

# Initiatives in Australia

closing disparities in cancer for Indigenous Australians

Professor Gail Garvey

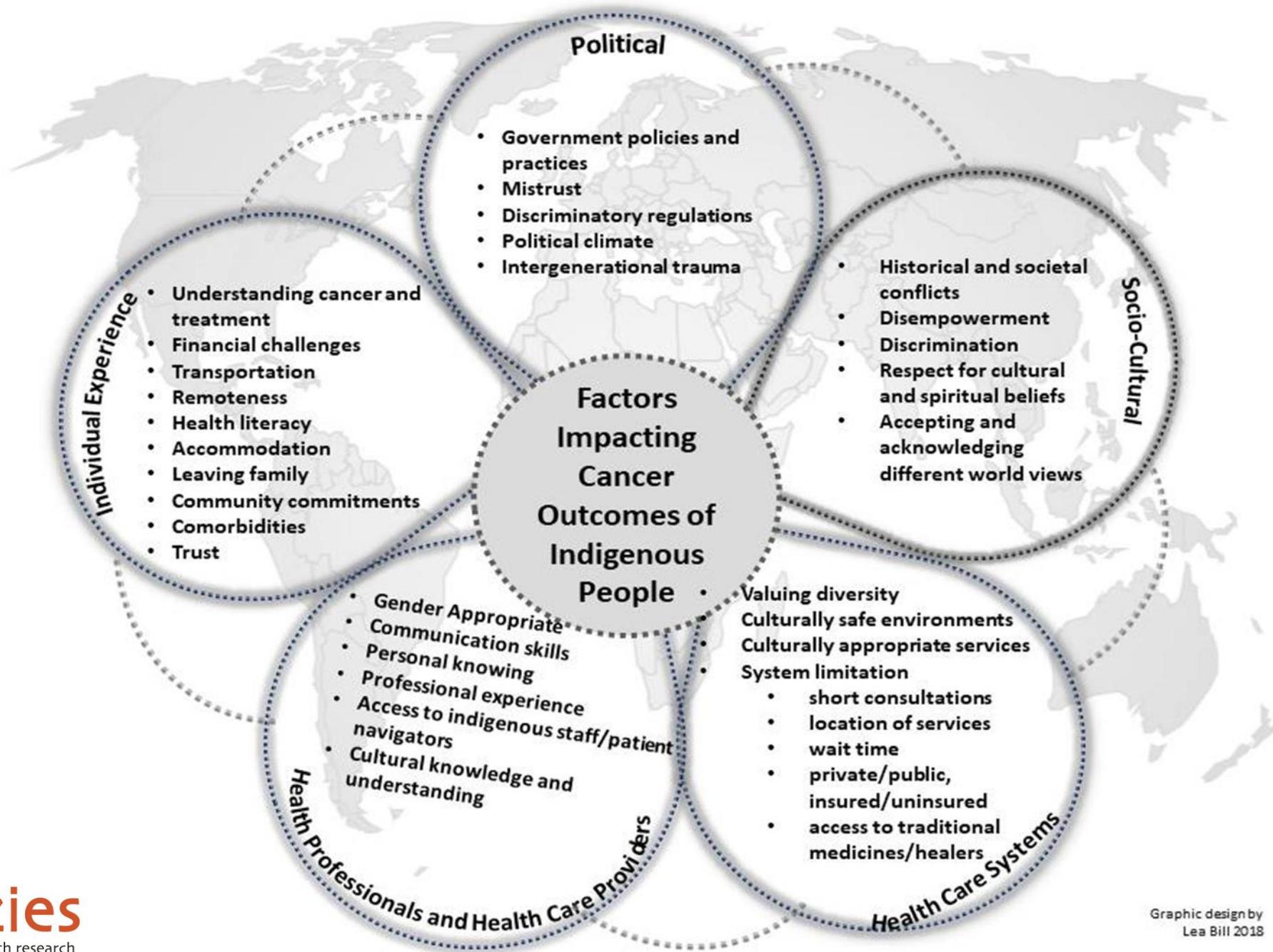
[gail.garvey@menzies.edu.au](mailto:gail.garvey@menzies.edu.au)

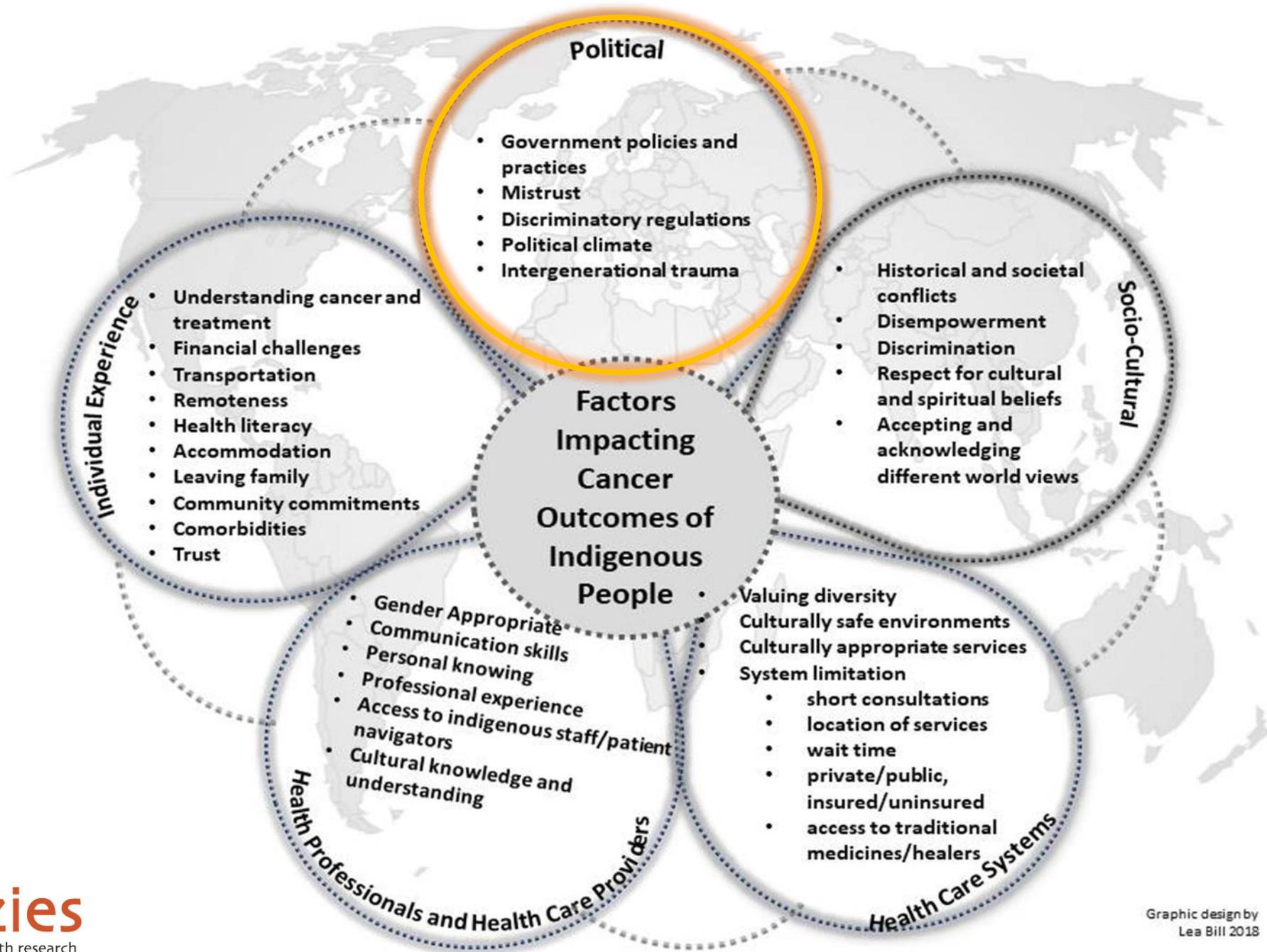


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# Apology Ten Year Anniversary

