

# Barriers and facilitators to adherence to Optimal Care Pathways for diagnosis and treatment of cancer for Aboriginal and Torres Strait Islander people

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## ABSTRACT

**Background.** The Optimal Care Pathways (OCP) are a framework to promote high-quality and integrated cancer care for all Australians, from prevention through to end-of-life-care. Aboriginal and Torres Strait Islander people experience disproportionate cancer incidence and mortality, but little research has addressed whether cancer care for Aboriginal people meets the standards prescribed by the OCPs. This study aims to consider barriers and facilitators to quality cancer care for Aboriginal people. **Methods.** Semi-structured interviews were conducted with 30 health professionals who deliver care to Aboriginal people with cancer in primary care and hospital settings in New South Wales, Australia. Health professionals included Aboriginal Health Workers, nurses, general practitioners, and community workers. Interviews were conducted in 2019–2020 and explored participant perspectives of barriers and facilitators of optimal cancer care, particularly related to prevention, early detection, diagnosis, and treatment for Aboriginal people. Data were qualitatively analysed using framework analysis. **Results.** In general, participants perceived Aboriginal patients to have good access to preventive care. In terms of early detection and diagnosis, access to primary care, pathology, radiology, and some specialists (e.g. respiratory physicians) was seen as optimal. However, access to hospital-based gastroenterologists for colonoscopy was perceived to be poor due to long wait times. Access to optimal care for cancer treatment was perceived to be hindered due to the lack of bulk-billing for bowel cancer, breast cancer, and cardiothoracic surgery. Other barriers to care identified by participants included unclear referral pathways, poor communication between patient and the treating team, and a lack of timely provision of discharge summaries. **Conclusions.** Facilitators of optimal care during treatment and survivorship included: the Integrated Team Care and Close the Gap programs, and presence of key health workers to help patients navigate the health system. The major barriers to quality cancer care for Aboriginal people appeared to be to specialist and procedural access, demonstrating that the 'Inverse Care' law applied in reducing access for populations at higher risk of cancer.

**Keywords:** Aboriginal and Torres Strait Islander peoples, Australia, cancer, Indigenous peoples, integrated care, oncology, primary health care.

## Introduction

Aboriginal communities and health service providers continue to focus on reducing the 'gap' in life expectancy due to cancer compared to other Australians. The Aboriginal and Torres Strait Islander (respectfully referred hereafter as Aboriginal people) age-standardised incidence rate for all cancers combined in 2012–2016 was 14% higher and the all cancer combined age-standardised mortality rate in 2015–2019 for Aboriginal Australians was 45% higher than the rate for non-Aboriginal Australians (AIHW 2021). The gap in mortality has widened for over a decade, as mortality rates continue to increase for Aboriginal people, whereas they are decreasing for non-Aboriginal people (AIHW 2022). These disparities are underpinned by inequities in cancer prevention and early detection

(Dasgupta *et al.* 2020) and in cancer care and treatment (Garvey *et al.* 2011; Whop *et al.* 2017).

Improving cancer outcomes for Aboriginal people requires improving access to cancer services and the quality of cancer care. Strategies to do this include growing the Aboriginal health workforce, creating culturally safe environments in health care, and supporting Aboriginal Community Controlled Health Organisations (ACCHOs) to provide cancer services (Newman *et al.* 2008; Shahid *et al.* 2009; Thompson *et al.* 2014).

The tumour-specific best-practice Optimal Care Pathways (OCP) for the prevention, investigation and treatment, and follow-up care for many common cancers have been endorsed by Cancer Australia. The OCP describes a national standard for a model of care for cancer and is designed to promote quality, integrated cancer care for all Australians. Cancer Australia has developed a pathway for best practice cancer care for Aboriginal people, which is intended to be used alongside the tumour-specific OCP to guide delivery of culturally safe and supportive optimal cancer care (Cancer Council 2018).

Research around adherence to OCP has only recently been published, although a comprehensive assessment of the adherence of cancer care to the OCP for Aboriginal people is still lacking. In Queensland, de witt *et al.* (2022) conducted interviews with 26 health professionals in hospitals and primary care to identify perceived barriers to optimal and culturally safe care for Aboriginal people with cancer. A key barrier identified in this study was poor communication from hospital settings. Taylor *et al.* (2022) conducted interviews with service providers and consumers in Western Australia, finding that prevention and diagnosis components of OCPs were not seen as priorities in tertiary care centres and noted the need to reduce barriers to tertiary care.

