Kulay Kalingka Study

Aboriginal and Torres Strait Islander National Cancer Control Indicators (NCCI) Data Report

Kulay
Kalingka

Statement of Acknowledgement

Cancer Australia acknowledges Aboriginal and Torres Strait Islander people as the Traditional Custodians of Country throughout Australia. We pay our respects to Elders, past and present. We celebrate the ongoing connections of Aboriginal and Torres Strait Islander peoples to Country, culture, community, family and tradition and recognise these as integral to health, healing and wellbeing.

Cancer Australia acknowledges great diversity among Aboriginal and Torres Strait Islander peoples, and the contribution of the many voices, knowledge systems and experiences that guide all efforts to create a culturally safe and responsive cancer system that is equitable to all.

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The Kulay Kalingka Study: Aboriginal
and Torres Strait Islander National Cancer
Control Indicators (NCCI) Data Report
is funded by Cancer Australia.

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Background

Aboriginal and Torres Strait Islander peoples maintain the oldest living cultures in the world, with diverse languages, histories, and cultures.[1-3] The cultures of Aboriginal and Torres Strait Islander peoples remain strong, despite ongoing dispossession and dislocation from Country, culture, languages and families, as a result of colonisation.

Aboriginal and Torres Strait Islander people experience a higher burden of disease than other Australians, including of cancer. Cancer is the leading cause of death and a leading contributor to the burden of disease for Aboriginal and Torres Strait Islander peoples.[4] While cancer among Aboriginal and Torres Strait Islander people is receiving growing attention, there remains a lack of evidence on the experiences, needs, and care pathways for Aboriginal and Torres Strait Islander people diagnosed with cancer, and their families.[5] A key limitation to generating such evidence is the lack of data and information from Aboriginal and Torres Strait Islander peoples about cancer awareness, diagnosis, treatment, care pathways, and experiences.[6,7]

Cancer incidence is approximately 14% higher for Aboriginal and Torres Strait Islander people compared to other Australians,[8] and lung, breast, colorectal, prostate and head and neck cancers are the most common.[4] Moreover, Aboriginal and Torres Strait Islander people with cancer are more likely to have been diagnosed with advanced stage cancer, at a younger age, and require hospitalisation. They are less likely to have received optimal and timely treatment.[4] Cancer mortality is 45% higher for Aboriginal and Torres Strait Islander people than for other Australians, and this gap is widening over time.[8]

Key modifiable risk factors for cancer morbidity and mortality include tobacco smoking, alcohol consumption, obesity, and sun exposure.[8] Other upstream causal factors that may directly or indirectly affect cancer risk for Aboriginal and Torres Strait Islander people include experiences of discrimination and racism,[9-11] socioeconomic disadvantage, and access to cancer services including screening and treatment services.[12,13]

Cancer places a heavy burden on patients, families, carers, and communities. The Cancer Australia National Aboriginal and Torres Strait Islander Cancer Framework 2015, together with the Optimal Care Pathway (OCP) for Aboriginal and Torres Strait Islander people with cancer, guides those working to improve cancer outcomes and reduce inequities across the cancer care pathway, from pre-diagnosis through to survivorship and end of life for Aboriginal and Torres Strait Islander peoples.[14-16]

In 2023, Cancer Australia released the Australian Cancer Plan, which recognised the importance of improving cancer outcomes for Aboriginal and Torres Strait Islander peoples,[17] and was released alongside the National Aboriginal Community Controlled Health Organisation (NACCHO) Aboriginal and Torres Strait Islander Cancer Plan, which aims to provide a tailored approach to meeting the needs of Aboriginal and Torres Strait Islander people with cancer and their families.[18]

The National Aboriginal and Torres Strait Islander Cancer Control Indicators (NCCI) have been developed by Cancer Australia, with the aim of monitoring system performance across the cancer care pathway for Aboriginal and Torres Strait Islander people.[14] There are 33 indicators in total, assessed through 45 measures. These measures include 16 that are currently reported on and 29 for which there is no existing data and/or further progress for data development is required to allow for reporting.

Ensuring community and relational accountability and addressing ongoing cancer awareness, cancer care and improved outcomes, requires the ability to report on indicators for Aboriginal and Torres Strait Islander people and understand their attitudes, beliefs, and experiences of cancer. However, data on many measures for the NCCI for Aboriginal and Torres Strait Islander people are lacking. To overcome this lack of data and information, the Kulay Kalingka study was developed and undertaken to collect the required data and provide information for monitoring within the NCCI system.

The Kulay Kalingka study aims to provide information on the NCCI that describes Aboriginal and Torres Strait Islander peoples' beliefs about cancer, experiences with cancer care and treatment, and to undertake further analyses to understand what improves cancer awareness, cancer care experiences and outcomes for Aboriginal and Torres Strait Islander people with cancer. Importantly, this includes an examination of how cancer care experiences impact families. Findings will be used to inform Cancer Australia priority areas.

The Kulay Kalingka Study acknowledges and recognises that this report and data for the NCCI from this report, are a result of the contributions of many Aboriginal and Torres Strait Islander peoples who are at the heart of this research. We also acknowledge Cancer Australia as the funder for this project.

Methods

Study design: The Kulay Kalingka Study is a national cohort study that aims to understand attitudes, beliefs, and experiences of cancer for Aboriginal and Torres Strait Islander people. The study sought and received participation via two modes: partnering with community organisations to recruit participants, and from participants of Mayi Kuwayu: the National Study of Aboriginal and Torres Strait Islander Well-being.[19,20]

Priority: This study arose from community-identified need as well as from a Cancer Australia priority: to better understand and monitor progress of the NCCI for Aboriginal and Torres Strait Islander people across the cancer care pathway.