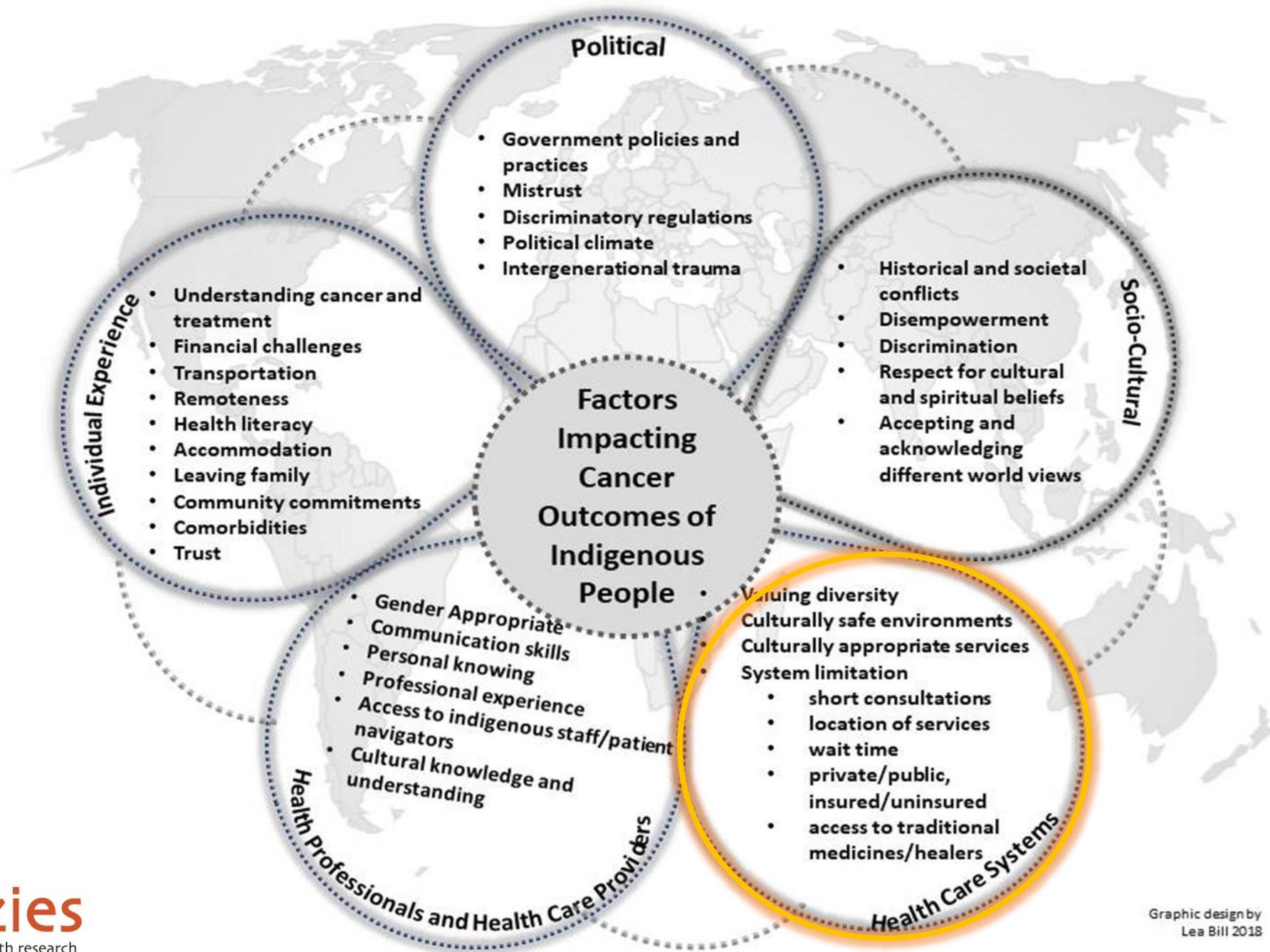
'**Sorry**' apology to Stolen Generations. On February 13th, 2008, Aboriginal people across all Australia were deeply moved and in tears: The Prime Minister of Australia, Kevin Rudd, had finally apologised to the Stolen Generations and said 'sorry'.



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Cancer Australia

**NATIONAL  
ABORIGINAL AND  
TORRES STRAIT ISLANDER  
CANCER FRAMEWORK  
2015**

## Purpose

Provide high-level guidance and direction for the many individuals, communities, organisations and governments whose combined efforts are required to address disparities and improve cancer outcomes for Aboriginal and Torres Strait Islander peoples.

## Aim

By providing this direction and identifying the priorities that most require attention, this Framework aims to improve cancer outcomes for Aboriginal and Torres Strait Islander peoples by ensuring timely access to good quality and appropriate cancer related services across the cancer continuum.

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# Concepts fundamental to Aboriginal and Torres Strait Islander health



Key concepts which are fundamental to Aboriginal and Torres Strait Islander health, including cancer control, have been considered in the development of this Framework.

## **A holistic approach to health and wellbeing**

Aboriginal and Torres Strait Islander concepts of health extend beyond the physical wellbeing of an individual to the social, emotional and cultural wellbeing of the whole community in which each individual is able to achieve their full potential as a human being.<sup>13</sup>