## Methods

### Researcher position

In 2015, the Illawarra Aboriginal Medical Service, an ACCHO located in Wollongong, New South Wales (NSW), Australia, established a Cancer Care Team (CCT) to improve cancer care for Aboriginal patients. The team began a collaborative program of work to co-design a manual to support health professionals working with Aboriginal people at risk of or diagnosed with cancer. To inform the development of the manual, this study explored the views of health professionals on the barriers and facilitators to OCP-adherent cancer care for Aboriginal people diagnosed with breast, bowel and lung cancers. This project was led by the CCT in partnership with the Aboriginal Health and Medical Research Council (AHMRC), other ACCHOs, university researchers, and Primary Health Network clinicians. The lead investigator (RI)

is a non-Indigenous academic working in Aboriginal health research and a general practitioner for over 20 years. Co-authors include Aboriginal, Torres Strait Islander, and non-Indigenous partners. The need to identify and co-design practical ways to support health professionals to provide OCP-adherent optimal and culturally safe care for Aboriginal people with cancer was apparent.

### Study design

A qualitative study design was employed to gain insight into stakeholders' perceptions of barriers to and facilitators of OCP-adherent care for Aboriginal people with, or at risk of, breast, bowel, and lung cancers. These cancers were chosen as they are the commonest cancers for Aboriginal and Torres Strait Islander people in Australia (Haigh *et al.* 2018).

### Participants

Stakeholders aged >18 years who delivered cancer care to Aboriginal people in ACCHOs, mainstream general practices, hospitals and non-government organisations, were eligible for inclusion. Letters of invitation were sent to 10 NSW ACCHOs and via identified cancer care networks, with face-to-face consultation meetings being held with most services. All participants were given information about the project and asked to provide written (face-to-face) or verbal consent (online and recorded). Purposive recruitment was conducted to ensure a range of roles in different settings and in a range of regions. We purposively recruited Integrated Team Care (ITC) workers, Aboriginal workers funded by the Commonwealth government who are able to support consumers with chronic disease, including cancer. A number of ACCHOs expressed an interest and then declined participation due to pressures in responding to the coronavirus disease 2019 (COVID-19) pandemic.

### Data collection

Semi-structured interviews, utilising a Yarning approach, were conducted to gain rich data around key OCP domains (prevention, diagnostic investigation, treatment, and follow-up care) for three common cancer types (breast, bowel and lung). Bessarab and Ng'andu (2010) described 'Yarning' as a method suitable for use in Aboriginal health research, where qualitative information can be elicited by researchers in a relaxed and conversational manner that respects cultural protocols and establishes power balance between the interviewer and interviewee. Interviews were guided by an interview schedule and conducted by a non-Aboriginal clinician (RI) and/or Aboriginal investigator (KT). Online data collection was added to the study protocol in response to the COVID-19 pandemic and associated public health restrictions. Interviews were audio-recorded, with the recording being transferred to secure password-locked electronic storage, which was

backed up daily, and files were transcribed. For those participants who declined a recorded interview, the interviewer took handwritten notes. Participants were offered a copy of their transcribed interview and were able to amend it if they desired.

## Analysis

To analyse stakeholder views on OCP-adherent cancer care, one investigator (RI) used framework analysis (Ritchie and Lewis 2003; Hackett and Strickland 2019) to ascertain facilitators (strengths and opportunities) and barriers (weaknesses and threats) to quality care according to OCPs, with coding for the OCP tool reviewed by an Aboriginal coder (TL). This mode of analysis was chosen so as to address the categories of the OCP. We undertook coding by hand, using tabulation, to show barriers and facilitators to the OCP for cancer care, for the most common cancers, lung, bowel and breast cancers, and for the OCP Pathway for Aboriginal and Torres Strait Islander people with cancer (Tables 1, 2, 3 and 4).

## Ethical considerations

Research was carried out as per the AHMRC Ethics Committee approval (1404/18).