Governance: The Kulay Kalingka study is governed by Aboriginal and Torres Strait Islander peoples. Aboriginal and Torres Strait Islander peoples led and were involved in all project phases of the study from conception, governance, questionnaire development, testing, and participation, through to compilation of analysis and interpretation. More information on the study development has been published here.[20]

Eligibility: Aboriginal and Torres Strait Islander people were eligible to participate if they were aged ≥18 years and:

- Were participants of the Mayi Kuwayu Study who consented to being recontacted by the project team for future research (Approximately 600 and 2,400 Mayi Kuwayu participants that self-reported ever having a doctor-diagnosed cancer or never having a cancer diagnosis, respectively), and
- Were people with or without a prior cancer diagnosis in study partner Aboriginal and Torres Strait Islander communities from saltwater, freshwater, desert and Island groups, and living across urban, regional and remote Australia.

Respondents who were younger than 18 years at the time of the survey and/or were not Australian residents at the time of the survey were excluded. Respondents of the Ever Cancer survey who did not provide any information about their cancer diagnosis or treatment were excluded.

Participants were provided plain-language information sheets about the study and joined the study by completing a study questionnaire and providing informed consent. Eligible people from Mayi Kuwayu received postal invitations to join the study, while those in partner communities received invitations through community organisations. Participants were advised that they were free to withdraw from the study at any time.

Data: All data presented in this report are self-reported and were derived from the study questionnaire.

Analysis: Descriptive statistics are used to describe the cohort by selected demographic variables, and for each NCCI across the seven priority areas for people diagnosed with cancer and those without a cancer diagnosis.

This report includes the crude (sample estimate) prevalence for each indicator and represents the prevalence within the sample (participants), and is not intended to be representative of the whole Aboriginal and Torres Strait Islander population. The data tables provided as supplementary materials to this report contain the crude statistics for each indicator included in the report. Suppression techniques were used where cell counts were less than ten to protect confidentiality of participants, except in the case of missing cells which do not pose a risk of identification.

This report has been guided by the Thiitu Tharrmay Reference Group to ensure data is interpreted appropriately.

Study participation

Data collection occurred between 11 July 2023 – 23 January 24. Overall, 2,103 Aboriginal and Torres Strait Islander adults participated in the study; 588 participants had been diagnosed with cancer and 1,515 were without a cancer diagnosis. Key characteristics of the cohort are described in Table 1.

As shown in Table 1, 86.6% of participants identified as Aboriginal, 6.0% as Torres Strait Islander and 6.4% as both Aboriginal and Torres Strait Islander. Of those diagnosed with cancer, 13.9% were Torres Strait Islander and 13.9% were Aboriginal and Torres Strait Islander. The prevalence of cancer diagnosis in both Torres Strait Islander and Aboriginal and Torres Strait Islander peoples was higher than the respective prevalences in the population.

Among those diagnosed with cancer, there was similar representation from men and women (48.3% and 44.4%, respectively), while among those without a cancer diagnosis there was a higher percentage of women than men (58.0% and 37.3%).

Those diagnosed with cancer were older on average than those without a cancer diagnosis (mean age: 53.8 years, SD 15.8 vs. 50.4 years, SD 17.1).

Table 1. Characteristics of the Kulay Kalingka Cohort by cancer diagnosis.

	Total n=2,103 n(%)	**People diagnosed with cancer n=588 n(%)**	**People without a cancer diagnosis n=1,515 n(%)**
Aboriginal and/or Torres Strait Islander identity			
Aboriginal	1822(86.6%)	421(71.6%)	1401(92.5%)
Torres Strait Islander	127(6.0%)	82(13.9%)	45(3.0%)
Aboriginal and Torres Strait Islander	135(6.4%)	82(13.9%)	53(3.5%)
Missing	19(0.9%)	3(0.5%)	16(1.1%)
Gender			
Man	849(40.4%)	284(48.3%)	565(37.3%)
Woman	1140(54.2%)	261(44.4%)	879(58.0%)
Other/prefer not to say/missing	114(5.4%)	43(7.3%)	71(4.7%)
Age groups			
18-34	403(19.2%)	62(10.5%)	341(22.5%)
35-44	345(16.4%)	134(22.8%)	211(13.9%)
45-54	287(13.6%)	82(13.9%)	205(13.5%)
55-64	419(19.9%)	94(16.0%)	325(21.5%)
65+	540(25.7%)	176(29.9%)	364(24.0%)
Missing	109(5.2%)	40(6.8%)	69(4.6%)
Residential remoteness			
Major city	1101(52.4%)	310(52.7%)	791(52.2%)
Regional	881(41.9%)	221(37.6%)	660(43.6%)
Remote	27(1.3%)	11(1.9%)	16(1.1%)
Missing	94(4.5%)	46(7.8%)	48(3.2%)
Jurisdiction			
New South Wales	697(33.1%)	191(32.5%)	506(33.4%)
Victoria	225(10.7%)	94(16.0%)	131(8.6%)
Queensland	589(28.0%)	148(25.2%)	441(29.1%)
Northern Territory/South Australia	77(3.7%)	28(4.8%)	49(3.2%)
Western Australia	305(14.5%)	35(6.0%)	270(17.8%)
Tasmania	67(3.2%)	21(3.6%)	46(3.0%)
Australian Capital Territory	71(3.4%)	27(4.6%)	44(2.9%)
Missing	72(3.4%)	44(7.5%)	28(1.8%)

Priority Area 1: Cancer awareness and beliefs

Primary indicator(s): Recognition of symptoms (those diagnosed with cancer); awareness of signs and symptoms (those without a cancer diagnosis).

Secondary indicator(s): Beliefs about cancer risk, prevention and survivability.

1.1. Awareness of cancer signs and symptoms (Priority 1A)

Almost half (49.8%) of respondents diagnosed with cancer reported that they did not notice any cancer symptoms prior to their diagnosis, and 3.9% were unsure (Fig. 1).