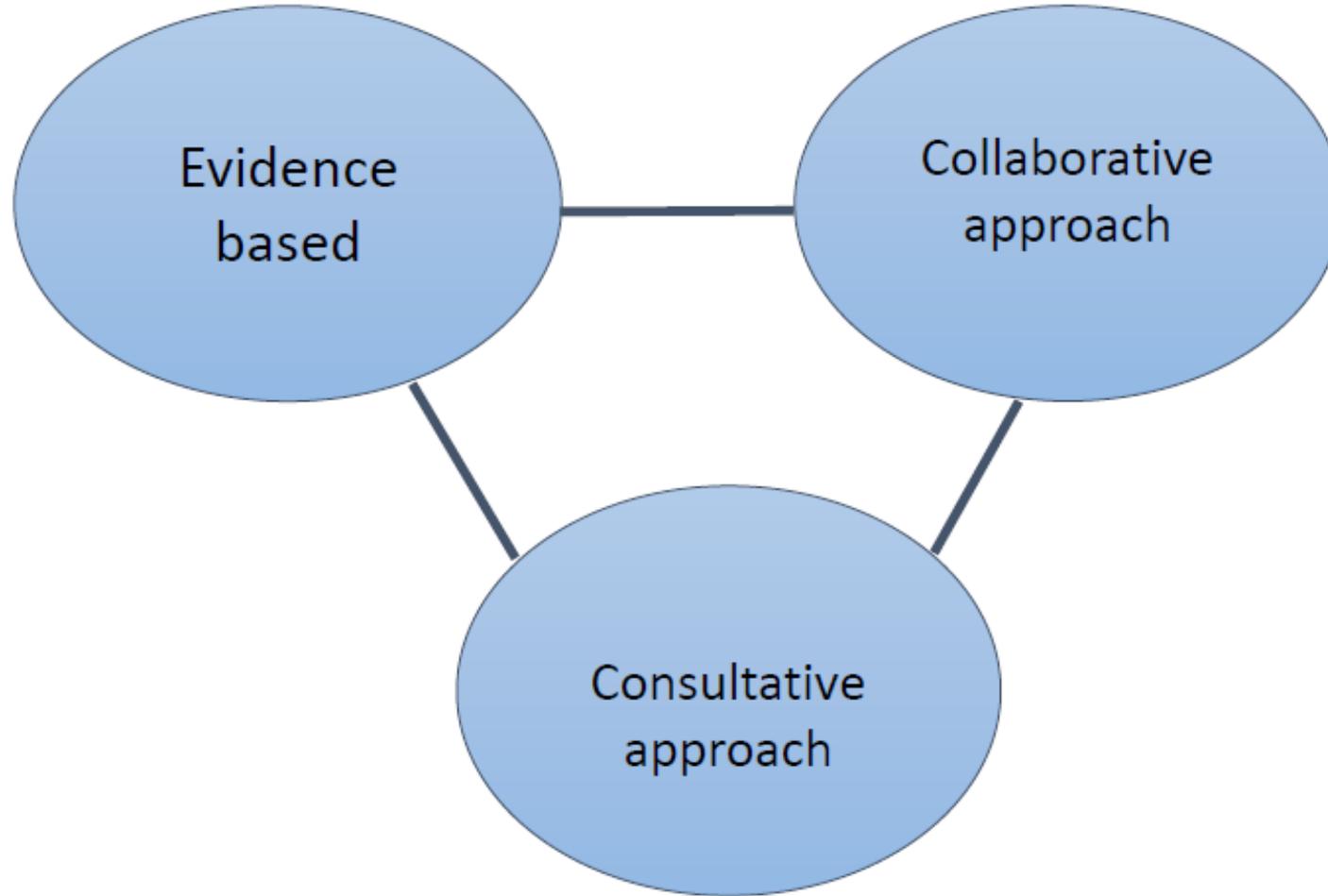
## **The diversity of Aboriginal and Torres Strait Islander peoples**

Aboriginal and Torres Strait Islander people and communities are diverse, including across gender, age, language, geographic location, sexual orientation, religious beliefs, family responsibilities, marriage status, life and work experiences, personality and educational levels.<sup>14</sup>

## **The social and cultural determinants of health**

Aboriginal and Torres Strait Islander health is significantly affected by the social and cultural determinants of health. Aspects of the broader social environment that can influence (in a negative or positive way) the capacity of individuals, families and communities to engage with health care and manage their own health.<sup>15</sup> For Aboriginal and Torres Strait Islander people, the social and cultural determinants of health may include support from family, community and church groups, connection to culture and country, a sense of empowerment or self-efficacy, education and literacy levels, poverty, marginalisation from the dominant culture, racism, poor housing, poor nutrition, smoking and other high risk behaviours, and living in remote areas.<sup>16-20</sup>

# Underpinning approach to delivering a National Aboriginal and Torres Strait Islander Cancer Framework

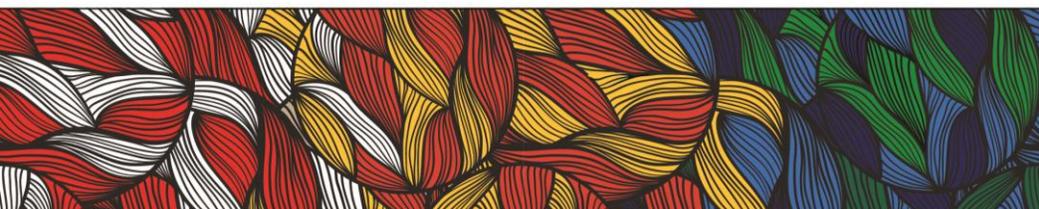


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# National Aboriginal and Torres Strait Islander Framework Priorities:

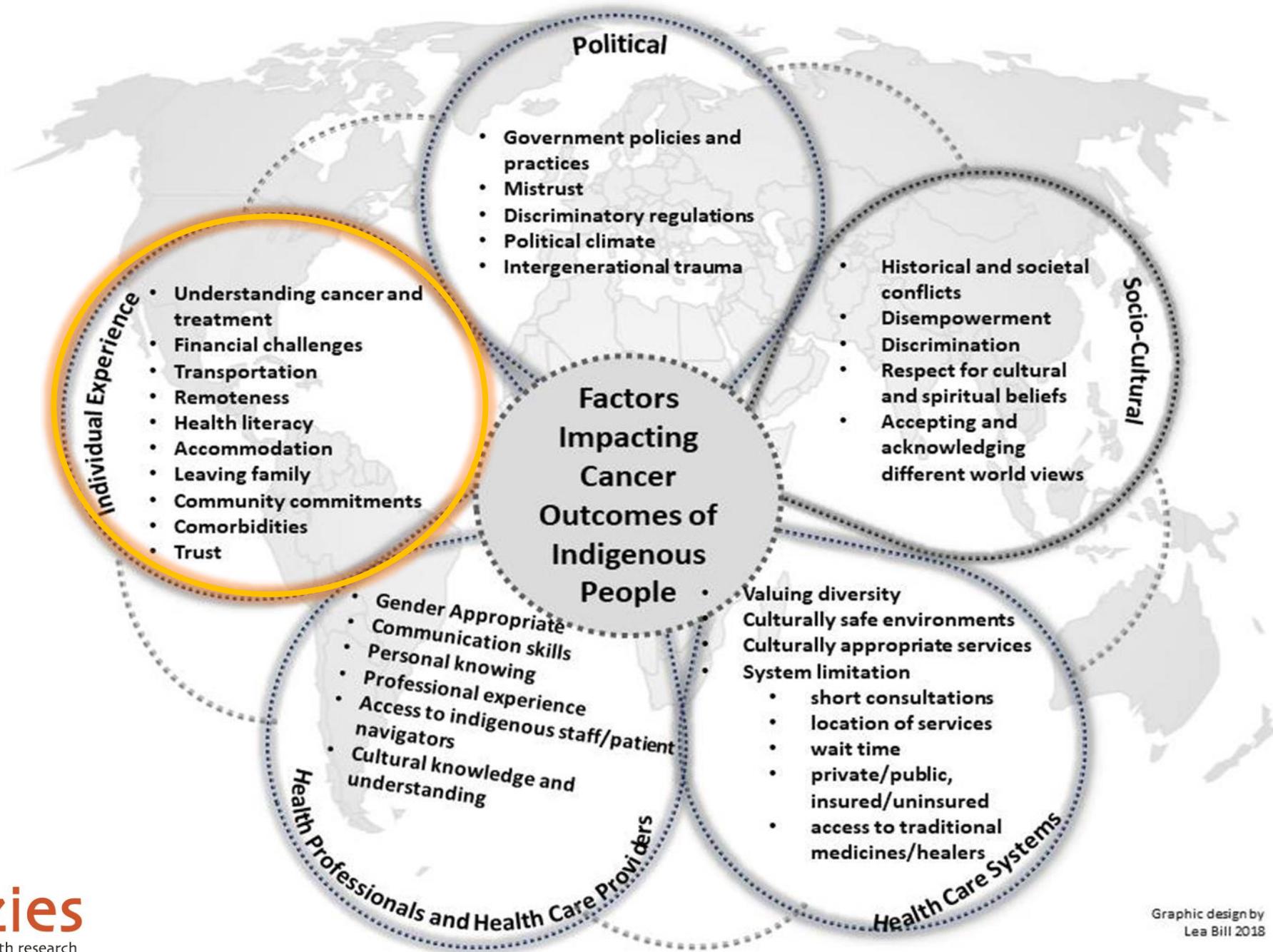
- Improve knowledge, attitudes and understanding of cancer by individuals, families, carers and community members (across the continuum)
- Focus prevention activities to address specific barriers and enablers to minimise cancer risk for Aboriginal and Torres Strait Islander peoples
- Increase access to and participation in cancer screening and immunisation for the prevention and early detection of cancers
- Ensure early diagnosis of symptomatic cancers
- Ensure Aboriginal and Torres Strait Islander people affected by cancer receive optimal and culturally appropriate treatment, services, and supportive and palliative care
- Ensure families and carers of Aboriginal and Torres Strait Islander people with cancer are involved, informed, supported and enabled throughout the cancer experience
- Strengthen the capacity of cancer related services and systems to deliver good quality, integrated services that meet the needs of Aboriginal and Torres Strait Islander people.



