






Understanding the needs and preferences for cancer care among First Nations people: An integrative review

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Abstract

Aim: This systematic review aimed to identify the needs and preferences for cancer care services among Australian First Nations people.

Design: Integrative review.

Data Sources: An integrative review was conducted. A wide range of search terms were used to increase the sensitivity and specificity of the searches in electronic databases. Methodological quality assessment, data extraction, was conducted independently by two reviewers, and a narrative synthesis was conducted.

Results: Forty-two studies were included. A total of 2965 Australian First Nations adults, both men and women of various ages across the lifespan, were represented; no First Nations children affected by cancer were represented in the studies. Three themes emerged which included: (1) discrimination, racism and trauma, resulting from colonization, directly impacted First National people's cancer care experience; (2) cultural ways of knowing, being and doing are fundamental to how First Nations people engage with cancer care services; and (3) First Nations people need culturally safe person-centred cancer care services that address practical needs.

Conclusion: Most participants represented in this review experienced discrimination, racism and trauma, resulting from colonization, which directly negatively impacted Aboriginal peoples' cancer care experience. While the Optimal Cancer Pathway (OCP) was launched in Australia several years ago, people with cancer may continue to experience distressing unmet care needs.

Patient or Public Contribution: Our team includes both First Nations people, non-First Nations researchers and healthcare professionals with expertise in cancer care. The researchers employed decolonizing restorative approaches to ensure voice, respect, accountability and reciprocity in this review work.

Implications for Nursing Practice: Members of the multidisciplinary team including nurses and policymakers should reflect on these findings, ensure that they have up-to-date cultural safety training and stand together with Indigenous and non-Indigenous

cancer leaders to take proactive steps to stamp out and dismantle oppression in health, and safely implement the OCP.

KEYWORDS

cancer care, first nations, indigenous, supportive care, unmet needs

1 | INTRODUCTION

When Australia's colonization began, Aboriginal and Torres Strait Islander peoples were recorded as living long lives compared to the settlers and being healthy in appearance (Wilson et al., 2020). Aboriginal midwives were sought after by the first settlers because the women and babies they cared for were more likely to survive than the women who were attended to by settler midwives (Adams et al., 2018). The impact of dispossession, traumatic removal from country, family, traditional food sources and a stripping of identity, culture and knowledge have dramatically impacted Australia's First Nations peoples. Researchers and research have played a significant destructive role for people who are custodians of the world's oldest living cultures that have also contributed to harm (Sweet, 2017). Overall disparity in life expectancy between Australia's First Nations and dominant populations has slowly been reducing over recent years (Australian Institute of Health and Welfare, 2023a); however, disparity in cancer outcomes remains poorer for First Nations people (Meiklejohn et al., 2020). Cancer survival in Australia overall has observed a 20% improvement in mortality rates (Australian Government, 2023), but these data are not shared by First Nations survival figures. First Nations Australians are two and a half times more likely to die within 5 years following a cancer diagnosis (Valery et al., 2006). Given that First Nations people comprise 3.2% of the Australian population (Australian Bureau of Statistics, 2023) and given the recognized ~10-year gap in expected life expectancy of this population (Australian Institute of Health and Welfare, 2023b), focused intervention is needed.

First Nations Australians can experience reduced rates of cancer screening (Condon et al., 2016), late cancer presentations at diagnosis and overall receive less cancer treatment than other cancer groups (Moore et al., 2011; Valery et al., 2006). Moreover, many can experience absent culturally safe care or appropriate services resulting in sub-optimal cancer care (McGough et al., 2022; Rooney et al., 2022; Shahid et al., 2013; Treloar et al., 2014) and institutional racism (Markwick et al., 2019; Meiklejohn et al., 2015), including challenges with hospital transport, expenses, somewhere to stay during treatment and difficulties with the hospital environment, which all pose barriers to equitable services (Clifford et al., 2015; Wilson, 2016). Despite focused health and social national strategy to 'Close the Gap' of disparity generally, it has been recognized that the gap is widening overall and this factor contributes to explaining the broader context for the poorer health of First Nations people, including cancer profiles (Australian

Government, 2020). It is important to highlight that several interventions have been developed to address these shortcomings including the introduction of patient navigators (Whop et al., 2012), developing of cultural competency (Clifford et al., 2015) and better remote access to cancer services (Davy et al., 2016; Hayman et al., 2009), but nevertheless, poorer disparity in morbidity and mortality remains.

Cancer and its associated treatments can have profound negative consequences on quality of life, cultural and social interactions, self-image and self-esteem (Paterson et al., 2022). Important domains for quality cancer care include services that are delivered in a culturally safe context; incorporation of appropriate traditional therapies, supported self-management, timely access to continuity of care, good communication and a therapeutic relationship with healthcare professionals. However, across this suite of systematic reviews (Paterson et al., 2022), little has been described to represent the needs and preferences for cancer care among First Nations people affected by cancer. This underscores that First Nations people are under-represented in cancer care research, largely due to past failures to engage and recruit First Nations communities, and continuing requests to participate in research which has led to research exhaustion and the use of culturally inappropriate methods (Maar et al., 2011).

Greater efforts are needed to understand the unique perspectives of supportive care needs of First Nations people affected by cancer (Australian Government, 2020; Hayman et al., 2009; Meiklejohn et al., 2020; Shahid et al., 2013; Treloar et al., 2014; Valery et al., 2006). There is a pressing clinical need to take and critically synthesize existing evidence that directly draws upon First Nations people's own perspectives of their 'needs and preferences' across a range of cancer care service provisions in terms of their own self-determination to inform future interventions. It is important when undertaking this integrative review to identify the definition of health held by First Nations Australians differs from that generally used in healthcare settings, 'Health is not just the physical well-being of an individual but the social, emotional, and cultural well-being of the whole community. This is a whole-of-life view and includes the cyclical concept of life-death-life' Bullinah Aboriginal Health Service (2023). This systematic review addressed the following research question that was developed with the knowledge and guidance of Australian First Nations traditional custodians and knowledge holders:

- What are the needs and preferences for cancer care for Australian First Nations people?

2 | METHODS

Our team included First Nations people, non-First Nations researchers and healthcare professionals with expertise in cancer care. The researchers employed a decolonizing restorative approach that privileged the knowledge and voices of traditional custodians and aboriginal knowledge holders to ensure voice, respect, accountability and reciprocity in this review work (Freene et al., 2021; Whanganui, 2023). The terminology used in this paper to represent Aboriginal and Torres Strait Islander peoples was agreed to be Australia's First Nations people guided by the traditional custodians and knowledge holders involved in the study.

2.1 | Design

This integrative review was reported in keeping with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Page et al., 2021). A priori systematic review protocol is available upon request.

3 | PRE-SCREENING ELIGIBILITY CRITERIA

Types of studies:

- Studies which explored the experiences of cancer care among Australian First Nations people affected by cancer and their communities across the cancer care continuum.
- All qualitative, quantitative and mixed methods studies irrespective of design.
- Relevant systematic reviews were scrutinized for potentially relevant studies for screening.
- Studies published in Australian First Nations languages or English language.
- Studies conducted with Australian First Nations adults (≥ 18 years old) or children (< 18 years old).