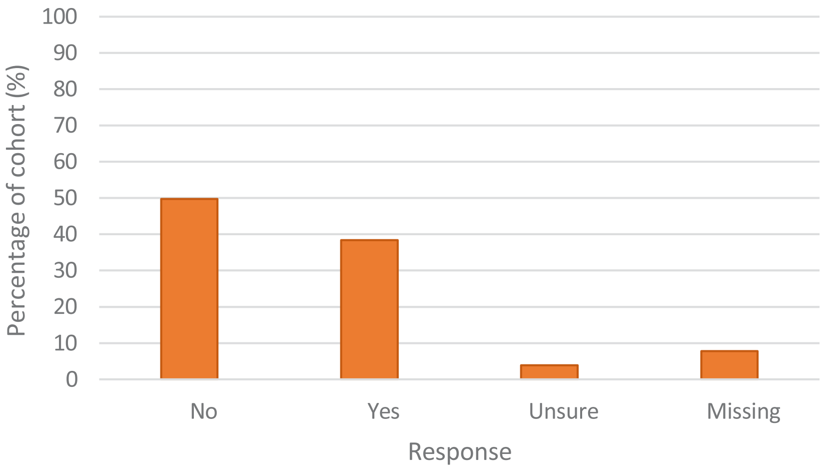

Fig. 1. The percentage of people diagnosed with cancer (n=588) who noticed cancer symptoms prior to their diagnosis.

Respondents without a cancer diagnosis were asked to identify potential signs or symptoms of cancer from a pre-defined list of 14 established cancer symptoms. The ten most common signs and symptoms recognised by this group were:

- Coughing up blood (78.1%)
- Changes to an existing mole (77.2%)
- A lump anywhere on your body (75.6%)
- Blood mixed through a bowel motion (75.3%)

- Changes on your skin (72.8%)
- Blood in urine (71.9%)
- Unexplained, significant weight loss (64.4%)
- A change in bowel habits that lasts more than 6 weeks (63.4%)
- Cough or hoarseness that does not go away (62.8%)
- Trouble swallowing (61.5%)

On average, respondents without a cancer diagnosis recognised 13 of the 22 pre-identified signs and symptoms of cancer (mean 13.1, standard deviation (SD) 7.3), and over one-quarter recognised between 20 to 22 signs and symptoms (Fig. 2).

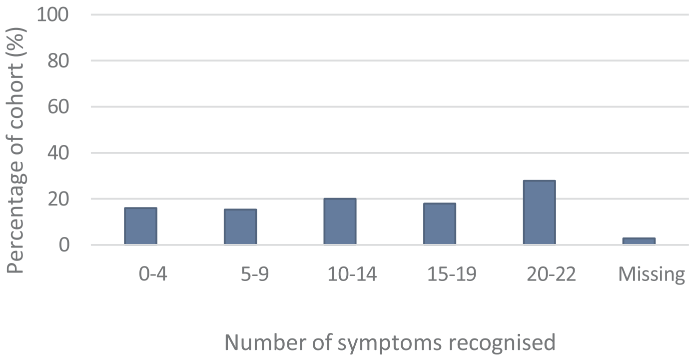

Fig. 2. Number of signs and symptoms of cancer recognised by those without a cancer diagnosis (n=1,515).

1.2. Beliefs about risk (Priority 1A)

Most participants believed that cancer is common among Aboriginal and Torres Strait Islander people (65.6% of those diagnosed with cancer and 59.0% of those without a cancer diagnosis) (Fig. 3). Furthermore, 21.9% of those diagnosed with cancer and 32.4% of those without a cancer diagnosis were unsure if cancer was common for Aboriginal and Torres Strait Islander peoples.

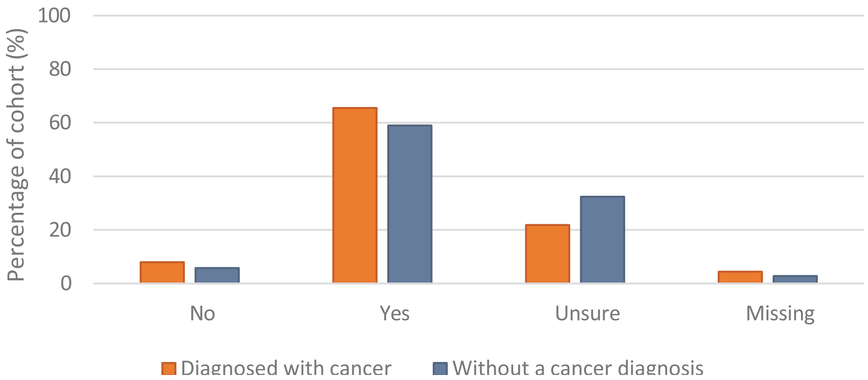

Fig. 3. Percentage of those diagnosed with cancer (n=588) and without a cancer diagnosis (n=1,515) that believe cancer is common in the Aboriginal and Torres Strait Islander population.

Most participants (7 in 10) were aware that cancer risk increases with age, however some participants disagreed with this statement (10.5% of those diagnosed with cancer and 5.4% of those without a cancer diagnosis) or were unsure (10.9% and 18.0%, respectively) (Fig. 4).

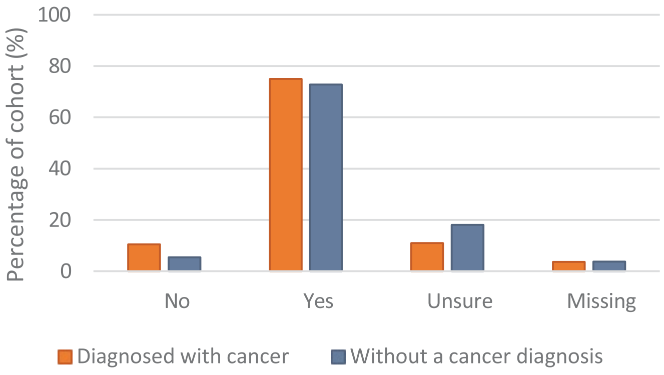

Fig. 4. Percentage of those diagnosed with cancer (n=588) and without a cancer diagnosis (n=1,515) that believe the risk of developing cancer increased with increasing age.