## Results

We conducted interviews between June 2019 and July 2020, with 30 stakeholders aged 22 to 63 years (where stated), of whom 22 were female and eight were male. Eighteen participants were Aboriginal and 12 were non-Aboriginal. Stakeholders included Aboriginal Health Workers (AHW)/Practitioners ( $n = 4$ ), primary care nurses ( $n = 7$ ), general practitioners ( $n = 6$ ), a cancer care counsellor ( $n = 1$ ), ITC Workers ( $n = 4$ ) and receptionists or community workers ( $n = 8$ ). Most were based in ACCHOs ( $n = 25$ ), with three from hospitals and two from non-government organisations. Of the participants, one was based in a major city (Modified Monash (MM) 1), 25 were based in a regional city (MM1), three were based in two rural centres (MM3) and one participant was located in a remote area (MM7).

## Prevention

Most participants, including those based in primary care and in hospitals, discussed the importance of prevention programs and considered this the domain of primary care. Most participants perceived that the annual health check covered under Australia's universal health insurance scheme was well-delivered in the ACCHO setting and provided an opportunity to ask about cancer risk factors such as family history of inherited cancers or smoking. Some participants stated it was more difficult to deliver in mainstream primary care due to

lack of time and lack of AHW. Some participants mentioned interventions such as provision of nicotine replacement therapy or exercise programs could address cancer risk factors such as smoking and obesity and that ACCHOs or non-government organisations were able to deliver such programs. Some stakeholders perceived that ACCHOs were able to support national screening programs relevant to the OCPs through the coordination of screening days and reminder systems. For example, participants from two services mentioning that their services had coordinated visits for groups of women for breast screening, based on reminder systems. Only a few participants discussed promotion of national cancer screening programs at the annual health check (Refer to Tables 1–4).

## Diagnosis and treatment

Only a few stakeholders identified a lack of cancer symptom awareness as a barrier to early diagnosis. Participants identified that there were financial barriers to healthcare presentation, diagnostic investigations, and treatment. Although access to primary care was perceived as being timely in both ACCHOs and mainstream services where bulk-billing was offered, some participants mentioned that private-billing general practices were less accessible. Transport to primary care and specialist appointments was routinely available for ACCHO clients and available to mainstream GP clients via the ITC program. Participants from rural or remote areas and the participant based in a tertiary referral centre mentioned that coordination of travel to tertiary centres was part of their role; for example, this was funded under a State travel scheme.

The provision of bulk-billing pathology and radiology services for investigation of cancer was seen as routine by most clinicians and waiting times were perceived to be appropriate according to the OCP. Access to some respiratory physicians (for lung cancer) was seen as excellent by clinical stakeholders, in terms of timeliness and financial accessibility. Some physicians bulk billed, with private providers more likely to bulk bill clients from an ACCHO compared to clients from mainstream practices. Access to specialist gastroenterologists for colonoscopy following a positive faecal occult blood test or symptoms/signs of bowel cancer was viewed to be financially accessible via public clinics (often with no specialist appointment required); however, wait times exceeded OCP recommendations, demonstrating systems failure in the delivery of best practice cancer care. General practitioner respondents reported that referral processes involved mailing or hand-delivering referrals, with faxed or electronic referral not accepted, and there was little communication back to the primary care service about prioritisation of appointments, unless the patient did not attend the appointment. No participants mentioned clients accessing private services (Refer to Table 3).

Most cancer care physician services, such as oncologists and radiation oncologists, were perceived by clinicians as