Exclusion:

- Commentaries, editorials and studies where experiences of cancer care for First Nations people were not explicitly reported.

4 | MATERIALS AND METHODS

4.1 | Literature search

The following electronic databases were searched (Cochrane, MEDLINE, CINAHL and Web of Science) using key search terms related to cancer care, needs, preferences, First Nations people and Aboriginal and Torres Strait Islanders; see [Table S1](#) for detailed search

strategy. Databases were searched from the earliest date available to July 2022, including only publications in the English Language or those published in an Australian First Nations Language. All the references were managed using Endnote Reference Manager software and transferred to Covidence Systematic Review software. The search strategy was developed in conjunction with an academic research librarian and with the review team. It was guided, critiqued and supported by the Aboriginal Knowledge Holders who enabled this review. The population, intervention, comparison and outcomes (PICO) mnemonic was used to create the search architecture. The integrative review considered studies that included Australian First Nations children and adults affected by cancer (P) and their experiences of cancer care services (I) when they are receiving care in the community or hospital setting (Co).

4.2 | Selection of studies

Duplicate articles were removed in Covidence. A minimum of two review authors screened the titles and abstracts, and full-text publications of the identified records for eligibility. Any disagreements were resolved by discussion. The study selection process has been described and reported using the PRISMA guidelines (see [Table S2](#) for the completed checklist) (Page et al., 2021).

4.3 | Data extraction and management

Data extraction was conducted by several review authors, and a second review author quality checked all data extractions for accuracy. Any disagreements were resolved by discussion with the First Nations Knowledge Holders guiding the resolution. A data extraction table was developed and piloted before its use in a small number of studies. In case of any incomplete reported data, the study authors were contacted.

Data extracted included: study design; dates defining the start and end of recruitment and follow-up; countries and institutions where the data were collected; demographic and clinical characteristics of the study sample; the numbers of participants who were included in the study; study funding sources; losses and exclusions of participants, with reasons; ethical approval; power calculation; limitations; and data related to the review research question.

4.4 | Assessment of risk of bias in included studies

All included studies underwent a methodological quality assessment. The Mixed Methods Appraisal Tool (Hong et al., 2018) was used as it enabled a range of studies designed to be assessed in keeping with the integrative review design. This tool included seven targeted questions that were ranked as 'Yes' (green), 'Unclear' (yellow) or 'No'

(red). All studies were included to enable an understanding of the current state of the evidence base.

4.5 | Data synthesis

All qualified quantitative and qualitative data were pooled using the JBI methodology for mixed-methods systematic review approach (Stern et al., 2021). All qualitative data were synthesized into categories. Qualified findings were integrated into the qualitative categories if they applied to the qualitative category. Qualified findings that did not belong to a qualitative category were synthesized into their own categories. Both the qualitative and qualified categories were then integrated into synthesized findings, following JBI methodology (Stern et al., 2021).

5 | RESULTS

The flow of studies through the review process is presented in Figure 1. A total of 199 full-text papers were reviewed and 157 excluded with documented reasons. A total of 42 papers were included, which consisted of 10 quantitative descriptive studies, 2 quantitative non-randomized controlled studies, 28 qualitative studies and 2 mixed methods; see Table 1. The study designs were all cross-sectional in nature, meaning that little is known about how cancer care experiences in this patient group changes overtime from the point of cancer diagnosis, prehabilitation, treatment, survivorship and end-of-life care. The sample size ranges from 12 to 318 with a total of 2965 Australian First Nations people represented. There was representation of both men and women of various ages across the lifespan, with exception of no First Nations children represented affected by cancer. For the most part, the individual studies included heterogeneous cancer types (Adams et al., 2015; Bernardes et al., 2012, 2014, 2018, 2019; Diaz et al., 2016; Garvey et al., 2016, 2018; Green et al., 2018; Meiklejohn et al., 2017, 2018, 2020; Newman et al., 2017; Reilly et al., 2018; Shahid et al., 2013; Tam et al., 2018; Thewes et al., 2016; Valery et al., 2017) with the exception of bowel (Christou & Thompson, 2012) and breast screening (Pilkington et al., 2017), pap smears (Dorrington et al., 2015), breast cancer (Dembsky, 2014; McMichael et al., 2000), gynaecological cancer (Gall et al., 2019), vulvar cancer (McGrath et al., 2015; McGrath & Rawson, 2013a), lung cancer awareness (Page et al., 2016) and some studies did not report cancer types (Cuesta-Briand et al., 2015, 2016; Lyford et al., 2018; McGrath et al., 2006; McGrath & Rawson, 2013b; Mooi et al., 2012; Prior, 2009; Shahid et al., 2010, 2011, 2016; Shahid, Finn, Bessarab, & Thompson, 2009; Shahid, Finn, & Thompson, 2009; Thompson et al., 2011; Treloar et al., 2013, 2014). It is helpful to some degree to have broad representation of mixed cancer groups for the transferability of review findings, but this means little is known about the nuanced and specific supportive care needs of various individual cancer groups and differences between 'men and

women's business'. Central to Aboriginal and Torres Strait Islander culture is the spiritual connectedness and custodianship of country, and given the size of Australia and diversity of its peoples, there is a reaching impact of different languages, customs and lore for the many nations groups that contribute to Australians rich cultural heritage. This diversity creates many views about gender, and there is a view by some that there should be separation of men's and women's business. This separation is not a sexist separation or discriminatory, or is it to the detriment of either party. Rather it focuses on particular roles, ceremonies and lore that is sacred and specific to men and women individually (Story, 2023).

5.1 | Quality assessment

Overall, the methodological quality of the qualitative studies was good. There were some methodological shortcomings in the quantitative studies related to sampling bias, and the lack of transparency of the integration of data within the mixed methods studies. There was also a distinct lack of inclusion of theoretical models in the studies included, and only seven (16%) of the studies reported on using theory in their designs (health belief model, social construction framework, social ecological model and social inclusion theory); see Table 2 for methodological quality results.

5.2 | Findings

Data extracted in this review have been synthesized and guided by the people whose communities are most impacted by the problem, Australian First Nations traditional custodians and knowledge holders using a decolonizing restorative approach to ensure voice, respect, accountability and reciprocity with the aim of informing future service reconfiguration of cancer care in this population (Freene et al., 2021; Whanganui, 2023). When interpreting these results, it is critical to acknowledge that First Nations people represent over 250 different language groups or nations (Hill et al., 2023) (AIATSIS), and as such, assumptions cannot be made about the individual care needs of each Aboriginal person (Green et al., 2018).

Through the process of data reduction, integration and comparison, three themes have emerged:

1. Discrimination, racism and trauma, resulting from colonization, directly impact First Nations peoples' cancer care experience.
2. Cultural ways of knowing, being and doing are fundamental to how First Nations people engage with cancer care services.
3. First Nations people need culturally safe person-centred cancer care services that address practical needs.

Table 3 makes connections between these overarching themes and sub-themes and Figure 2 provides a network diagram for the supportive care needs.