The majority of participants believed that you could develop cancer without having symptoms present (82.5% of those diagnosed with cancer and 78.7% of those without a cancer diagnosis). For respondents diagnosed with cancer, 9.4% disagreed and 4.6% were unsure of this statement. For those without a cancer diagnosis, 2.7% disagreed and 14.8% were unsure (Fig. 5)

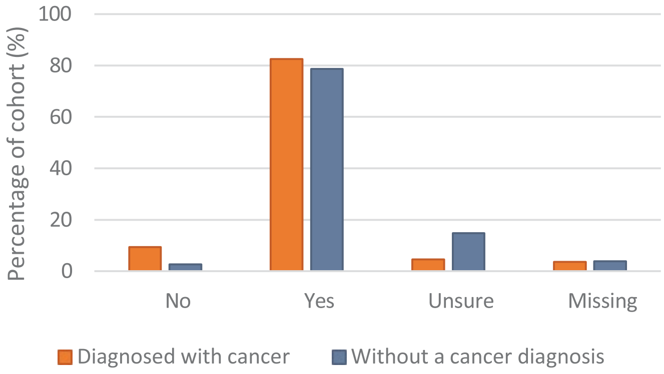

Fig. 5. Percentage of those diagnosed with cancer (n=588) and without a cancer diagnosis (n=1,515) who believed that it was possible to develop cancer without symptoms.

1.3. Beliefs about prevention (Priority 1B1)

Only participants without a cancer diagnosis were asked about their beliefs about cancer prevention. Among these participants, the majority agreed (42.2%) or strongly agreed (25.5%) with the statement that there are things that individuals can do to reduce their risk of developing cancer (Fig. 6). Approximately 10% disagreed (6.9% disagreed and 3.2% strongly disagreed) with this statement and 18.7% were unsure.

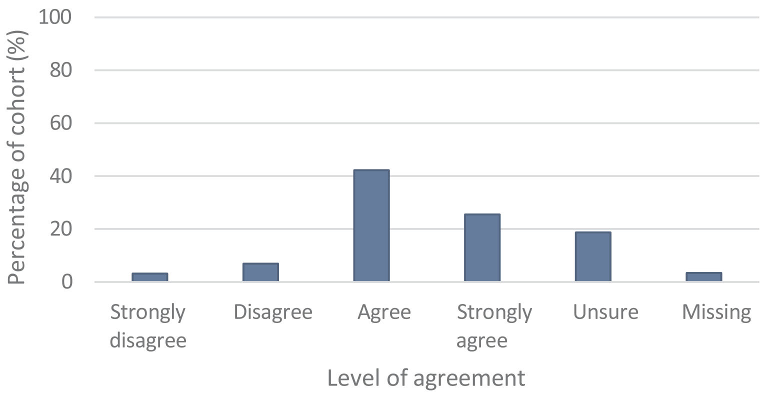

Fig. 6. The level of agreement that individuals can do things to prevent cancer among those without a cancer diagnosis (n=1,515)

1.4. Beliefs about survivability (Priority 1B2)

As shown in Fig. 7, most participants either agreed (37.2% of those diagnosed with cancer and 48.6% of those without a cancer diagnosis) or strongly agreed (42.3% and 24.8%, respectively) with the statement that cancer is survivable. Fourteen percent of participants with cancer disagreed or strongly disagreed with the statement, as did 6.4% of those without a cancer diagnosis. Among those without a cancer diagnosis, 16.8% were uncertain. It is important to note that the survey for people with a cancer diagnosis did not include the 'unsure' response option, and therefore results between the two cohorts are not directly comparable.

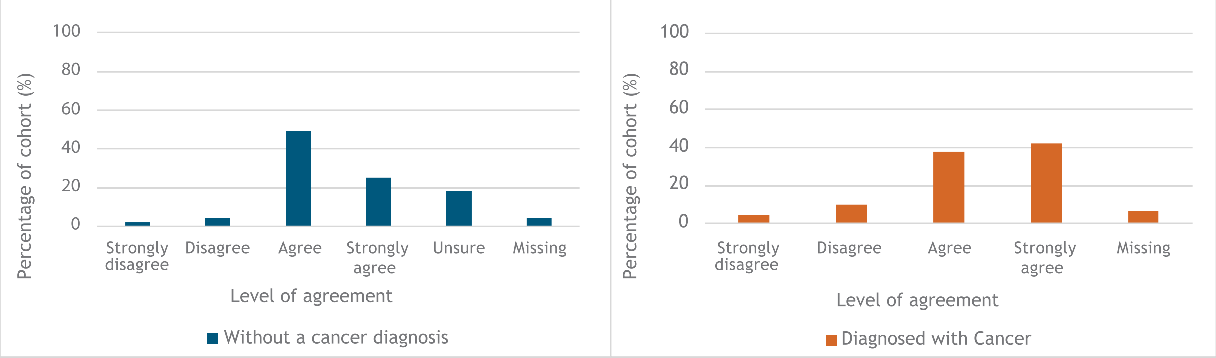

Fig. 7. Percentage of those diagnosed with cancer (n=588) and without a cancer diagnosis (n=1,515) that believe cancer is survivable.

Priority Area 2: Prevention and risk factor awareness

Primary indicator(s): Awareness of risk and protective factors, prevention, and risk reduction activities.

2.1. Awareness of protective factors and preventive/risk reduction activities (Priority 2A)

Respondents diagnosed with cancer reported on secondary preventive and risk reduction activities that they had taken since their initial cancer diagnosis (Table 2). Over one-quarter of the participants reported that they did not make any changes at this time (29.8%). The most common preventative/risk reduction activities undertaken, selected from a defined list of 16 items, were improving diet (32.7%), cancer screening (22.1%), physical activity (19.9%) and changing eating habits (19.9), as shown in Fig. 8.

Table 2. Prevention and risk reduction activities undertaken by those since initial diagnosis of cancer.