**Table 1.** Lung cancer OCP.

Lung cancer	Action	Participant comments
Prevention and early detection	Advice about risk factors (smoking)	<ul style="list-style-type: none"> <li>• Asked routinely at Aboriginal health checks</li> <li>• Smokers asked about smoking status every visit</li> <li>• Cessation support – nicotine patches on script supported by Close the Gap (CTG) in clinics</li> <li>• Staff trained in delivering smoking cessation advice</li> <li>• Mainstream services less likely to conduct health checks and thus less likely to ask about smoking</li> <li>• Poor awareness in the community of the need to get symptoms such as a chronic cough assessed</li> </ul>
	Referred for chest X-ray if suspicious symptoms were observed for >3 weeks	<ul style="list-style-type: none"> <li>• Able to get a walk -in appointment within a day</li> <li>• Able to obtain an X-ray on the same day, bulk billed</li> <li>• Transport available</li> </ul>
Presentation, initial investigations and referral	Test results to patient within 1 week	<ul style="list-style-type: none"> <li>• Mostly possible in ACCHO</li> <li>• Recall system in place (urgent, non-urgent)</li> <li>• Some patients difficult to contact even with recall protocol including multiple phone calls, SMS, registered mail or personal visit</li> </ul>
	Computerised tomography (CT) if symptoms persist and the X-ray is clear	<ul style="list-style-type: none"> <li>• Available within a week</li> <li>• Bulk billed</li> <li>• Transport available</li> </ul>
Diagnosis, staging and treatment planning	CT chest/upper abdomen/brain (and positron emission tomography (PET)/bronchoscopy/nuclear medicine tests as appropriate)	<ul style="list-style-type: none"> <li>• CT body/brain available within a week, bulk billed</li> <li>• PET scans referred by specialist</li> <li>• Access to respiratory specialist good, access within a week, several specialists bulk billed</li> <li>• Bronchoscopy at public hospital access good</li> <li>• Biopsy access at public hospital good</li> <li>• Bone scan available within a week, bulk billed</li> </ul>
	Management by multidisciplinary team (MDT)	<ul style="list-style-type: none"> <li>• Little reporting to primary care staff re MDT</li> </ul>
Treatment	Surgery	<ul style="list-style-type: none"> <li>• Access to urgent appointments to cardiothoracic surgeons facilitated by respiratory specialists</li> <li>• Surgeons did not bulk bill for consultations</li> <li>• Surgery available in a public hospitals in the city</li> <li>• Required care plan, referral to Integrated Team Care (ITC), approval only for those already diagnosed with cancer</li> <li>• Transport required</li> </ul>
	Radiotherapy as appropriate	<ul style="list-style-type: none"> <li>• Available in public hospital, good access</li> </ul>
	Chemotherapy	<ul style="list-style-type: none"> <li>• Available in public hospital, good access</li> </ul>
Care after initial treatment and recovery	Treatment summary to patient, carer and GP	<ul style="list-style-type: none"> <li>• Discharge summaries slow to arrive, often not available to primary care follow-up appointments</li> <li>• Uncertain if patients received a copy of their treatment plan</li> </ul>
	Follow-up care plan to patient, carer and GP	<ul style="list-style-type: none"> <li>• Follow-up plan to patient often in form of nursing discharge summary only</li> </ul>
Managing recurrent, residual and metastatic disease	Regular monitoring (annual review), referral back to team	<ul style="list-style-type: none"> <li>• Monitoring and annual review well supported</li> <li>• Specialist visits covered by ITC</li> <li>• Transport available</li> <li>• CTG available to support cost of medications</li> </ul>
	Care plan	<ul style="list-style-type: none"> <li>• Care plan routinely provided by ACCHO</li> <li>• Health check 9–12 monthly by ACCHO</li> </ul>
End-of-life care	Palliative care offered early	<ul style="list-style-type: none"> <li>• Good links to palliative care in hospital and ACCHO, good support where there was an Aboriginal palliative care worker available in a hospital</li> </ul>
	Advanced care plan	<ul style="list-style-type: none"> <li>• Advance care plan offered by ACCHO, patient tended to be in the terminal phase</li> </ul>

accessible and timely, which was seen to be due to provision of care in the public hospital, bulk billing and effective triage systems, respectively. Access to surgical appointments (breast, bowel or cardiothoracic) was considered more cumbersome, as appointments were booked with private specialists as outpatients.

Stakeholders reported that major financial barriers experienced by some patients could be overcome, at least in part, through ITC program funding, as this funding could be utilised to pay for additional payments required for specialist consultations. However, some respondents noted