PRISMA 2009 Flow Diagram

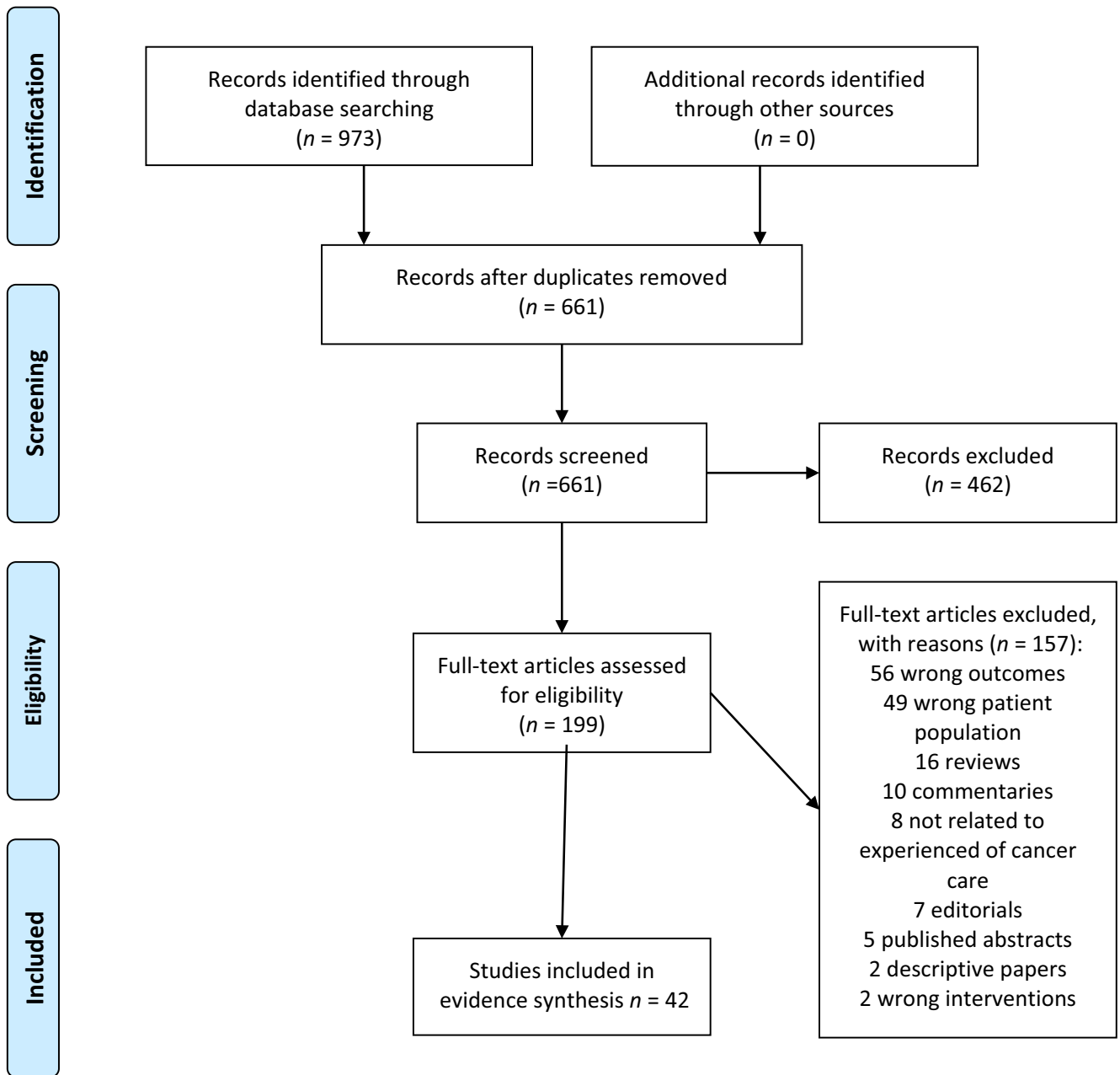


FIGURE 1 Results of PRISMA.

5.2.1 | Theme 1: Discrimination, racism and trauma, resulting from colonization, directly impact First Nations peoples' cancer care experience

Ten authors have documented the embarrassment, disrespect, anger, frustration and /or racism experienced by First Nations people within cancer healthcare services (Cuesta-Briand

et al., 2015; Gall et al., 2019; Garvey et al., 2018; Green et al., 2018; Newman et al., 2017; Reilly et al., 2018; Shahid, Finn, Bessarab, & Thompson, 2009; Thompson et al., 2011; Treloar et al., 2013; Valery et al., 2017) as illustrated by the following quotes.

There were instances when Aboriginal people had to wait on the veranda, sit on the veranda outside

TABLE 1 Overview of the included studies.

Author and year	Purpose	Sample size, mean age (SD, years) and gender	Participants	Clinical information	Sampling/setting	Response rate	Design and theoretical model	Time points (number of time points and dates)	Data collection tools
Adams et al., 2015	To report findings from prevalence and profile of TM and CAM use and users among Indigenous Australians with cancer (component of larger project in QLD to investigate the supportive care needs of Indigenous adults with cancer)	Sample size: 396 were eligible n = 248 participated in interviews Mean age: 52.7 years (SD 12.8) Range = 20-78 years Gender: Women: n = 141 (56.9%) Men: n = 107 (43.1%)	Education: <High school: n = 166 (67%) High school and more: n = 80 (32.3%) 67.5% had level of junior high school (<year 12) Language: English at home: n = 214 (86.3%) Geographical group: Accessible: n = 228 (91.9%) Remote: n = 20 (8.1%) Of which 37.1% lived in outer regional area Marital status: Spouse/partner/de facto: n = 115 (46.3%) Single: n = 83 (33.5%) Separated/divorced: n = 31 (12.5%) Widowed: n = 49 (7.7%) Employment status: Unemployed: n = 187 (75.4%) Socio-economic status: Advantaged: n = 139 (56.1%) Disadvantaged: n = 109 (43.9%)	Cancer type: Breast: n = 60 (24.2%) Lung: n = 34 (13.7%) Blood related: n = 32 (12.9%) Digestive organs: n = 31 (12.5%) Head and neck: n = 22 (8.9%) Gynaecological: n = 18 (7.3%) Male genital organs: n = 18 (7.3%) Cancer stage: Not reported Comorbidities: Not reported Treatments: Not reported CAM and TM use: 19% (n = 47) of people reported using at least 1 CAM for support with cancer	Sampling: Purposive Setting: 69.4% were hospital out-patient clinics (from 4 major cancer-treating hospitals across QLD)	Not reported	Cross-sectional None	Time points: 1 Dates: September 2010–December 2012	Tools: Structured questionnaire delivered via face-to-face interviews (socio-demographic characteristics, previous and current use of treatment, accessed any community/allied health services for support with cancer) Remoteness: ARIA – using postcode of residence Socio-economic status: SEIFA Reliability & validity: Not clearly reported
Bernardes et al., 2012	Describing the use of community and allied health services by indigenous cancer patients undergoing treatment in QLD (from larger study investigating supportive care needs of indigenous adults undergoing cancer treatment)	Sample size: n = 318 Eligible: n = 272/318 (85.5%) Mean age: 52 years Gender: Female: 54.1%	Education: Primary: n = 63.2% High school or more: n = 29.9% Language: English: 84.5% no other Aboriginal or Torres Strait Islander language: 53.5% Geographical location: Queensland, Australia Outer regional: 40% 51% travel away from home to receive treatment (Brisbane, Cairns, Townsville hospitals) Marital status: Not reported Employment status: Not reported Socio-economic status: 55.4% classified as having 'advantaged socio-economic status' (>30 days prior)	Cancer type: Breast: (22.3%) Blood related: (14.0%) Lung: (12%) Gastroenterological: (10.8%) Head and neck: (9.6%) Gynaecological: (8.9%) Male genital organs: (9.6%) Cancer stage: Not reported Comorbidities: Not reported Treatments: At the time of interview 67.5% receiving outpatient cancer treatment (chemotherapy, radiotherapy or surgery); or recently completed treatment (>30 days prior)	Sampling: Purposive Setting: Hospitalized or attending out-patient clinics for treatment or follow-up care in city areas	n = 157 183 were invited to take part: 157 (57.7% response rate) were interviewed, 26 (9.6%) refused. Patients missed n = 89 (32.7%)	Quantitative descriptive None	Time points: 1 Dates: September 2010–November 2011	Tools: Structured questionnaire delivered via face-to-face interviews Reliability & validity: Data analysis was conducted using SPSS Inc. version 17.11. Chi-squared tests used to test proportions