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# Supportive care needs



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# Why Assess 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
- *Cultural differences* in Indigenous people's: perceptions of cancer, information needs, decision-making style and coping with illness
- Support needs may vary across cultures



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# Assessment of unmet support needs?

- What tools are used?
- Are these tools suited to assess the needs of Indigenous cancer patients?
- Accurate measurement is important to provide a clear picture of the components and extent of unmet support needs



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# Supportive Care Needs Study

## Stage 1

Face & content validation- SCNS-SF34 and identification of additional cultural items

**Outcomes:** SCNS-34 did not adequately address some of the language, culture and specific needs of Indigenous people with cancer.

Initial version SCNAT-IP consisted of 39 items + 1 open-ended item

Garvey G, et al., *Development of a supportive care needs assessment tool for indigenous people with cancer*: BMC Cancer: 2012.

## Stage 2

Used this tool in 4 large hospitals (n=248)

**Outcomes:** Most common moderate/high unmet needs:

- Money worries (22%)
- Concerns about the worries of those close to you (15%)
- Worry about the illness spreading (14%)
- Feeling sad or down (13%)

Garvey G et al., *Psychometric properties of an Australian Supportive Care Needs Assessment Tool for Indigenous People with cancer*: Cancer 2015.



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# Psychometric Properties of an Australian Supportive Care Needs Assessment Tool for Indigenous Patients With Cancer

Gail Garvey, MEd<sup>1</sup>; Vanessa L. Beesley, PhD<sup>2,3</sup>; Monika Janda, PhD<sup>3,4</sup>; Peter K. O'Rourke, PhD<sup>5</sup>;  
Vincent Y.F. He, BSc (Hons)<sup>1</sup>; Anna L. Hawkes, PhD<sup>3</sup>; Jacinta K. Elston, MPH<sup>6</sup>; Adele C. Green, PhD<sup>7,8</sup>;  
Joan Cunningham, ScD<sup>1</sup>; and Patricia C. Valery, PhD<sup>1</sup>



Cancer  
Volume 121, Issue 17, pages  
3018–3026, September 1,  
2015

**BACKGROUND:** There are significant disparities in cancer outcomes between Indigenous and non-Indigenous Australians. Addressing the unmet supportive care needs of Indigenous Australians with cancer is imperative to improve their health and quality of life. The current study was to test the psychometric properties of a supportive cancer care needs assessment tool (SCNAT-IP) with cancer. **METHODS:** The SCNAT-IP was administered to 248 Indigenous Australians of various cancer types and stages, and who received treatment in 1 of 4 Queensland hospitals. The data were analyzed using exploratory factor analysis to determine internal consistency and convergent validity to validated psychometric instruments (physical and psychological, hospital care, information and communication, practical and cultural). **RESULTS:** Exploratory factor analysis revealed four factors accounting for 68% of the variance. Internal consistency of the factors was acceptable. Convergent validity was supported. **CONCLUSIONS:** The SCNAT-IP is a valid and reliable measure of supportive care needs for Indigenous Australians with cancer. **Distress:** 2015; 17(17):3018-3026. doi:10.1002/cncr.29487

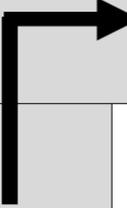
Initial support for the SCNAT-IP, as a measure of multiple supportive care needs domains specific to Indigenous Australians with cancer undergoing treatment.

**Final Tool:**  
**Supportive care needs assessment tool for Indigenous People**

- ★ Physical and psychological (11 items)
- ★ Hospital needs (4 items)
- ★ Information and communication (6 items)
- ★ Practical and cultural (5 items)



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

	<b>If you answered <u>YES</u>, How much help did you need?</b>			
	<u>Satisfied</u> with help received	Needed a <u>little</u> <u>more</u> help	Needed <u>some</u> <u>more</u> help	Needed <u>a lot</u> <u>more</u> help

<b>1</b> Physical pain (e.g., hurt)	No <input type="checkbox"/>	Yes <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
<b>2</b> Feeling tired (e.g., sleeping OK)	No <input type="checkbox"/>	Yes <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
<b>10</b> Keeping you strong in your spirit (e.g., staying positive)	No <input type="checkbox"/>	Yes <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
<b>21</b> Having an Indigenous person to interpret and help with communication with health professionals	No <input type="checkbox"/>	Yes <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
<b>22</b> Finding a place to stop or stay while receiving treatment	No <input type="checkbox"/>	Yes <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

# Supportive Care Needs Study

## Stage 3 – Feasibility

Pilot testing of the SCNAT-IP in usual care  
Developed a training manual and trained cancer care staff to use the tool

**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.

Patients reported: Liked being asked about needs; Felt “*empowered*”; Felt heard

*‘It’s made me feel good that someone’s showing interest, you know.’ (Male, Head and Neck Cancer, Aged 45)*

*‘Yes she [the social worker] gave me some information because of some of my answers. I don’t think I would have got that information otherwise.’ (Female, Gynaecological cancer, Aged 51 )*

Garvey G, et al., [Indigenous cancer patient and staff attitudes towards unmet needs screening using the SCNAT-IP](#). Support Care in Cancer 2015

Thewes B, .....Garvey G. [Routine screening of Indigenous cancer patients' unmet support needs: a qualitative study of patient and clinician attitudes](#). Int J Equity Health. 2016.

## Stage 4

National implementation and training of staff to use the tool

In progress

Funded by Cancer Australia

# Tumour Specific Optimal Cancer Care Pathways (OCPs)

- OCPs - optimal cancer care for **specific tumour types**.
- OCPs map the **patient journey**, with the aim of fostering an understanding of the whole pathway and its distinct components to **promote quality cancer care and patient experiences**.
- **Specific steps, or critical points** along the care pathway are identified as well as the **recommended care at each point**.