**Table 2.** Breast cancer OCP.

Breast cancer	Action	Participant comments
Prevention and early detection	Advice about risk factors (family history, obesity, alcohol)	<ul style="list-style-type: none"> <li>• Asked routinely at Aboriginal health checks</li> <li>• Link between risk factors and breast cancer other than family history not discussed</li> <li>• Mainstream services less likely to conduct health checks</li> </ul>
	Mammography for those aged 50–74 years, referral to high-risk clinic for those at risk	<ul style="list-style-type: none"> <li>• ACCHO maintained recall and reminder system for mammography, poor response to reminders</li> <li>• ACCHO organised group Breastscreen days</li> <li>• Transport available</li> <li>• High-risk genetics clinic – poor access, not available locally</li> </ul>
Presentation, initial investigations and referral	A patient with signs and symptoms seen by a GP within 2 weeks	<ul style="list-style-type: none"> <li>• Appointment at walk-in clinic available daily, booked appointment with transport available within 2 weeks, sometimes longer for specific GP</li> </ul>
	Triple test done within 2 weeks	<ul style="list-style-type: none"> <li>• Available locally within a week</li> <li>• Fine needle biopsy (FNAB) available at private radiology, bulk billed</li> <li>• Core biopsy harder to access, privately billed</li> <li>• Transport available</li> </ul>
Diagnosis, staging and treatment planning	Seen by surgeon within 2 weeks	<ul style="list-style-type: none"> <li>• Access to surgeon good, access within 2 weeks following positive needle biopsy</li> <li>• Several specialists bulk bill</li> <li>• No surgeons bulk billed</li> <li>• Required referral to ITC, care plan available to both ACCHO and mainstream general practice patients</li> <li>• Transport available, via ACCHO or via ITC</li> <li>• Surgery available at public hospital</li> </ul>
	Management by multidisciplinary team (MDT)	<ul style="list-style-type: none"> <li>• Little reporting to primary care staff as to whether patients were discussed at a MDT meeting</li> </ul>
Treatment	Surgery within 1 month of decision for surgery	<ul style="list-style-type: none"> <li>• Surgery available in public hospital and private hospital</li> <li>• Transport available</li> </ul>
	Chemotherapy/endocrine treatment within 4 weeks of surgery	<ul style="list-style-type: none"> <li>• Chemotherapy available in a public hospital, good access</li> <li>• Endocrine treatment available on CTG</li> <li>• Transport available, parking available</li> </ul>
	Radiotherapy within 8 weeks of surgery	<ul style="list-style-type: none"> <li>• Available in a public hospital, good access</li> <li>• Transport available, parking available</li> </ul>
Care after initial treatment and recovery	Treatment summary to patient, carer and GP	<ul style="list-style-type: none"> <li>• Discharge summaries slow to arrive, often not available to primary care follow-up appointments</li> <li>• Uncertain if patients received a copy of treatment plan</li> </ul>
	Follow-up care plan to patient, carer and GP	<ul style="list-style-type: none"> <li>• Discharge summaries often not received or received late</li> </ul>
Managing recurrent, residual and metastatic disease	Regular monitoring (annual review), referral back to team	<ul style="list-style-type: none"> <li>• Monitoring and annual review well supported in ACCHO</li> <li>• Recall systems for mammograms in ACCHO</li> <li>• Specialist visits covered by ITC</li> <li>• Transport available</li> <li>• CTG available to support cost of medications</li> </ul>
	Care plan	<ul style="list-style-type: none"> <li>• Care plan routinely provided by ACCHO</li> <li>• Health check 9–12 monthly by ACCHO</li> </ul>
End-of-life care	Palliative care offered early	<ul style="list-style-type: none"> <li>• Good links to palliative care in the hospital and ACCHO, good support where there was an Aboriginal palliative care worker available in a hospital</li> </ul>
	Advanced care plan	<ul style="list-style-type: none"> <li>• Advance care plan offered by ACCHO, patient tended to be in the terminal phase</li> </ul>

that participation in the ITC program entailed preparation of Chronic Disease Management Plans and referral forms by primary care staff, which sometimes delayed appointments being booked. It was noted that as ITC funding is only eligible to patients already diagnosed with cancer, diagnostic appointments were generally not covered. Surgery was, however,

available in the public system with reasonable waiting times for those with cancer (Refer to [Tables 1–3](#)). Knowledge and use of the Close the Gap (CTG) Scheme, a national program that supports free or discounted medication prescriptions for Aboriginal people, was widespread in primary care. Some participants reported that many specialists