TABLE 1 (Continued)

Author and year	Purpose	Sample size, mean age (SD), years and gender	Participants	Clinical information	Sampling/setting	Response rate	Design and theoretical model	Time points (number of time points and dates)	Data collection tools
Bernardes et al., 2014	To explore the levels of interest among Indigenous Australians with cancer and identifying families and seeking genetic counselling	Sample size: n = 252 500 Indigenous patients identified, 396 (79.2%) eligible for the study and 295 (74.5%) invited to take part Mean age: 52.6 years (range 20–78 years), SD 12.807 Gender: Female: n = 143/252 (56.7%) Male: 109/252 (43.3%)	Education: <Year 12: n = 168/252 (66.7%) Language: English: n = 218/252 (86.5%) Geographical location: Outer regional: n = 95/252 (37.7%) Geographical group: Aboriginal: n = 192/252 (76.2%) Torres Strait Islander: n = 34/252 (13.5%) Aboriginal and Torres Strait Islander: n = 12/252 (4.8%) Other Indigenous: n = 14/252 (5.6%) Study Interviewers: n = 6/9 (67%) were Aboriginal and/or Torres Strait Islander descent Marital Status: Husbands/partners: n = 115/252 (45.6%) Single: n = 86/252 (34.1%) Separated/divorced: n = 32/252 (12.7%) Widowed: n = 19/252 (7.5%) Employment status: Unemployed: n = 191/252 (75.8%) Socio-economic status: Advantaged: n = 141/252 (56%)	Cancer type: Breast: n = 63/252 (25%) Blood related: n = 33/252 (13.1%) Lung: n = 27/252 (10.7%) Head and neck: n = 24/252 (9.5%) Female genital organs: n = 24/252 (9.5%) Gastroenterological: n = 23/252 (9.1%) Male genital organs: n = 20/252 (7.9%) Cancer stage: Not reported Comorbidities: Not reported Treatments: Not reported	Sampling: Purposeful (handed flyers to patients/ assessing monthly hospital reports) Setting: 4 large QLD hospitals n = 174/252 (69%) were utilizing hospital outpatient services Interviews were conducted in places convenient to both the participant and the interviewer	n = 252/396 (63.6%) response rate n = 43/396 (10.9%) refused n = 100/396 (25.2%) were 'missed'	Cross-sectional (as part of larger study) None	Time points: 1 Date: Patients attending outpatient clinics between September 2010 and December 2012	Tools: Structured questionnaire delivered via face-to-face interviews in English Remoteness: ARMA - Accessibility/ Remoteness Index of Australia Socio-economic Status: SEIFA - Socio-economic Indexes for Areas IRSAD - Index of relative socio-economic advantage and disadvantage Reliability & validity: Interviewers received standardized interview training. First few interviews were recorded and reviewed by the project manager to ensure consistency across the four study sites
Bernardes et al., 2018	Describe and reflect on the lessons learnt while training an IPN (Indigenous Patient Navigator) and implementing an intervention with Indigenous cancer patients in an Australian context To highlight to health professionals and researchers the methodological challenges faced when implementing interventions with this group	Sample size: IPN: n = 1 Participants: n = 26 Approached: n = 26 Participated: n = 18 Mean age: IPN: not reported Participants: 55 years (SD not reported) Gender: IPN: not reported Participants: Half were females (no other information was reported)	Education: IPN: not reported (previously worked as a health worker in a regional hospital and undertook IPN training and other role-specific workshops) Participants: not reported Language: IPN: not reported Participants: not reported Geographical location: IPN: not reported Participants: n = 11 (61%) lived in major cities Marital status: IPN: not reported Participants: not reported Employment status: IPN: not reported Participants: not reported Socio-economic status: Participants most advantaged: n = 6 (33%) Participants low-to-intermediate advantage: n = 6 (33%) Participants disadvantaged: n = 6 (33%)	Cancer type: Participants: range of cancer types (breast, gastrointestinal, lung, male genital organ, lymphoma, throat, adrenal gland and multiple myeloma) Participants: not reported Comorbidities: not reported Treatments: not reported Participants: Surgery: n = 3 (16.6%) Chemotherapy: n = 12 (66.6%) Radiotherapy: n = 10 (55.5%)	Sampling: Convenience Setting: Patients were attending the Princess Alexandra Hospital (QLD) for their care. Recruited from outpatient clinics and hospital wards	n = 18/26 (69%) No reasons were provided for those who declined to participate (n = 8/31%)	Pilot study None	Time points: IPN: 1 (Training) July to December 2013 Participants: 2 (pilot intervention) July 2013 to March 2014 T1 (baseline): enrollment in study T2 (follow up): 2 months after enrollment (interval average of 66 days (SD 10.7))	Tools: Face-to-face interviews using 3 x standardized assessments Needs=SCNAT-IP Distress=DT Worry=CWC Satisfaction survey conducted at completion (7 closed and 5 open-ended questions) n = 7/18 (39%) Reliability & validity: 3 x screening tools were utilized, however, it was reported that the IPN did not systematically conduct the assessment using the tools (personal perception that they were too laborious and preferred to rather information in an informal way)

(Continues)

TABLE 1 (Continued)