Preventive activities undertaken since being diagnosed/treated for cancer	%
Improved diet*	32.7
Cancer screening	22.1
Physical activity	20.9
Changing eating habits*	20.9
Sought a healthy weight range	17.7
Completed a health check (e.g., “715” Aboriginal Health Check)	17.3
Decrease stress	15.8
Wore sunscreen	15.3
Quit cigarettes	14.6
House being smoke free	13.4
Cut down on alcohol	13.3
Quit alcohol	11.7
Participate in a health program	10.2

* Improved diet implies that people eat more healthily. Changed eating habits implies that some foods may or may not be consumed at all.

Those without a cancer diagnosis identified, from a defined list, factors that they believed were associated with reduced risk of cancer. They were also asked about preventive and risk reduction activities that they had undertaken in the past year. Results are presented in Table 3. The most common activities undertaken were improved diet (43.1%), completed a health check (40.1%) and increased physical activity (34.5%).

Table 3. Prevention/Risk Reduction factors and activities undertaken, participants without a cancer diagnosis (n=1,518)

Factors believed to be associated with decreased risk of cancer	%	Preventive/risk reduction activities undertaken in the past year	%
Being smoke free	80.3	Improved diet*	43.1
Undertaking cancer screening tests	78.0	Completed health check	40.1
House being smoke free	69.8	Increased physical activity	34.5
Being a healthy weight	68.2	Cut back on alcohol	28.4
Wearing sunscreen	67.9	Actively lost weight	26.7
Healthy diet*	66.9	Decreased stress	23.1
E-cigarette/vape free	65.4	Quit attempt with smoking cigarettes	17.4
House being e-cigarette free	61.9	Participating in cancer screening	17.4
Not drinking alcohol	58.7	Participate in health program	14.1
Physical activity	57.3	Quit alcohol	10.0

*Improved diet implies that people eat more healthily. Changed eating habits implies that some foods may or may not be consumed at all.

Priority Area 3: Access and participation in cancer screening

Primary indicator(s): receipt of offer/invitation to breast, cervical and colorectal cancer screening, self-reported participation in breast, cervical and colorectal cancer screening.

Secondary indicator(s): Intentions to participate, if eligible, in the new lung cancer screening program, and types of diagnostic investigations undergone.

3.1. Participation in cancer screening (Priority 3A)

Participants were asked if they had ever been offered and participated in Australia's national cancer screening programs for breast cancer, cervical cancer, and/or colorectal cancer.

3.1.1. Participation in breast cancer screening

Participants were considered eligible for breast screening if they were women aged 50-74 years and did not have a prior diagnosis of breast cancer at the time of completing the survey. Among eligible women with a diagnosis of a non-breast cancer, over three-quarters of women (77.1%) reported that they were offered and participated in breast screening (Fig. 8). Eligible women without a cancer diagnosis similarly reported being offered (81.8%) and participating in (78.0%) breast cancer screening. Among those offered breast screening, 93.8% of women with a diagnosis of a non-breast cancer and 91.4% of those without a cancer diagnosis participated.

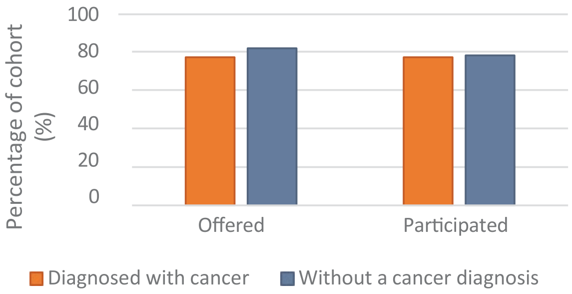

Fig. 8. Percentage of eligible women, with (n=83) and without (n=400) a cancer diagnosis, who were offered and participated in breast cancer screening.

3.1.2. Participation in cervical screening

Participants were considered eligible for cervical screening if they were women aged 25-74 years and did not have a prior diagnosis of cervical cancer at the time of completing the survey. Among eligible women with a diagnosis of a non-cervical cancer, almost half (49.2%) were offered and 40.4% participated in cervical screening (Fig. 9). Over half of the eligible women without a cancer diagnosis reported being offered (59.7%) and to have participated in (58.6%) cervical cancer screening. Among those offered cervical screening, 73.7% of women diagnosed with a non-cervical cancer and 90.7% of those without a cancer diagnosis participated.

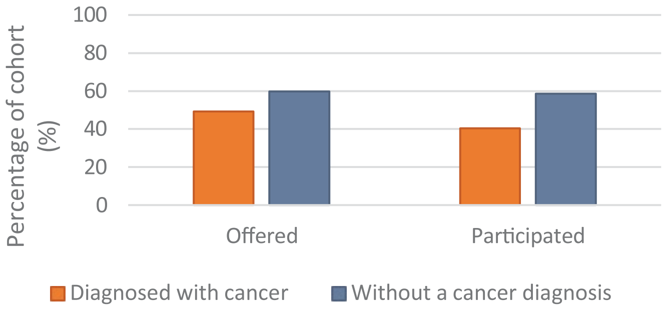

Fig. 9. Percentage of eligible women, with (n=193) and without (n=443) a cancer diagnosis, who were offered and participated in cervical cancer screening.

3.1.3. Participation in colorectal cancer screening

Participants were considered eligible for colorectal (bowel) cancer screening if they were aged 50-74 years and did not have a prior diagnosis of colorectal cancer at the time of survey. Among eligible respondents with a diagnosis of a non-colorectal cancer, almost three-quarters (73.1%) were offered and 68.6% participated in colorectal screening (Fig. 10). Two-thirds of the eligible respondents without a cancer diagnosis reported being offered (66.8%) colorectal cancer screening and 62% had participated in the program. Among those who reported being offered colorectal cancer screening, 90.2% of participants diagnosed with a non-colorectal cancer and 86.4% of those without a cancer diagnosis participated.