**Table 3.** Bowel cancer OCP.

Bowel cancer	Action	Participant comments
Prevention and early detection	Advice about risk factors (diet, obesity, alcohol)	<ul style="list-style-type: none"> <li>• Asked routinely at Aboriginal health checks</li> <li>• Link between risk factors and bowel cancer other than family history not discussed</li> <li>• High risk genetics clinic – poor access, not available locally</li> </ul>
	Faecal Occult Blood (FOB) test if patient is in the eligible age group (last 2 years)	<ul style="list-style-type: none"> <li>• Able to get a walk-in appointment within a day</li> <li>• FOB results received electronically</li> <li>• No recall system in place at one ACCHO, possible to implement</li> </ul>
Presentation, initial investigations and referral	Test results to patient within 1 week	<ul style="list-style-type: none"> <li>• FOB results received electronically</li> <li>• Recall system in place (urgent, nonurgent) to recall those with positive tests to refer for colonoscopy</li> <li>• Some patients difficult to contact even with recall protocol including multiple phone calls, SMS, registered mail or personal visit</li> </ul>
	Specialist appointment, referred for colonoscopy within 4 weeks	<ul style="list-style-type: none"> <li>• Outdated referral processes including only accepting mailed or hand-delivered referrals</li> <li>• Lengthy and unpredictable waiting times</li> <li>• No communication with primary care service to indicate when procedure would be undertaken</li> <li>• Done in public hospital</li> <li>• ITC unable to cover private procedures</li> <li>• Transport available</li> </ul>
Diagnosis, staging and treatment planning	Diagnostic workup – tests (CT/MRI etc.) completed within 2 weeks (if not presenting to the emergency department (ED))	<ul style="list-style-type: none"> <li>• CT body/brain available within a week, bulk billed</li> <li>• MRI only bulk billed if referred by specialist</li> <li>• Pathology bulk billed</li> </ul>
	Management by MDT	<ul style="list-style-type: none"> <li>• Little reporting to primary care staff as to whether patients were discussed at a MDT meeting</li> </ul>
Treatment	Surgery as appropriate	<ul style="list-style-type: none"> <li>• Surgeons did not bulk bill</li> <li>• Require care plan, referral to ITC, approval only for those already diagnosed with cancer</li> <li>• Transport available</li> <li>• Surgery available in a public hospital, timely</li> </ul>
	Radiotherapy within 3 weeks	<ul style="list-style-type: none"> <li>• Available in a public hospital, good access</li> </ul>
	Chemotherapy within 8 weeks of surgery	<ul style="list-style-type: none"> <li>• Available in a public hospital, good access</li> </ul>
Care after initial treatment and recovery	Treatment summary to patient, carer and GP	<ul style="list-style-type: none"> <li>• Discharge summaries slow to arrive, often not available to primary care follow-up appointments</li> <li>• Uncertain if patients received a copy of their treatment plan</li> </ul>
	Follow-up care plan to patient, carer and GP	<ul style="list-style-type: none"> <li>• Follow-up plan to patient appears to be in a form of a nursing discharge summary only</li> </ul>
Managing recurrent, residual and metastatic disease	Regular monitoring (annual review), referral back to team	<ul style="list-style-type: none"> <li>• Monitoring and annual review well supported</li> <li>• Specialist visits covered by ITC</li> <li>• Transport available</li> <li>• CTG available to support cost of medications</li> </ul>
	Care plan	<ul style="list-style-type: none"> <li>• Care plan routinely provided by ACCHO</li> <li>• Health check 9–12 monthly by ACCHO</li> </ul>
End-of-life care	Palliative care offered early	<ul style="list-style-type: none"> <li>• Good links to palliative care in ACCHO, good support where there was an Aboriginal palliative care worker available in a hospital</li> </ul>
	Advanced care plan	<ul style="list-style-type: none"> <li>• Advance care plan offered by ACCHO, patient tended to be in the terminal phase</li> </ul>

were apparently unaware of the correct annotation for a CTG-eligible prescription, meaning that Aboriginal people were not always able to access discounted or free medications on specialist prescriptions.

For all three cancers, communication to the patient, carer and primary care provider was perceived as being very poor

by most clinical respondents (especially general practitioners and nurses), with no receipting of referrals, poor provision of discharge summaries, or absence of specialist cancer treatment plans at first primary care visit post-admission.