Author and year	Purpose	Sample size, mean age (SD, years) and gender	Participants	Clinical information	Sampling/setting	Response rate	Design and theoretical model	Time points (number of time points and dates)	Data collection tools
Bernardes et al., 2019	Aim was to describe and compare the prevalence and type of unmet needs between Indigenous and non-Indigenous people with cancer	Sample size: Indigenous: n = 125 (Included in cross-sectional data) *Original study Eligible: n = 396 Approached: n = 295 (74.5%) Interviewed: n = 252 (85.4%) Final sample: n = 248 (98.4%) Non-Indigenous: n = 125 (Included in cross-sectional data) *Original study Eligible: n = 809 Approached: n = 444 (54.8%) Interviewed: n = 290 (65.3%) Final sample: n = 288 (99.3%) Indigenous and Non-Indigenous were matched 1:1 in study data.	Education: Indigenous and non-Indigenous were matched 1:1 in study data For all (p = 1.000) Primary school or less/high school: n = 90/125 each (72%) Total for both groups: n = 180/250 (72%) Post-secondary school: n = 35/125 each (28%) Total for both groups: n = 70/250 (28%) Language: Not reported Geographical Location: For all (p < .001) Major city Indigenous: n = 49/125 (39%) Non-Indigenous: n = 97 (80%) *Not clearly reported - some participants unaccounted for* Outer/inner/regional Indigenous: n = 58/125 (46%) Non-Indigenous: n = 23 (19%) *Not clearly reported - some participants unaccounted for* Remote/very remote: Indigenous: n = 18/125 (14%) Non-Indigenous: n = 1/121 (0.8%) Marital status: Indigenous and Non-Indigenous were matched 1:1 in study data. For all (p = 1.000) Lives with partner: n = 67/125 each (54%) Total for both: n = 134/250 (54%) Does not live with partner: n = 58/125 each (46%) Total for both: n = 116/250 (46%) Employment status: Not reported Socio-economic status: For all (p = .033) Most disadvantaged to intermediate disadvantaged Indigenous: n = 60/125 (72%) Non-Indigenous: n = 101 (84%) *Not clearly reported - some participants unaccounted for* Most disadvantaged: Indigenous: n = 35/125 (28%) Non-Indigenous: n = 20 (17%) *Not clearly reported - some participants unaccounted for*	Cancer type: For all (p = .002) Breast Indigenous: n = 29/125 (23%) Non-Indigenous: n = 23/125 (18%) Respiratory (intra-thoracic organs) Indigenous: n = 15/125 (12%) Non-Indigenous: n = 20/125 (16%) Lymphoid, haematopoietic (and related) Indigenous: n = 12/125 (12%) Non-Indigenous: n = 36/125 (29%) Digestive Indigenous: 15/125 (12%) Non-Indigenous: 20/125 (16%) Lip, oral cavity and pharynx Indigenous: n = 13/125 (10%) Non-Indigenous: n = 10/125 (8%) Male genital organs Indigenous: n = 8/125 (6%) Non-Indigenous: n = 4/125 (3%) Female genital organs Indigenous: n = 9/125 (7%) Non-Indigenous: n = 0/125 (0%) Eye, brain and other CNS Indigenous: n = 8/125 (6%) Non-Indigenous: n = 3/125 (2%) Unknown primary site Indigenous: n = 13/125 (10%) Non-Indigenous: n = 9/125 (7%) Cancer stage: For all (p = .037) Local/regional Indigenous: n = 77 (65%) Non-Indigenous: n = 59 (48%) *Not clearly reported - some participants unaccounted for in both groups* Distant Indigenous: n = 24 (20%) Non-Indigenous: n = 38 (31%) *Not clearly reported - some participants unaccounted for in both groups* Not applicable Indigenous: n = 18 (15%) Non-Indigenous: n = 25 (21%) *Not clearly reported - some participants unaccounted for in both groups Comorbidities: Not reported Treatments: Not reported	Sampling: Purposive Setting: QLD Indigenous study: identified from 4 public hospitals (admitted or outpatient) Non-Indigenous study: 1 x public hospital (outpatient clinics and wards)	Not applicable (data from 2 previous cross-sectional studies)	Data from 2 x cross-sectional studies None	Time points: 1 Dates: Not reported Time since diagnosis to receiving treatment: Indigenous (n = 61/49%) Non-Indigenous (n = 28/22%) 91 days + Indigenous (n = 64/51%) Non-Indigenous (n = 97/78%)	Tools: Needs assessments Indigenous: SCNAT-IP Non-Indigenous: SCNS-SF34 (and some of the questions from SCNAT-IP) Socio-demographic: interview Remoteness: ARIA - using postcode of residence Socio-economic status: IRISAD Reliability & validity: Used standardized assessments to assess needs

TABLE 1 (Continued)

Author and year	Purpose	Sample size, mean age (SD), years and gender	Participants	Clinical information	Sampling/setting	Response rate	Design and theoretical model	Time points (number of time points and dates)	Data collection tools
Christou & Thompson, 2012	To identify important factors influencing the decision to undertake screening using faecal occult blood testing (FOBT) among Indigenous Australians	Sample size: n = 93 Mean age: Range: 45–54 years Gender: Female: 76.3% Male: n = 23.7%	Education: Completed senior high school or post-school qual: n = 44% Language: English: n = 94% Self-rated English reading ability: Poor-fair: n = 28% Geographical location: 2 regional and 1 metropolitan sites in WA Marital status: Married/de facto: n = 52.7% Separated/divorced/widowed: n = 12% Single: n = 26% Not reported: n = 5% Employment status: Full-time/part-time: n = 34% Unemployed/unable to work/other: n = 32% Home duties: n = 19% Not reported: n = 5% Socio-economic status: >\$20,000: n = 42% <\$20,000: n = 33%	Cancer type: Bowel cancer screening Cancer stage: N/A Comorbidities: Not reported Treatments: Not reported/applicable	Sampling: Convenience Setting: Face-to-face questionnaire administration	Not reported	Quantitative cross-sectional Health Belief Model	Time points: 1 Dates: November 2009–March 2010	Tools: Interviewer administered survey Reliability & validity: Small sample size Sampling strategy was non-random, the results of this study cannot be considered representative of all Indigenous Australians
Cuesta-Briand et al., 2016	Exploration of the roles played by Aboriginal women's cancer support network operating in regional town in WA (part of a study investigating cancer experiences, attitudes and beliefs among Aboriginal Australians)	Sample size: n = 24 Workers and representatives from aboriginal service providers: n = 3 Representatives from mainstream cancer services and agencies: n = 8 Network members: n = 6 Network clients: n = 4 Potential clients: (n = 3) Mean age: Not reported Gender: Female: n = 22 Male: n = 2	Education: Not reported Language: Not reported Geographical location: Regional Australia, 400 km from Perth, WA Marital status: Not reported Employment status: Not reported Socio-economic status: Not reported	Cancer type: Not reported Cancer stage: Not reported Comorbidities: Not reported Treatments: Support service in operation for approx. 9 months, providing support to an estimated 50 women affected by cancer	Purposive (Recruitment from key informants from Aboriginal and mainstream health service providers operating in the region, network members and clients) Setting: Individual and group interviews	n = 24	Qualitative Semi-structured interviews None	Time points: 1 Dates: 2008	Tools: Individual and group interviews Reliability & validity: Interviews were audio recorded and transcribed verbatim. Thematic analysis of transcripts Nvivo10 was used to manage data and assist analysis
Cuesta-Briand et al., 2015	To explore different understandings of how a cancer support group should operate and the impact of unresolved tensions following the establishment of Indigenous women's cancer peer-support network in a regional town in Western Australia	Sample size: n = 24 Indigenous service providers: n = 3 Mainstream service providers: n = 8 Network members: n = 8, Network clients: n = 4 Mean age: Not reported Gender: Female: n = 22 (92%) Male: n = 2 (8%)	Education: Not reported Language: Not reported Geographical location: Not reported Marital status: Not reported Employment status: Not reported Socio-economic status: Not reported	Cancer type: Not reported Cancer stage: Not reported Comorbidities: Not reported Treatments: Not reported	Purposive sampling Setting: Network fortnightly meetings were held at a local community venue	Not reported	Qualitative None	Time points: Interviews undertaken separately on 2 occasions. Participants were also brought together formally at a workshop forum Dates: Not reported	Tools: Open-ended interviews Reliability & validity: Followed data analysis technique set out by Green et al., 2018 brought together Nvivo 10 and Model feature used. Rigour was enhanced through team member checking, coding validation and peer debriefing
Dembinsky, 2014	Part of a broader study focused on the lived experiences of breast cancer in Yamatji women. This study sought to analyse perceptions and use of palliative care services	Sample size: n = 28 Aboriginal: n = 25 Non-Aboriginal: n = 3 Women with breast cancer (36%) Kin (36%) AHW: Aboriginal (18%) Non-Aboriginal (10%) Mean age: Range: early 30s to late 80s Gender: Female: n = 26 Male: n = 2	Education: Not reported Language: Not reported Geographical group: Yamatji people – Midwest rural areas Western Australia Marital status: Not reported Employment status: Not reported Socio-economic status: Not reported	Cancer type: Breast Cancer Cancer stage: Not reported Comorbidities: Not reported Treatments: Palliative care services	Purposive (n = 5) then snowball sampling Setting: Midwest region of Western Australia – called Yamatji; land: total population of 54,500	n = 28	Qualitative None	Time points: Not reported Dates: Data collection began in 2010	Tools: Informal interviews and observation Reliability & validity: Interviews were recorded, transcribed, coded and thematically analysed using NVivo 9 (QSR International), a qualitative data analysis programme