## Optimal care pathway for people with lung cancer

### Quick reference guide



Please note that not all patients will follow every step of this pathway:

#### Step 1

Prevention and early detection

##### Prevention:

- All current smokers should be offered advice to quit smoking. **Effective strategies include:**
  - advice on quitting smoking and structured interventions by health professionals
  - individual or group counselling programs such as Quit (refer to [www.quit.org.au](http://www.quit.org.au))
  - nicotine replacement therapy and other pharmacological agents.

##### Risk factors:

- Lifestyle factor:
    - tobacco smoking
  - Environmental factors:
    - passive smoking
    - radon exposure
    - occupational exposure (such as asbestos and diesel exhaust)
    - air pollution
  - Personal factors:
    - age
    - family history of lung cancer
    - chronic lung disease
- Early detection:** No form of population screening has been shown to improve lung cancer outcomes.

#### Step 2

Presentation, initial investigations and referral

##### Signs and symptoms:

The following unexplained or persistent signs or symptoms lasting more than three weeks (or less than three weeks in people with known risk factors) require urgent referral for a chest x-ray: unexplained haemoptysis or persistent new/changed cough, chest/shoulder pain, breathlessness, hoarseness, weight loss, finger clubbing, unresolved chest infection, abnormal chest signs, features suggestive of metastasis from a lung cancer, and signs of pleural effusion.

**Persistent haemoptysis and/or signs of superior vena cava obstruction require urgent referral to a specialist linked to a multidisciplinary team. Massive haemoptysis and/or signs of stridor require immediate referral to an emergency department.**

##### General/primary practitioner investigations:

Chest x-ray; if cancer is suspected refer immediately. Contrast spiral computed tomography (CT) of the chest and upper abdomen if the chest x-ray is clear and symptoms persist. Immediate referral if the CT is abnormal. Test results should be provided to the patient within one week. The first specialist appointment should take place within two weeks of referral.

**Referral:** Refer all patients with suspected or proven lung cancer to a specialist linked with a multidisciplinary team.

##### Communication – lead clinician to:

- explain to the patient/carer who they are being referred to and why
- support the patient and carer while waiting for specialist appointments.

#### Step 3

Diagnosis, staging and treatment planning

**Diagnosis:** May be obtained from bronchoscopy including endobronchial ultrasound (EBUS), CT-guided biopsy, excisional biopsy or biopsy of metastasis, or sputum cytology (rarely).

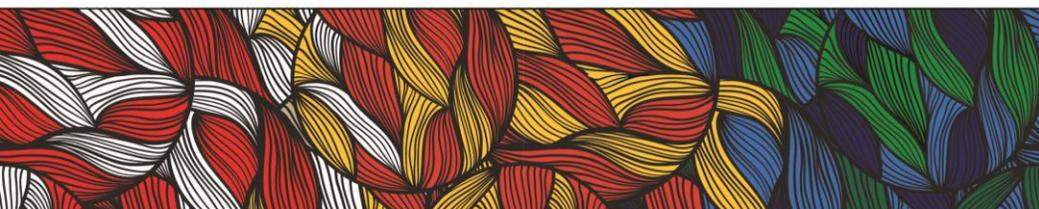
**Staging:** Radiological staging based on CT scan of the chest and upper abdomen and one of the brain. Other tests to confirm the cancer stage may include bronchoscopy, thoracoscopy, thoracotomy, mediastinoscopy, endobronchial/oesophageal ultrasound (EBUS/EUS) and nuclear medicine tests including bone and positron emission tomography (PET) scans, with biopsies to establish pathology.

**Treatment planning:** All patients with suspected or proven lung cancer should be discussed by a multidisciplinary team before treatment begins.

**Research and clinical trials:** Consider enrolment where available and appropriate.

##### Communication – lead clinician to:

Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals or organisations.



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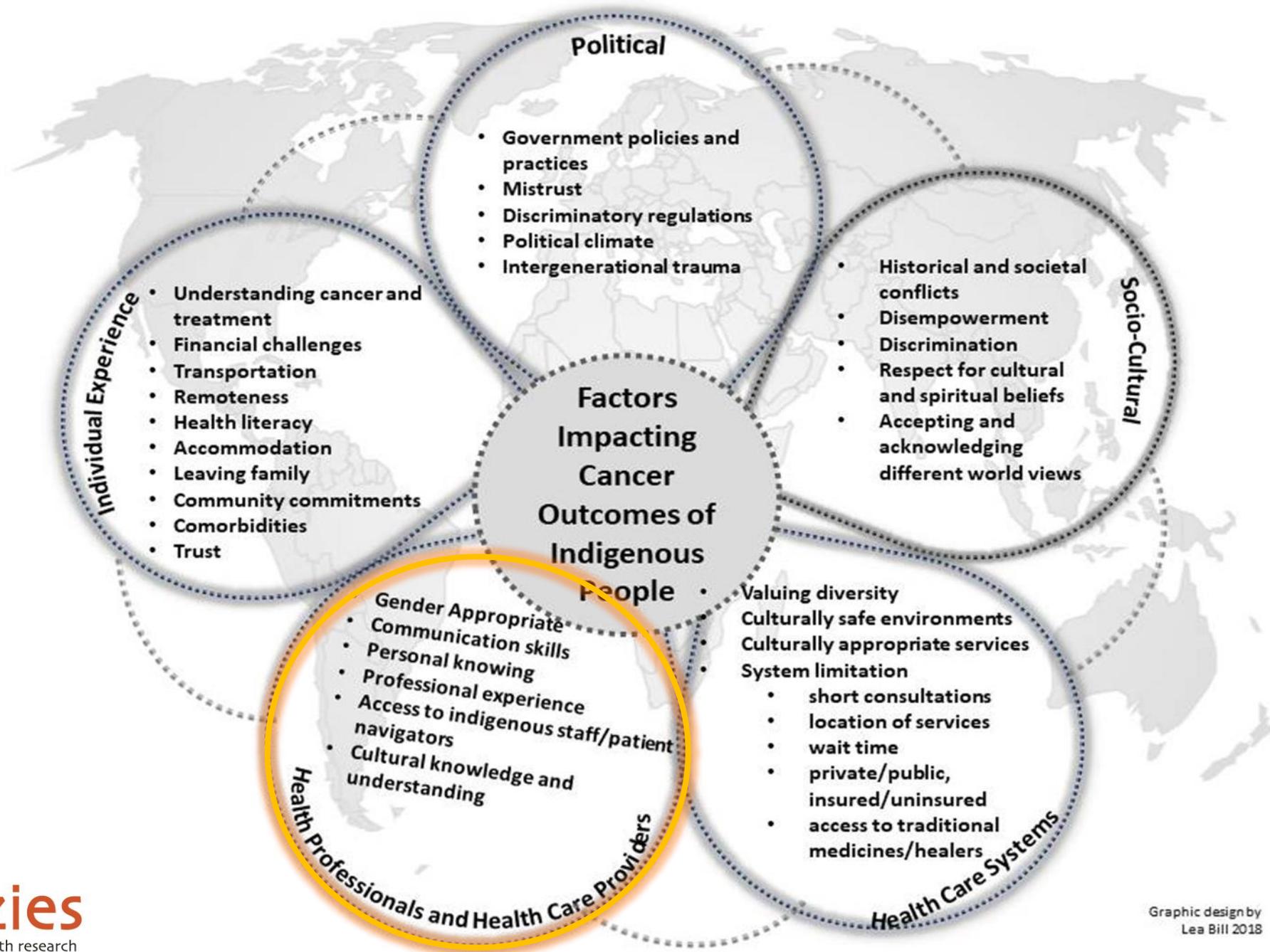
# Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer *Draft*

The purpose of the OCP for Aboriginal and Torres Strait Islander people with cancer is to complement the tumour-specific pathways to facilitate the delivery of culturally safe and competent care.