Most participants identified racism and/or culturally unsafe care as potentially barriers to optimal care, but did

**Table 4.** Aboriginal and Torres Strait Islander OCP.

Aboriginal health pathway	Action	Participant comments
Prevention and early detection	Health check in the last year	<ul style="list-style-type: none"> <li>Offered to most clients at ACCHO</li> <li>Delivered to a lesser extent in mainstream general practice</li> </ul>
	Access to culturally accessible, affordable care	<ul style="list-style-type: none"> <li>ACCHO offers Aboriginal Health Worker (AHW) and employs other Aboriginal staff such as drivers</li> <li>ITC available at both ACCHO and mainstream general practices</li> <li>CTG available to all Aboriginal patients</li> </ul>
Presentation, initial investigations and referral	Support patient with culturally appropriate support person	<ul style="list-style-type: none"> <li>ITC able to offer support of AHW to arrange appointments, accompany patients to appointments and provide transport, but limited availability, used for higher-needs clients; for example, the elderly, those with an intellectual disability or those with poor social supports</li> <li>Staff identified that many clients requires a staff member to attend appointments with them at specialist clinics or hospital clinics, as providing transport alone was insufficient</li> </ul>
	Identify support needs	<ul style="list-style-type: none"> <li>Cancer care workers are aware of the existing Supportive Care Needs Assessment Tool for Indigenous People</li> <li>Other stakeholders not aware</li> </ul>
Diagnosis, staging and treatment planning	Involve AHW in hospital care	<ul style="list-style-type: none"> <li>Aboriginal Liaison Officer/Aboriginal Health Practitioner or palliative care worker available in hospitals; however, insufficient capacity to support all Aboriginal inpatients</li> </ul>
	Refer to culturally appropriate resources	<ul style="list-style-type: none"> <li>Culturally appropriate available resources available at ACCHOs but not always used, health promotion resources available in hospitals, Aboriginal rooms and artwork at hospital</li> </ul>
Treatment	Support for travel, accommodation	<ul style="list-style-type: none"> <li>Transport to primary care appointments, investigations and specialist appointments available via ACCHOs and ITC programs</li> <li>Accommodation available via ITC for those from regional areas for treatment in the city</li> <li>Accommodation and travel costs more accessible for those from more rural areas</li> </ul>
	Support for specialist fees, medication costs	<ul style="list-style-type: none"> <li>Specialist fees support available via ITC</li> <li>CTG available</li> </ul>
	Consider cultural and family obligations when planning treatment	<ul style="list-style-type: none"> <li>Support available via ACCHO, AHWs in non-government organisation ITC program and AHWs in hospitals</li> </ul>
Care after initial treatment and recovery	Treatment summary to patient, carer and GP	<ul style="list-style-type: none"> <li>Discharge summaries slow to arrive, often not available to primary care follow-up appointments</li> </ul>
	Follow-up care plan to patient, carer and GP	<ul style="list-style-type: none"> <li>Discharge summaries often not received or received late. Oncology care plans rarely received in primary care</li> </ul>
Managing recurrent, residual and metastatic disease	Regular monitoring (annual review), referral back to team	<ul style="list-style-type: none"> <li>Monitoring and annual review well supported</li> <li>ACCHO provided Yarning Circle for survivorship peer support</li> </ul>
	Care plan	<ul style="list-style-type: none"> <li>Care plan routinely provided by ACCHO</li> </ul>
End-of-life care	Palliative care offered early	<ul style="list-style-type: none"> <li>Good links to palliative care in ACCHO, good support where there was an Aboriginal palliative care worker available in a hospital</li> </ul>
	Advance care plan, consideration of cultural practices	<ul style="list-style-type: none"> <li>Advance care plan offered by ACCHO</li> <li>Support for funerals</li> <li>Grief support at ACCHO</li> </ul>

not perceive patients' fear of racism in treatment or culturally unsafe care to be a major barrier to cancer care. They reported that anxiety about being diagnosed with cancer was sometimes a barrier to care, but more often was a facilitator to care with many people being diligent in attending appointments due to the threat of cancer. Participants commented that many Aboriginal people with cancer had competing priorities, including obligations to family and attending funerals, but viewed these as manageable, especially with support from Aboriginal health professionals such as AHWs in ACCHOs or hospitals. AHWs, ITC workers and other

Aboriginal health professionals such as nurses were able to play a role in coordinating care, in patient advocacy, and in giving positive support when people with cancer transitioned from primary care to hospital settings.

### Cancer survivorship and end-of-life care

Most participants believed that ACCHOs were able to support people with cancer during cancer survivorship; for example, by providing regular review, support in organising monitoring investigations or specialist reviews, in provision of chronic

disease management or by support such as Yarning circles or counselling. Many participants commented on the role of Aboriginal health professionals acting as navigators through the care system. Participants believed support at the end of life could be appropriately delivered by an ACCHO team or mainstream team working with hospital or community palliative care teams, including Aboriginal palliative care workers. A few participants, including ACCHO staff and hospital staff, commented on the provision of other aspects of end-of-life care, including advance care plans, and support to return to Country, and support for family around the time of 'sorry business'.

