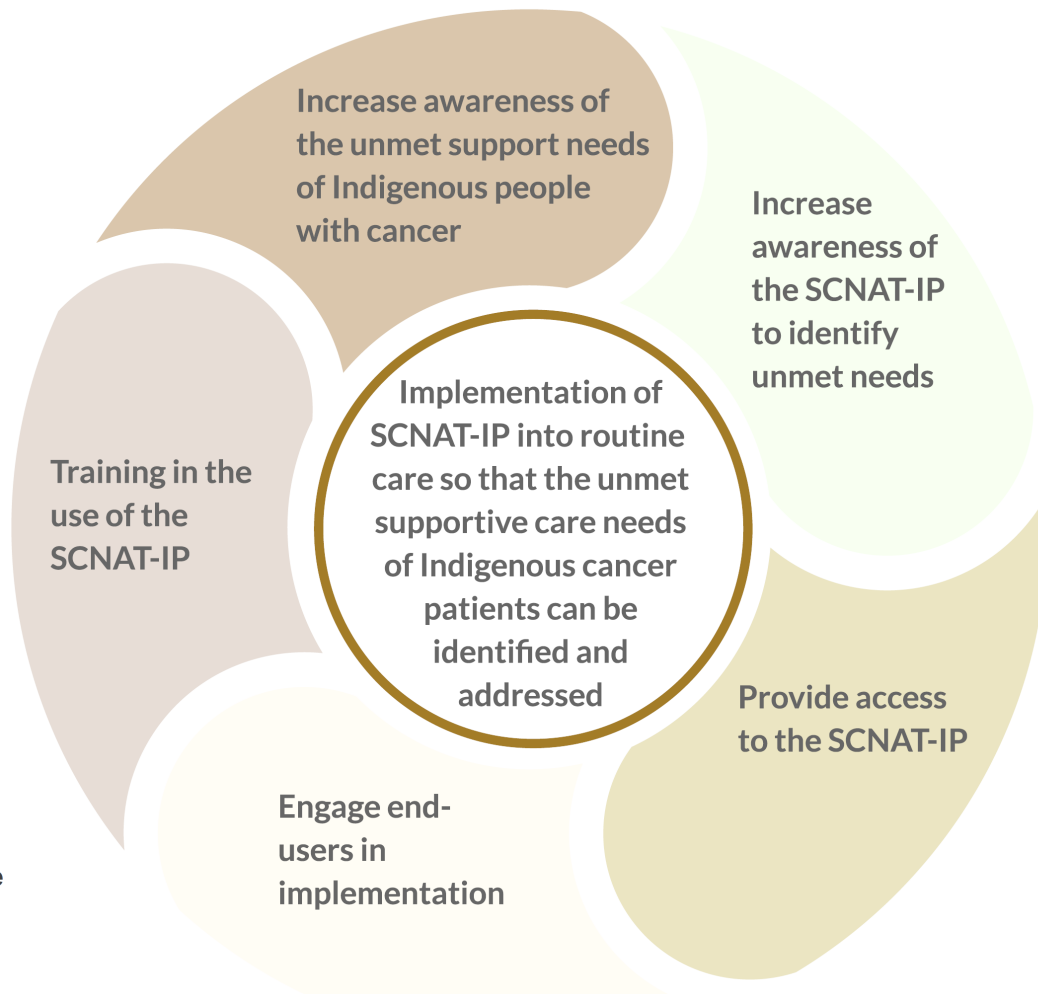
Outcomes: In progress

Using the SCNAT-IP

Video: *Using the SCNAT-IP in clinical practice*

SCNAT-IP Implementation project

National Implementation Study is funded under a Cancer Australia 'Supporting people with cancer Grant initiative' funded by the Australian Government, to:

Increase awareness of the unmet support needs of Indigenous people with cancer

Increase awareness of the SCNAT-IP to identify unmet needs

Training in the use of the SCNAT-IP

Implementation of SCNAT-IP into routine care so that the unmet supportive care needs of Indigenous cancer patients can be identified and addressed

Provide access to the SCNAT-IP

Engage end-users in implementation

- train health care professionals in the use of the tool
- evaluate the implementation of the tool into the routine care of Indigenous people with cancer.
- assess uptake of the tool in cancer care centres(CCC)

Next Steps

1. Implement SCNAT-IP in 5 cancers centres around Australia.
2. Evaluate the implementation.
3. Provide on-line training module for health professionals and access to the tool.
4. Full implementation of the SCNAT-IP into the routine cancer care of Indigenous people in Australia.

Acknowledgements

NICaN Ambassadors Aunty Celia Moore and Adelaide Saylor

- Indigenous cancer patients and hospital staff who tested the tool
- Indigenous community Ambassadors- Ambassadors are Aboriginal and Torres Strait Islander people who have had cancer or have a family member or friend with cancer and are passionate about educating their community about cancer
- ASPOG, and particularly Dr Fiona Haines, for the opportunity to present today