For health services to be effective in Aboriginal and Torres Strait Islander health they must operate in ways that show both understanding of and respect for Aboriginal and Torres Strait Islander culture.

This document focuses on the aspects of the cancer care pathway that need to be responsive to the needs of Aboriginal and Torres Strait Islander people with cancer.

Themes covered include for example: -healthcare environment; relationship building with the local community; cross-cultural communication; men's and women's business; health literacy; culturally appropriate resources.



# Bowel cancer and bowel cancer screening in Australia

National Indigenous Bowel Screening Project funded by the Commonwealth Department of Health



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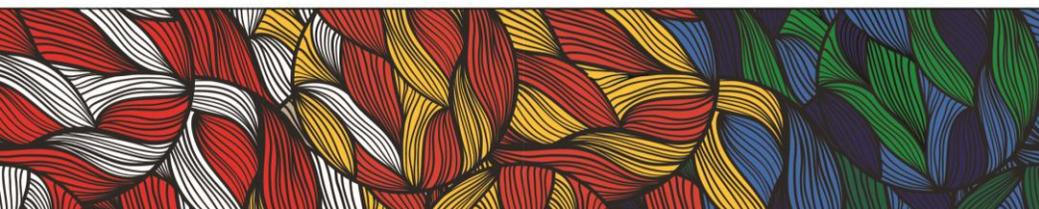
**Australia has one of the highest rates of bowel cancer in the world.**

Around 1 in 23 Australians will develop bowel cancer during their lifetime.

3<sup>rd</sup> most common cancer among Indigenous Australians

## **National Bowel Cancer Screening Program invites people**

- via a mail out
- aged 50 - 74 (without symptoms)
- free, test at home



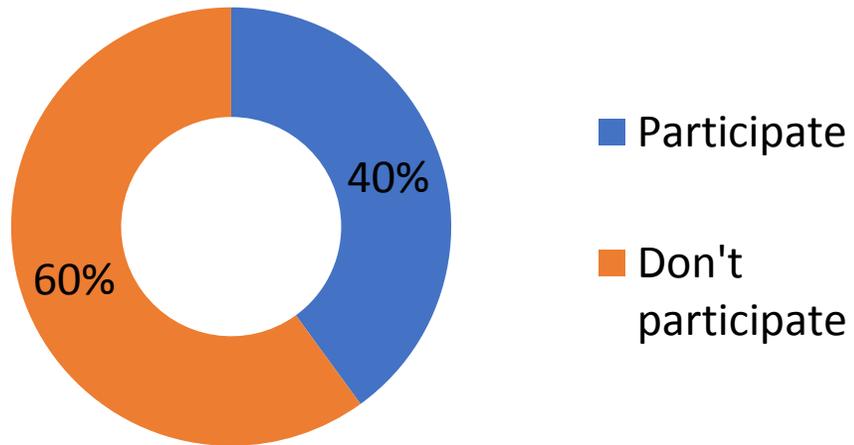
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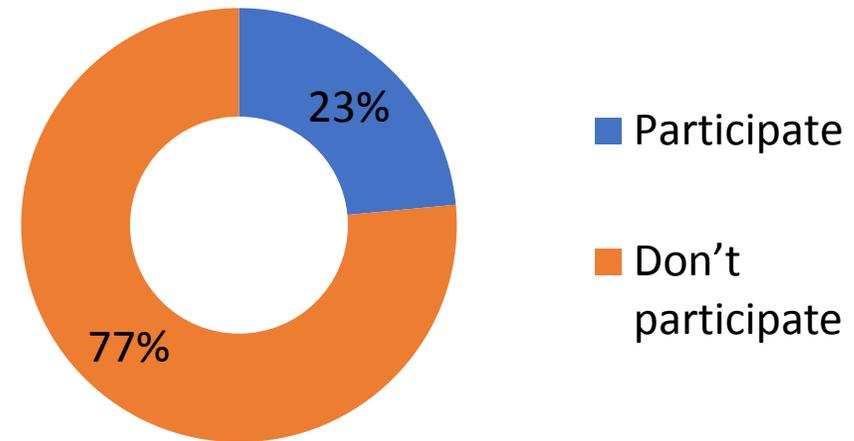


# NBCSP population participation

General



Indigenous (estimated )

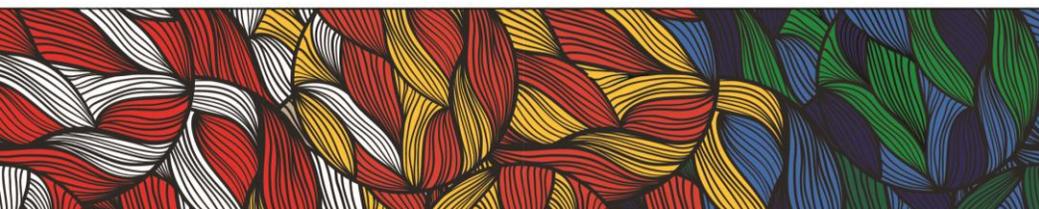


Reference: Australian Institute of Health and Welfare 2017. National Bowel Cancer Screening Program: monitoring report 2017. Cancer series no.104. Cat. no. CAN 103. Canberra: AIHW.



# Barriers to participation

- There is **limited awareness** about bowel cancer and the benefits of bowel screening in the Australian population generally.
- Bowel screening has **not been widely seen as a primary health care** role.
- Nature of the **test** and its **distribution, shame** associated.



# An Alternative Pathway to deliver screening for Indigenous Australians

- Give out the **kits at PHC centres** - from trusted health professional
- Embed bowel screening into **routine practice** at PHC centres
- **Raise awareness** among **PHC professionals** about bowel screening
- **Build the skills, knowledge and confidence of PHC professionals to talk to their clients**
- Provide **resources with key messages** about bowel screening **that work for Aboriginal and Torres Strait Islander people.**