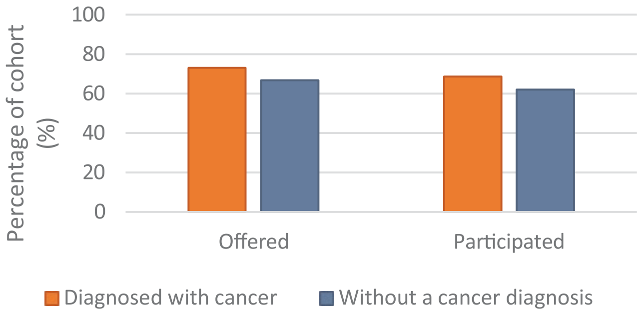

Fig. 10. Percentage of eligible respondents, with (n=223) and without (n=707) a cancer diagnosis, who were offered and participated in colorectal cancer screening.

3.2. Intentions to participate in lung cancer screening (Priority 3A)

Respondents were asked if they would participate in the national lung cancer screening program, which is due to launch in Australia in 2025, if they were eligible. Most said they would (68.0% of those diagnosed with a non-lung cancer and 74.9% of those without a cancer diagnosis). However, over 15% of those with a non-lung cancer and over 5% of those without a cancer diagnosis said they did not intend to participate, and almost 9% of those with cancer and over 16% of those without a cancer diagnosis were unsure (Fig. 11).

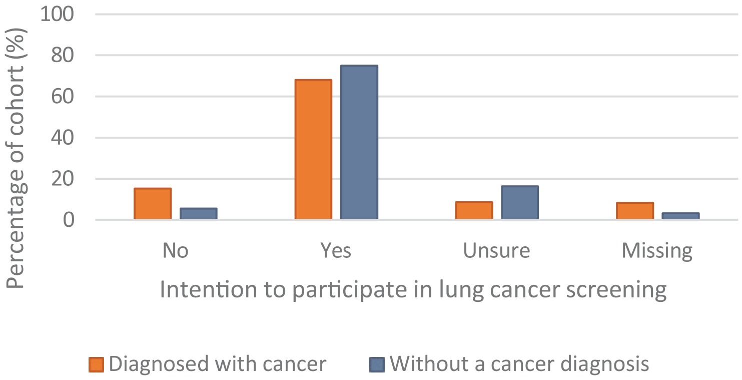

Fig. 11. Percentage of participants with a diagnosis of a non-lung cancer (n=521) and without a cancer diagnosis (n=1,515) who said they intended to participate in lung cancer screening if eligible.

3.3. Receipt of diagnostic investigations (Priority 3D1)

The following follow-up investigations were the most commonly undertaken among participants who did not have a cancer diagnosis:

- Blood tests (29.6%)
- Physical examinations (22.8%)
- Colonoscopy (21.6%)
- Urine tests (18.2%)

- Biopsy (18.2%)
- Ultrasound (16.3%)
- CT scan (14.5%)

It is unclear whether these investigations were to follow-up abnormal screening results or not, and if they were, for what screening test.

Priority Area 4: Ensure early diagnosis of symptomatic cancers

Primary indicator(s): Prevalence of cancer types, stage of cancer at diagnosis

Secondary indicator(s): Prevalence of each stage of cancer at diagnosis

4.1. Prevalence of cancer types (Priority 4A)

Among participants who had been diagnosed with cancer, almost 1 in 5 (17.9%) had been diagnosed with a second cancer and 4.1% had been diagnosed with three or more cancers (Fig. 12).

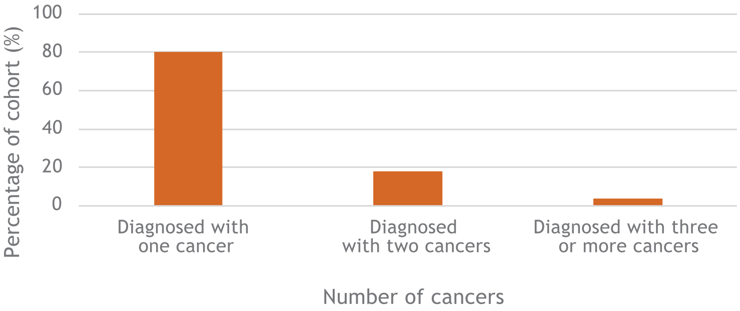

Fig. 12. Number of cancers diagnosed among participants with a cancer diagnosis.

As shown in Fig. 13, the most common cancers diagnosed in the cohort were breast cancer (17.9%), melanoma (13.3%), prostate cancer (12.9%), and lung cancer (11.4%).