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TABLE 1 (Continued)

Author and year	Purpose	Sample size, mean age (SD, years) and gender	Participants	Clinical information	Sampling/setting	Response rate	Design and theoretical model	Time points (number of time points and dates)	Data collection tools
Diaz et al., 2016	Examine the relationship between comorbidity and supportive care needs among newly diagnosed Indigenous cancer patients	Sample size: n = 183 Mean age: 52.3 years Gender: 57.9% Female; 43.1% Male	Education: Not reported Language: Not reported Geographical location: Queensland Most socio-economically disadvantaged areas: n = 29.5% Very remote/remote: n = 21.9% Outer regional: n = 24.6% Marital status: Not reported Employment status: Not reported Socio-economic status: Not reported	Cancer type: Breast: n = 23% Digestive: n = 14.2% Respiratory: n = 13.1% Blood related: n = 21% Lip and oral: n = 19% Other: n = 51% Cancer stage: Of the 146 staged: Localized: n = 47% Regional spread: n = 54% Metastatic: n = 30.8% Distant mets: n = 45% Not reported: n = 13% N/A: 24% Comorbidities: Diabetes: n = 30.1% Respiratory disease: 25.7% Cardiovascular: n = 14.8% Treatments: 88.5% treatment in past 30 days	Sampling: Purposeful Setting: Not reported	Eligible: n = 396 Included: N = 183/396 (46%)	Quantitative None	Time points: 1 Dates: Recruited November 2010–December 2012	Tools: Face-to-face interview using structured questionnaire Charlson Comorbidity Index The Supportive Care Needs Assessment Tool for Indigenous patients (SCNAT-IP) Socio-economic: Accessibility/Remoteness Index of Australian (ARIA+) classifications Reliability & validity: Standardized measures were used Patients received questionnaires via verbal administration and written form Interviewers received standardized training and were continually monitored
Dorrington et al., 2015	Use of translational research and continuous quality improvement process to identify and address barriers and facilitators to pap smear screening within an urban Aboriginal community-controlled health service	Sample size: Survey: n = 30 Data collection tool by GP during consultation: n = 213 Mean age: 38 years (18–70 years) survey Gender: Female	Education: Not reported Language: Not reported Geographical location: Not reported Marital status: Not reported Employment status: Not reported Socio-economic status: Not reported	Cancer type: Pap smear screening Cancer stage: Not reported Comorbidities: Not reported Treatments: Not reported Study was done on Pap smear screening, not among people diagnosed with cancer	Sampling: Convenience sampling Setting: Urban Aboriginal community-controlled health service	Survey 76% Data collection tool by GP during consultation 98%	Translational research Interventional study None	Time points: 1 10 months follow up	Tools: GP administered tool to gather information regarding pap smear history, use of reminders and whether a pap smear was performed during consultation, reason for completion or not Reliability & validity: Researcher made tool, not mentioned validity and reliability of the tools
Gall et al., 2019	To explore the beliefs, attitudes and experiences related to T&M use and disclosure among Indigenous women undergoing gynaecological cancer investigations	Sample size: n = 18 Mean age: Quant: n = 14 (48.5 years; SD 14.9) Quat: n = 7 (56 years; SD 11) Gender: Female: n = 18 (100%)	Education: Education beyond year 10: 57% Language: English as main language at home: 57% Geographical location: Half of the participants lived in non-urban areas (50%) Marital status: Not reported Employment status: Unemployed at time of interview (57%) Socio-economic status: Lived in the most socio-economically disadvantaged areas (57%)	Cancer type: Gynaecological cancers (most common during phase 2 following confirmed diagnosis was endometrial cancer) Cancer stage: Information collected; however, due to incompleteness or lack of specificity, it was unable to be used in analysis Comorbidities: Two-thirds of participants had comorbidities such as hypertension, cardiovascular disease, renal disease and/or respiratory disease. Diabetes was most prevalent (54%) Treatments: Information collected; however, due to incompleteness or lack of specificity, it was unable to be used in analysis	Sampling: Purposeful (single-site recruitment) Setting: Specialist gynaecology cancer clinic QLD (in a major urban setting attached to a large public hospital)	N = 14/18 (78%) completed the questionnaire n = 7/14 (50%) completed interviews	Sequential explanatory mixed-methods design None	Time points: Data collected in 2 phases Phase 1 (pre-confirmed diagnosis): Quantitative data collection Phase 2 (post-confirmed diagnosis): Qualitative data collection Dates: September 2016–January 2018	Phase 1: RI-CAM-Q (face-to-face) Phase 2: In-depth semi-structured interviews

TABLE 1 (Continued)