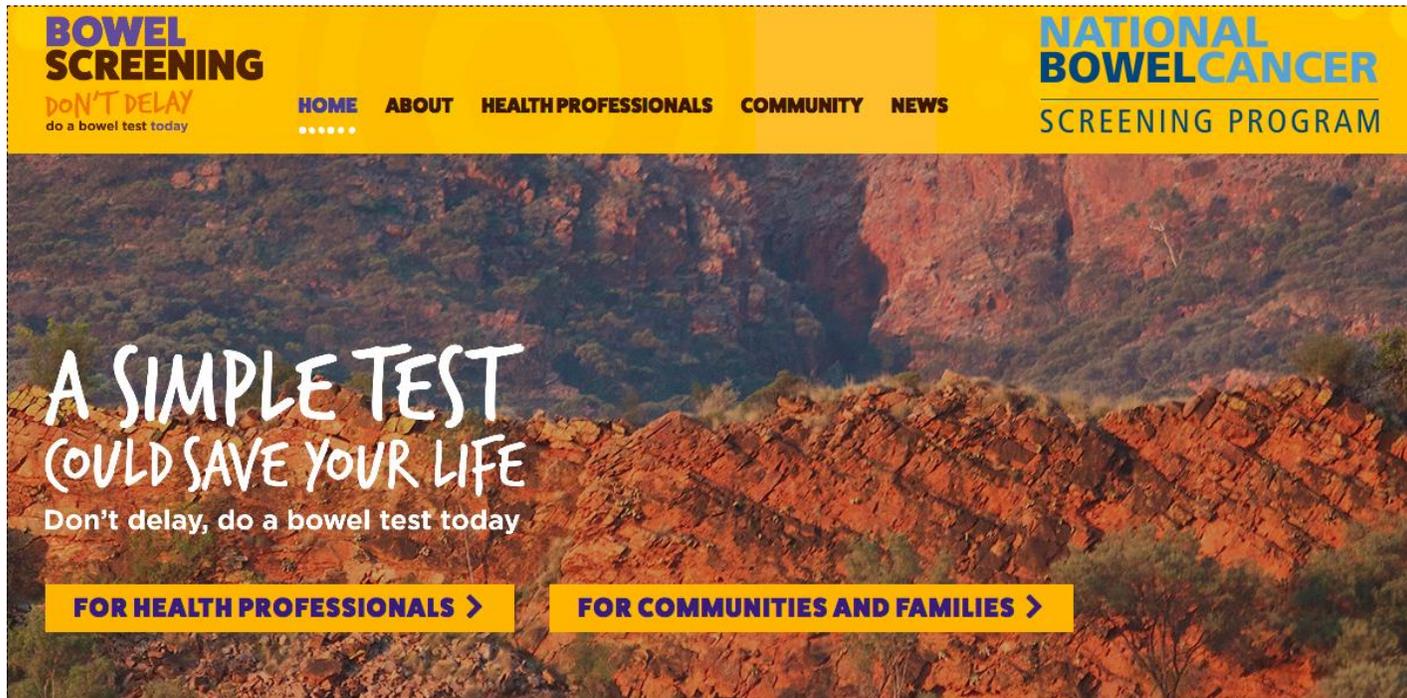
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# Resources

www.indigenousbowelscreen.com.au



**BOWEL SCREENING**  
DON'T DELAY  
do a bowel test today

HOME ABOUT HEALTH PROFESSIONALS COMMUNITY NEWS

**NATIONAL BOWEL CANCER SCREENING PROGRAM**

**A SIMPLE TEST COULD SAVE YOUR LIFE**  
Don't delay, do a bowel test today

**FOR HEALTH PROFESSIONALS >** **FOR COMMUNITIES AND FAMILIES >**

## HEALTH PROFESSIONALS

Your clients will probably not raise the subject of bowel screening so it is important that you do. Research has shown that many Aboriginal and Torres Strait Islander people would like their doctor, nurse or health worker to talk to them about it.

On this page are resources you can use to start the bowel screening conversation or refresh your knowledge about the NBCSP, bowel cancer and bowel screening.

### Resources for health workers and nurses



#### NEW Online training module

All you need to know to promote bowel screening with your patients.

[READ MORE](#)



#### Information sheet for health workers

A resource for health workers for talking about the test.

[READ MORE](#)



#### APNA webinar

Webinar on bowel screening from the Australian Practice Nurses Association.

[READ MORE](#)



#### Making Tracks - SA Health

Bowel cancer resources 'Making Tracks' produced by SA Health which includes a video and flip chart.

[READ MORE](#)



#### Webinar: How to encourage patients to do a bowel screening test

Gain skills, knowledge and confidence to talk about the tricky subject of bowel cancer and bowel screening.

[READ MORE](#)

## HEALTH PROFESSIONALS

### Resources for GPs

### Resources for health workers and nurses

### Resources to use with patients



NOVEMBER 13, 2017

#### Webinar: How to encourage your patients to do a bowel screening test

Join Professor Gail Garvey, Dr Brad Murphy and Peggy Manton-Williams for this webinar that aims to give health professionals skills, knowledge and confidence to encourage Aboriginal and Torres Strait Islander patients to bowel screen and participate in the National Bowel Cancer Screening Program (NBCSP).

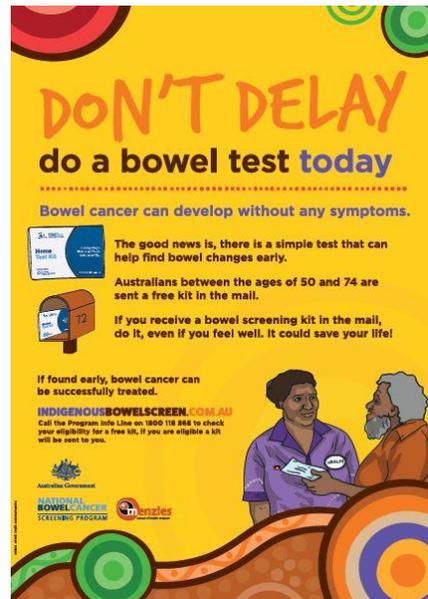
[LEARN MORE](#)

When I turned 50 my doctor advised me to have a full health check including a bowel screen. Initially I felt fear but I went ahead because it was the only way to be sure.

—PAUL  
ABORIGINAL COMMUNITY MEMBER



# Resources for consumers



Poster



MAY 4, 2017

#### Poster

Poster to raise awareness about bowel screening.

[READ MORE](#)



MAY 4, 2017

#### Check 'em – music video

Muludja community spreads the word of doing the test.

[READ MORE](#)



MAY 4, 2017

#### Postcard

Yarn about bowel screening.

[READ MORE](#)