## Discussion

The study showed that ACCHOs provide a culturally safe and familiar base for cancer support activities including prevention. The annual health check available for Aboriginal and Torres Strait Islander people provides an evidence-based vehicle for screening for and delivering preventive care for cancer; for example, through reviewing family history, asking about smoking, alcohol and measuring body mass index, and provides an opportunity to ask about participation in cancer screening programs (NACCHO and RACGP 2018). ITC workers were able to support Aboriginal people who attended mainstream primary care as well as ACCHOs. Facilitators of OCP-adherent cancer care included familiar, geographically close primary care services, routine provision of annual health checks funded by Medicare, CTG funding for prescriptions, and financially accessible (bulk billed) diagnostic testing. The importance of the familiarity and continuity of primary care, and strong therapeutic relationships was also noted in the review by Meiklejohn *et al.* (2017) of perspectives of Aboriginal and Torres Strait Islander cancer survivors. A survey of Victorian health professionals conducted by Ristevski *et al.* (2022) also confirmed that Aboriginal primary health services were appropriate locations for support outside of hospital.

Systems barriers were most apparent around the delay in access to colonoscopy and financial access to surgical services. Better access to colonoscopy services in particular is required; electronic referrals and rapid access programs might provide better access.

A major barrier to integrated, quality OCP-adherent cancer care was cumbersome referral processes to and communication from specialists and hospitals, supporting the finding by de Witt *et al.* (2022) in Queensland and the findings by Taylor *et al.* (2022) in Western Australia. Electronic referral and receipting systems, triage systems and electronic communication of discharge summaries and cancer care plans back to primary care, are technically possible, yet not implemented for many services. Timely information exchange is likely to enhance adherence to OCP.

Despite Aboriginal people being at the greatest risk of developing and dying from cancer, cancer and other health

services are rarely designed to meet the needs of this population; a phenomenon referred to by Tudor Hart (1971) as the Inverse Care Law. Aboriginal people experience significant barriers to health care. Most received cancer care through the publicly funded system, which was associated with lengthy wait times and complex referral processes. Access to ITC program funding, so as to allow funding of specialist visits for diagnosis of cancer, as well as for treatment of established cancer, would allow better access to care, especially for services that were not available via the public system, such as surgical outpatient appointments.

## Data considerations

The findings reported here reflect the views of providers in five regions in NSW, with rural areas being under-represented in this sample. Aboriginal people with cancer in rural and remote areas might experience more delays in treatment due to transport times than in urban and regional areas. Due to the COVID-19 pandemic and the associated restrictions, recruitment was hindered. It was unclear if thematic saturation was reached prior to this point. Females were overrepresented in this study, which reflected the health workforce. Primary health professionals from ACCHOs were over-represented and hospital staff under-represented. In particular, no non-Aboriginal hospital staff were included.

Aboriginal consumers of health care might have different views to health professionals. Future research could seek the views of Aboriginal people with cancer. Quantitatively, cancer care could be assessed against the OCP through analysis of patient medical records and routinely collected public health data (e.g. cancer screening registers, cancer registries, hospital admissions).

## Conclusion

Many of the barriers to quality cancer care for Aboriginal people according to OCP were a result of health system issues, including complicated referral processes, lack of financially accessible outpatient surgical care, and poor access to procedures such as colonoscopy, rather than factors that were specific to Aboriginal people or Aboriginal health services. Participants noted poor integration of primary and hospital care, in particular paper-based referral systems with no communication about appointments, and lack of communication back to primary care, including from outpatient specialists and via discharge summaries. Facilitators included support by Aboriginal health professionals, including in ACCHOs, in Aboriginal ITC teams, or when employed in hospital settings. Other key facilitators included having financially accessible (bulk billed) primary care, specialist oncology services and diagnostic pathology and radiology. Enhancement of the number of Aboriginal health professionals employed in all settings, of funding for specialist appointments, and of electronic communication between primary care, specialist



and outpatient settings is likely to result in better adherence to OCP for cancer and might result in better cancer outcomes for Aboriginal people.

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**Data availability.** The data that support this study will be shared upon reasonable request to the corresponding author.

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