Author and year	Purpose	Sample size, mean age (SD, years) and gender	Participants	Clinical information	Sampling/setting	Response rate	Design and theoretical model	Time points (number of time points and dates)	Data collection tools
Garvey et al., 2016	The objective of the current study was to explore the feasibility of using the Supportive Care Needs Assessment Tool (SCNAT-IP) in routine cancer care and the degree to which Indigenous Australians with cancer and health professionals find the SCNAT-IP useful and acceptable in routine care	Sample size: n=46 Cancer patients: n=36 Clinicians: n=10 Mean age: M=53.7 years, SD11.2 Gender: Female: n=25 Male: n=11	Education: Year 10 or below: n=21 Year 12 (matriculation): n=6 Tertiary: n=4 Language: English: n=21 Indigenous language: n=15 Geographical location: NSW Major city: n=4 Inner regional: n=6 Outer regional: n=20 Rural: n=3 Remote: n=3 Marital status: Single: n=10 Married/ de facto: n=19 Widowed/separated/divorced: n=7 Employment status: Employment: n=9 Unemployed: n=13 Retired/pension: n=11 Home duties: n=2 Socio-economic status: Not reported	Cancer type: Breast: n=13 Bowel: n=7 Head and neck: n=6 Lung: n=3 Gynaecological: n=2 Other: n=3 Cancer stage: Local disease: n=12 Regional spread: n=6 Distal metastases: n=12 Not applicable: n=3 Not known: n=3 Comorbidities: No known comorbidities: n=24 Diabetes: n=8 Cardiovascular: n=10 Respiratory: n=9 Other: n=16 Treatments: Receiving treatment: n=17 Newly diagnosed: n=5 Follow-up care: n=14 Surgery Completed: n=23 Planned: n=3 No/not applicable: n=9 Chemotherapy: Yes: n=23/No: n=13 Radiotherapy: Yes: n=21/No: n=15 Other cancer treatments: Yes: n=14/No: n=22	Purposive Setting: Two large tertiary care treatment centres and two regional oncology clinics	Invited: n=45 Consented: n=36 (90%)	Descriptive study None	Time points: One point of time and a follow-up	Tools: Brief, purpose-designed questionnaires and interviews Patient clinical and demographic characteristics Patient acceptability survey Service delivery outcomes form Health professional acceptability and feasibility survey Reliability & validity: Not reported
Garvey et al., 2018	Identify the level of and factors associated with distress in Indigenous Australian cancer survivors approximately 6 months post-diagnosis	Sample size: n=155 Part of a larger longitudinal study (n=248) Mean age: 51.6 years (range 20-78), SD not reported 18-39 years: n=29/155 (18.7%) 40-59 years: n=84/155 (54.2%) ≥60 years: n=42/155 (27.1%) Gender: Female: n=93/155 (60%) Male: n=62/155 (40%)	Education: Primary or less: n=43/155 (27.7%) Secondary: 69/155 (44.5%) Post-secondary: n=42/155 (27.1%) Language: Non-English: n=20/155 (12.9%) English: 134/155 (86.5%) Geographical location: Major city: n=31/155 (20%) Regional: 80/155 (51.6%) Remote: n=44/155 (28.4%) Geographical group: Aboriginal: n=118/155 (76.1%) Torres Strait Islander: n=30/155 (19.4%) Both Aboriginal and Torres Strait Islander: n=7/155 (4.5%) Marital status: Married: n=71/155 (45.8%) Single: n=50/155 (32.3%) Separated/divorced/widowed: n=34/155 (21.9%) Employment status: Employed: n=43/155 (27.7%) Unemployed: n=111/155 (71.6%) Socio-economic status: Advantaged: n=31/155 (20%) Intermediate: n=80/155 (51.6%) Disadvantaged: n=44/155 (28.4%)	Cancer type: Breast: n=41/155 (26.5%) Digestive: 69/155 (44.5%) Respiratory and intrathoracic: n=18/155 (11.6%) Leukaemia/lymphoma: n=18/155 (11.6%) Other: n=59/155 (38.1%) Cancer stage: Local: n=43/155 (27.7%) Regional: n=48/155 (31%) Distant: n=31/155 (20%) N/A: n=20/155 (12.9%) Comorbidities: Not reported Treatments: Surgery: n=25/155 (16.1%) Surgery and non-surgery treatment: n=78/155 (50.3%) Non-Surgical only: n=52/155 (33.5%) Admission Status: Inpatient: n=56/155 (36.1%) Outpatient: n=99/155 (63.9%)	Purposive Setting: Recruited from one of four major QLD public hospitals Interviews occurred in hospitals for inpatients at a time and place convenient for outpatients	N=155 (62.5% of larger longitudinal study 155/248)	Exploratory (as part of larger longitudinal study) None	Time points: 1 approx. 6 months post-diagnosis (range 4-6 months; mean 182.7 days) Dates: November 2010-December 2012	Individual interviews were conducted to collect socio-demographic data and in/outpatient status Hospital and medical records were reviewed to collect participants' clinical characteristics DT was used to assess distress (did not use accompanying problem checklist) ARIA - used to determine remoteness of residence Reliability & validity: DT is a valid screening tool

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TABLE 1 (Continued)

Author and year	Purpose	Sample size, mean age (SD, years) and gender	Participants	Clinical information	Sampling/setting	Response rate	Design and theoretical model	Time points (number of time points and dates)	Data collection tools
Green et al., 2018	Purpose: (a) identify the key components of patient experience that should be included in any experience of care measurements for Indigenous patients with cancer; and (b) elicit participants' views on the appropriateness and likely acceptability of various data collection approaches for this patient group, from the perspectives of Indigenous people affected by cancer, and health professionals involved in care provision to Indigenous patients with cancer. This information will provide important evidence to guide the development of tools and approaches to measure Indigenous Australian cancer patients' experiences of care and, ultimately, to drive system improvement	Sample size: n = 52 Round 1: n = 48 (n = 26 (54%) were Indigenous) <i>Indigenous cancer patients</i> : n = 17 (32%) Round 2: n = 48 (n = 5 (9.5%) Indigenous health workers were affected by cancer) Mean age: Range: 40–59 years Gender: Female: n = 42 Male: n = 10	Education: Not reported Language: Not reported Geographical location: Victoria, NSW, NT Marital status: Not reported Employment status: Not reported Socio-economic status: Not reported	Cancer type: Breast: n = 5 Prostate and bowel: n = 2 Cancer stage: Not reported Comorbidities: Not reported Treatments: Not reported	Sampling: Purposeful Setting: Phone interviews: n = 49 (58%) Face-to-face interviews: n = 23 (27%) Discussion groups: n = 12 (14%)	Not reported	Qualitative None	Time points: 2 rounds of semi-structured interviews and focus groups Dates: May and November 2016	Tools: Semi-structured interviews and focus groups Reliability & validity: Interviews were audio recorded and transcribed Checking of transcripts and comments: NVivo software to develop coding and themes Detailed and repeated coding of transcripts by two researchers was undertaken and data were repeatedly reviewed
Lyford et al., 2018	Examination of benefits of a newly established rural-based radiotherapy unit in south-west WA	Sample size: n = 24 Patients: n = 3 Service providers: n = 21 Mean age: Not reported Gender: Female: n = 14 Male: n = 10	Education: Not reported Language: Not reported Geographical location: WA Marital status: Not reported Employment status: Not reported Socio-economic status: Not reported	Cancer type: Not reported Cancer stage: Not reported Comorbidities: Not reported Treatments: Radiotherapy	Sampling: Not reported Setting: South-west WA	Not reported	Qualitative None	Time points: Not reported	Tools: In-depth, semi-structured interviews. Audio recorded Reliability & validity: Verbatim transcription, NVivo data analysis. Analysis followed by Green et al., 2018—immersion, open coding, creating categories and identifying themes. Member checking, triangulation of service providers and team members' agreement on key themes
McGrath et al., 2006	To build an understanding between mainstream palliative care and Aboriginal culture by exploring the differing Indigenous and non-Indigenous and Western notions of cancer, its causation and treatment modalities To build an innovative model for Indigenous palliative care	Sample size: n = 72 Indigenous patients: n = 10 Indigenous caregivers: n = 19 healthcare workers: n = 41 Interpreters: n = 2 Mean age: Not reported Gender: Not reported	Education: Not reported Language: Not clearly reported For some interviews, an interpreter was used, as many of the language texts were influenced by a combination of English and the Indigenous language Geographical location: 4 × geographical areas of the NT, which included (1) East Arnhem Land (2) Katherine Region (3) Alice Springs (4) Darwin Marital status: Not reported Employment status: Not reported Socio-economic status: Not reported	Cancer type: Not reported Cancer Stage: Not reported Comorbidities: Not reported Treatments: Not reported	Sampling: Purposeful Setting: Not clearly reported aside from the 4 geographical areas	n = 72 interviews conducted	Qualitative (exploratory, iterative and open ended) None	Time points: 1 Dates: Not reported	Tools: Open-ended interviews conducted by experienced Indigenous person (the Aboriginal community extensively consulted and involved) Reliability & validity: Not reported