Postcard



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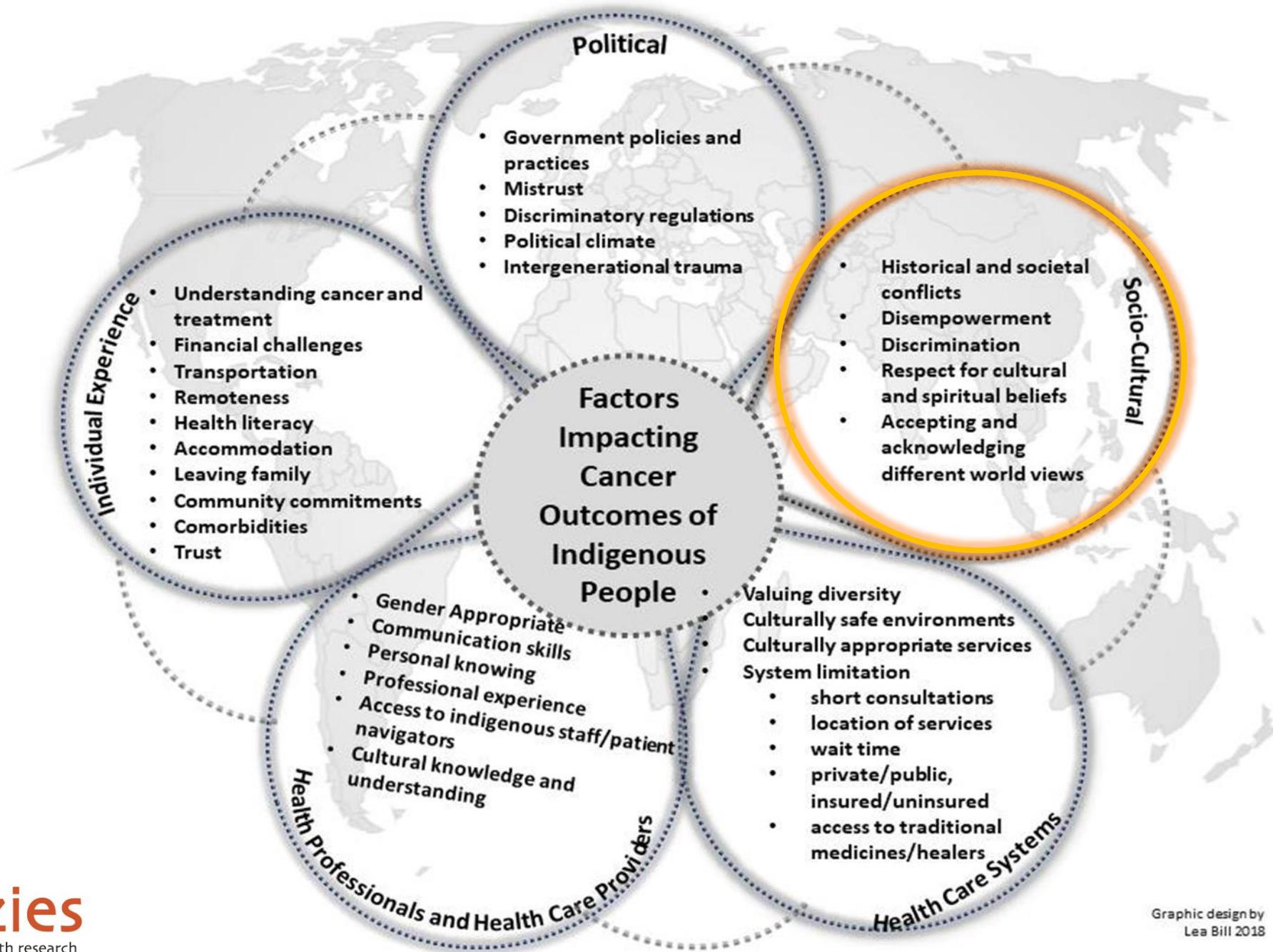
# Training and social media resources



Online training module



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# Family and cultural perspectives

## CHECK 'EM – MUSIC VIDEO



Young and old join in at Muludja community in the Kimberley to spread the story of staying healthy for your family and doing the bowel screening test. It's about caring for country and caring for your family, and how country and family nurture our health.

4 mins 25 secs



[BACK TO COMMUNITY](#)

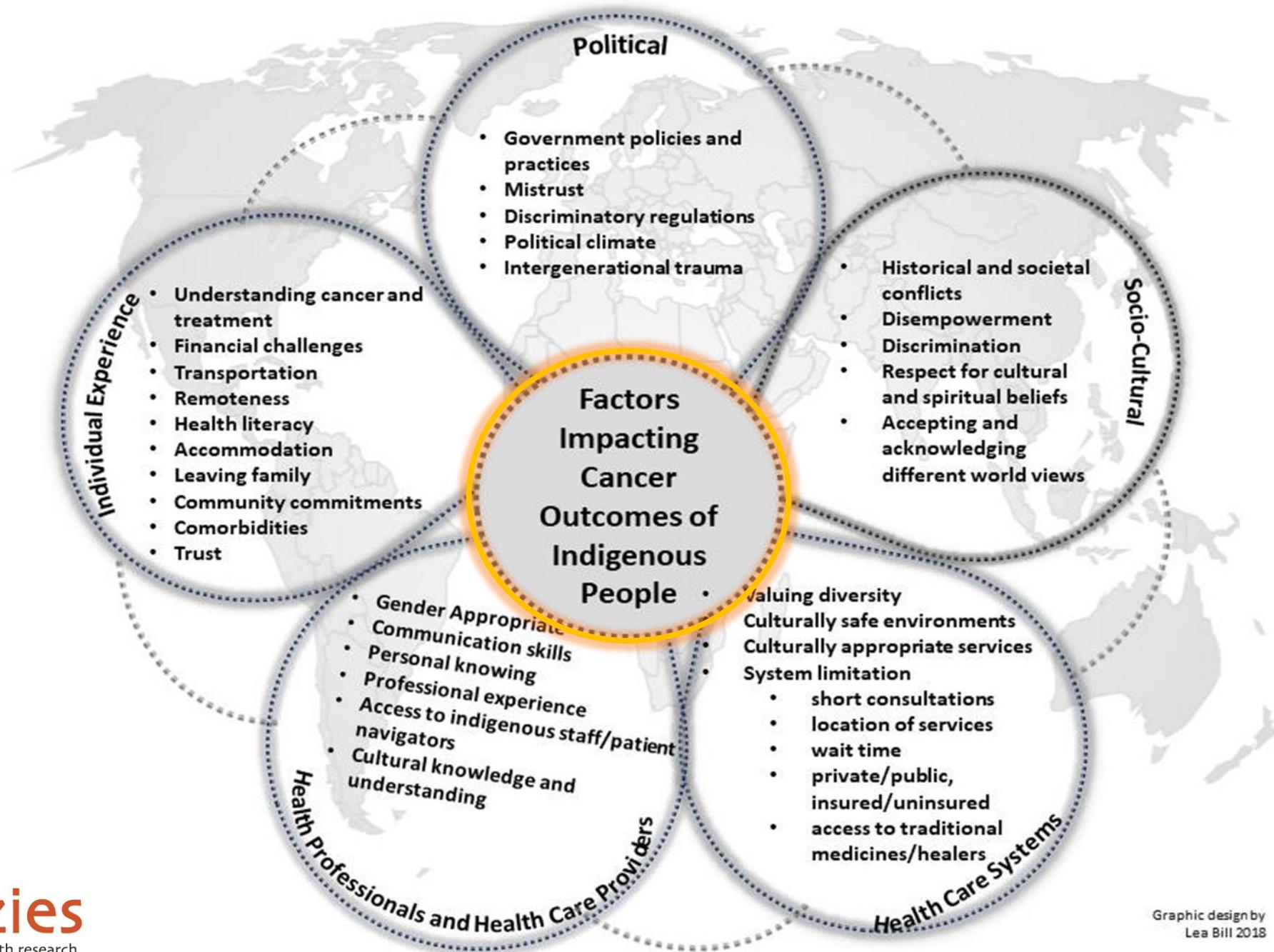
[BACK TO HEALTH PROFESSIONALS](#)



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# Cancer Ambassadors



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# Acknowledgements

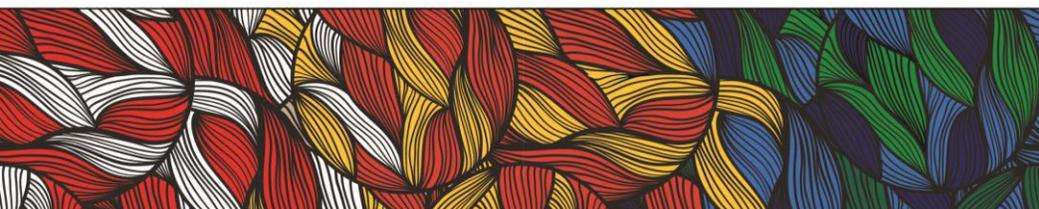


**Australian Government**  
**Australian Research Council**



**Australian Government**  
**National Health and Medical Research Council**

**Thanks also to our study participants, cancer care staff and collaborating organisations**



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