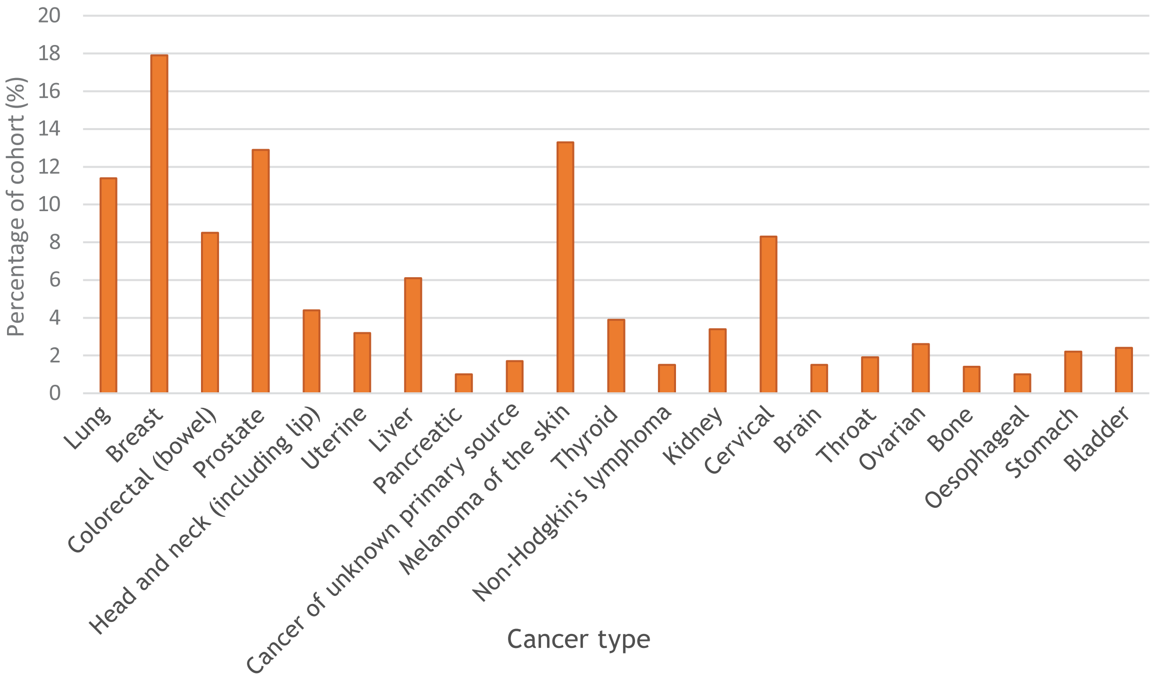

Fig 13. Prevalence of cancer types diagnosed (n=588).

4.2. Stage of cancer at diagnosis (Priority 4A)

This study collected information from participants on their stage of cancer at diagnosis. This variable requires clinical guidance to enable accurate coding and reporting. Data is pending this guidance.

Priority Area 5: Optimal and culturally appropriate care

Primary indicator(s): Experiences of discrimination in health services score, integrated cancer services score

Secondary indicator(s): Receipt of radiation therapy, inclusion of family/friends, clinical trial participation

5.1. Experiences of healthcare discrimination and racism (Priority 5B1)

5.1.1. *Healthcare discrimination*

Participants who had been diagnosed with cancer were asked about their experiences in the healthcare system. A global measure of experiences of discrimination in the healthcare system was created using Thurber et al.'s approach.[21] This was based on the type of experience (10 items) and the frequency at which it was experienced (not at all, a little, a fair bit, a lot), with possible scores ranging from 0 (no discrimination on all 10 items) to 30 (a lot of discrimination on 10 items). Four of the ten items were included in the original measure and validated. The extension to include 10 items within the revised Mayi Kuwayu Study instrument was based on community and stakeholder input; validation of the modified measure is underway. Among the respondents with a diagnosis of cancer, the mean discrimination score was 9.2 (SD 7.8).

One in five participants (20.6%) reported that they had not experienced discrimination in the healthcare system. Two in three (65.8%) reported experiencing at least a little bit of one or more forms of discrimination in the healthcare system. The items most commonly experienced (at least 'a little bit') were:

- Healthcare providers do not hear what I say (58.8%)
- Healthcare staff do not understand my culture (56.0%)
- Healthcare staff do not ask me what I need (53.7%)
- Healthcare staff do not take my needs seriously (52.4%)
- I go home without the care I need (51.0%)
- Healthcare staff make decisions about my care without consulting me (50.9%)
- I have to wait longer than other people (49.5%)

5.1.2. *Attributions of experiences of discrimination in healthcare to Indigeneity*

Among participants who had been diagnosed with cancer, those experiencing discrimination in healthcare were asked to indicate if, and to what extent, they thought the discrimination was on the basis of their Indigeneity. As shown in Figure 14, 15.3% of participants who been diagnosed with cancer experienced discrimination but did not attribute this to their Indigeneity (i.e., the discrimination could have been on the basis of gender, age, disability, or other characteristics). Over half of the cohort with cancer (50.5%) experienced discrimination that was attributed to their Indigeneity (i.e., they experienced racism in healthcare), a little (24.3%), a fair bit (17.2%), or a lot (9.0%). As people rarely know the reasons they are discriminated against, people may underestimate attribution, and thus this measure may underestimate experiences of racism in healthcare. This may be especially true if they are being discriminated against on the basis of multiple and intersecting identities.

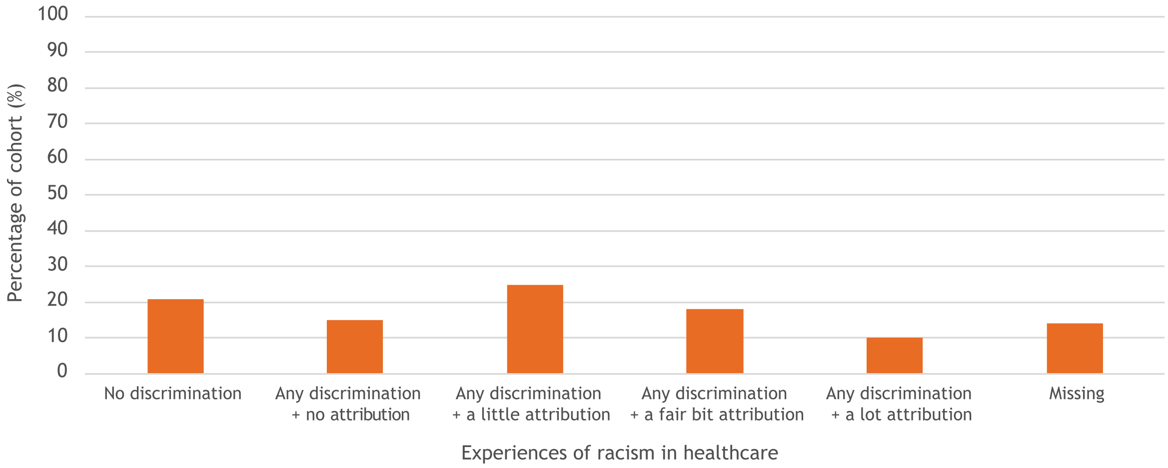

Figure 14. Experiences of racism in healthcare among Aboriginal and Torres Strait Islander people (n=588).

5.2. Integrated cancer services (Priority 5B5)

A global measure of how well cancer services were linked, and worked in partnership, with Aboriginal and Torres Strait Islander communities and other health organisations was created by summing items, from a pre-defined list of eight items, which were answered as "yes". Possible scores ranged from zero (services not integrated) to eight (services integrated). The mean score was 3.8 (SD 2.2) among those with a cancer diagnosis.

The items which were mostly commonly answered affirmatively were:

- Having an Aboriginal and/or Torres Strait Islander person to interpret and help with communication with health professionals (58.5%)
- Access to someone who understands culture (51.7%)

- Having an Aboriginal and/or Torres Strait Islander person to talk to and support you (48.0%)
- Ensuring family members were able to be present when talking with a health professional (41.8%)
- Having traditional bush tucker at hospital (39.6%)

5.3. Radiation therapy activities (Priority 5D)

In total, 22.4% of participants diagnosed with cancer reported that they received radiation therapy for their first cancer. The number of participants who self-reported receiving radiation therapy for subsequent cancers was too low to report. For the first cancer diagnosed, 28.8% of those who received radiation therapy for their cancer waited more than one month after diagnosis before commencing radiation treatment (Fig. 15).

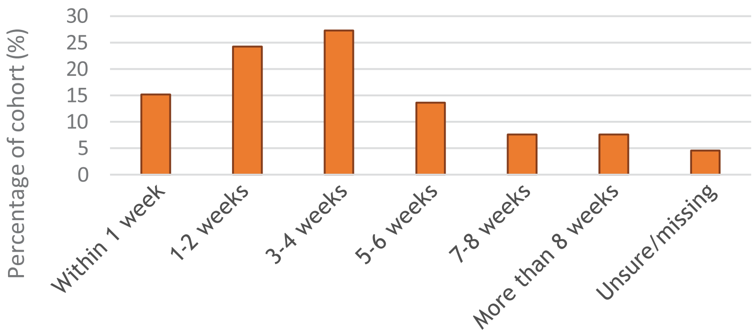

Fig. 15. Time from diagnosis to radiation therapy treatment commencement.

5.4. Transition between services (Priority 5E2)

A global measure of how well participants were able to transition between health services was created by summing the number of items, from a pre-defined list of seven items, which were answered positively (i.e., good transition). Where statements were phrased as negative (i.e., a bad experience of transition) it was reverse coded. The possible scores ranged from 0 (poor transition between services) to seven (good transition between services). The mean score was 3.5 (SD 1.4).

The following items related to positive service transition and were experienced by approximately half of the participants:

- Language was *not* a barrier (59.2%)
- It was *not* hard to get transport needed for treatment (51.9%)
- Family attended appointments with you (50.2%)
- Doctor talked to the specialist about treatment (48.0%)

5.5. Inclusion of family and friends (Priority 5E2)

Those with a cancer diagnosis were asked about the inclusion of family/friends in their healthcare:

- Family member/carer attended most appointments with you (62.6%)
- Someone took time off to help me attend appointments related to my cancer (38.6%)
- Someone took time off work unpaid to enable you to attend your appointments related to cancer (31.5%)
- Someone had to take time off school to attend appointments related to your cancer (29.8%)

5.6. Participation in clinical trials (Priority 5H)

Participants with a diagnosis of cancer were asked about their participation in clinical trials. One in five (21.9%) reported that they had participated in a cancer clinical trial, as a child or adult. Overall, 15.3% reported that their treatment for their first cancer was part of a clinical trial. This was most common among those aged younger than 55 years at the time of survey (18-34 years: 24.2%; 35-44 years: 26.9%; 45-54 years: 24.4%), and less common among those aged 55 years or older at survey (5.2%).

Priority Area 6: Supportive care for families and carers of Aboriginal and Torres Strait Islander people

Primary indicator(s): Presence of family/carers at healthcare appointments

6.1. Presence of family/carers at healthcare appointments

Over four in ten (41.8%) participants who had been diagnosed with cancer advised that they were able to have family members or carers present when they met or spoke with their healthcare professionals (Fig. 16).

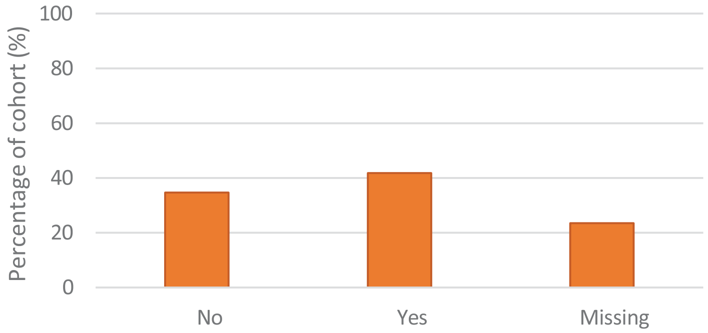

Fig. 16. Proportion of those diagnosed with cancer (n=588) that were able to have family/carers available when meeting with or speaking to their healthcare professionals.

Priority Area 7: Strengthen capacity of cancer services and systems to meet the needs of Aboriginal and Torres Strait Islander people

Primary indicator(s): Self-identification in healthcare services

7.1. Self-identification (Priority 7A2)

Participants with a cancer diagnosis reported that there were some healthcare services in which they did not identify as Aboriginal and/or Torres Strait Islander, including at hospital (8%) and with Medicare (5.1%) (Fig. 17). This was less commonly reported by participants at their regular healthcare providers (3.1%), potentially due to increased opportunities to build trusting relationships.

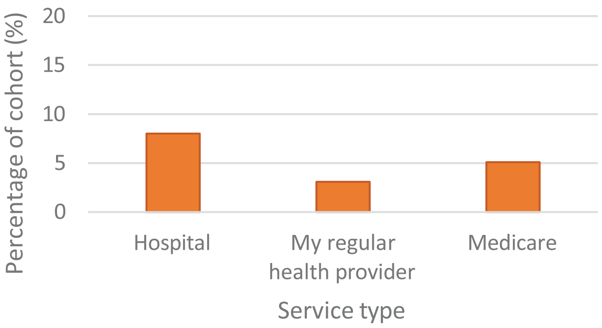

Fig. 17. The percentage of participants (n=588) with a cancer diagnosis who reported not identifying as Aboriginal and/or Torres Strait Islander within certain healthcare services.

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