TABLE 1 (Continued)

Author and year	Purpose	Sample size, mean age (SD, years) and gender	Participants	Clinical information	Sampling/setting	Response rate	Design and theoretical model	Time points (number of time points and dates)	Data collection tools
McGrath & Rawson, 2013a	To explore the experience of vulvar cancer from the perspective of Indigenous women and the health professionals who care for them. Particularly the major psychosocial factors associated with vulvar cancer that impact on the likelihood of women seeking out diagnosis and treatment	Sample size: n=40 Indigenous women with condition: n=12/40 (30%) AHW: n=14 (35%) Nurses: n=10 (25%) Doctors: n=3 (7.5%) Community member: n=1 (2.5%) Mean age: Not reported Gender: Indigenous women with condition: Female AHW/health professionals: not reported	Education: Not reported Language: Not reported Interviews were conducted by an Indigenous woman with experience as a linguist in Indigenous language who was aware of East Arnhem Land culture and kinship connections to the community Geographical group: East Arnhem Land, NT Marital status: Not reported Employment status: Not reported Socio-economic status: Not reported	Cancer type: Vulvar cancer (Women's business') Cancer stage: Not reported Comorbidities: Not reported Treatments: Not reported The treatment approach involves primary surgery, as well as radiation, often with concurrent chemotherapy. The women from East Arnhem Land have to travel away from the community to major treating hospitals in the metropolitan areas	Sampling: Purposive Setting: East Arnhem Land, NT. Interviews conducted with Indigenous women and AHW/health professionals in the community in allocation of their choice	n=40 Interviews conducted	Qualitative None	Time points: 1 Dates: Not reported	Tools: In-depth interviews conducted by an Indigenous woman who used the format of encouraging women to 'tell their story' No structured interview schedule but rather topics to introduce into the 'story telling' Reliability & validity: Not applicable
McGrath & Rawson, 2013a	Article discussing the experience of relocation for specialist care for Indigenous women diagnosed with vulvar cancer (information taken from findings of data collected looking at the experience of diagnosis and treatment for women with vulvar cancer)	Sample size: n=40 n=12 diagnosed with vulvar cancer (documentation between 1996 and 2005, n=21 diagnosed in the NT; 13 from this area) Mean age: Not reported Gender: Female	Education: Not specified Language: Indigenous language – not specified Geographical location: East Arnhem Land, Northern Territory, Australia Marital status: Not reported Employment status: Not reported Socio-economic status: Not reported	Cancer type: Vulvar Cancer Stage: Not reported Comorbidities: Not reported Treatments: Referred to specialist services in Darwin, Gove, Adelaide and Brisbane. For surgery, chemotherapy and radiotherapy	Sampling: Purposive Setting: Telephone: n=4 Face-to-face: n=36	Purposive	Qualitative None	Time points: 1 Dates: Not specified	Tools: In-depth interviews 'story-telling' pace set by participants Reliability & validity: Interviews were audio recorded and transcribed verbatim. Language text entered into QSR NVivo (version8) and coded. Data analysed thematically
McGrath et al., 2015	Explores the bioethical issues associated with the diagnosis and treatment of vulvar cancer for Indigenous women in East Arnhem Land, Northern Territory, Australia Major study funded by the National Health and Medical Research Council of Australia (NHMRC) (Condon et al., 2011–2012). the bioethical issues presented in this article come from the qualitative research component of the psychosocial study that explored community beliefs about possible causation of the disease and aspects of their cancer experience for the women affected	Sample size: n=40 Women diagnosed with condition: n=12 Health professionals: n=28 Community member: n=1 Mean age: Not mentioned Gender: Female	Education: Not reported Language: Not reported Geographical location: Not reported Marital status: Not reported Employment status: Not reported Socio-economic status: Not reported	Cancer type: Vulvar cancer Cancer stage: Not reported Comorbidities: Not reported Treatments: Not reported	Sampling: Purposive sampling Setting: In East Arnhem Land, Northern Territory, Australia community	40 (12 females diagnosed with the condition)	Qualitative In-depth interviews with a purposive sample of Indigenous women, Aboriginal Health Workers (AHWs) and health professionals in East Arnhem Land None	Time points: 1 Dates: Not specified	Tools: No structured interview tool Areas explored were (a) the experience of diagnosis and treatment for the women affected; (b) the potential psychosocial impact on the individual, their family and community; (c) additional supportive and healthcare strategies that would assist the women to cope with diagnosis and treatment; and (d) possible causes, with specific prompting on potential topical agents and whether the cancer was perceived as a recent problem Reliability & validity: Not reported

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TABLE 1 (Continued)

Author and year	Purpose	Sample size, mean age (SD, years) and gender	Participants	Clinical information	Sampling/setting	Response rate	Design and theoretical model	Time points (number of time points and dates)	Data collection tools
McMichael et al., 2000	To identify cultural, gender and logistical/distance issues that affected women's awareness, detection, treatment and post-treatment care and the availability of support for women with breast cancer	Sample size: Total: n=194 Indigenous female: n = 101/194 (52%) Male: n = 8/194 (4%) Health providers and professionals: n=85/194 (44%) Mean age: Indigenous women: most were over 40 years, but several younger women also participated. No further distinction was provided (SD not reported) Gender: Indigenous females: 101/194 (52%) Males: 8/194 (4%) Health Services/Professionals: Not reported	Education: Not reported Language: Not reported Geographical location: Urban: Brisbane and Sunshine Coast Rural: Cherbourg and Cunnamulla Remote: Mt Isa, Cairns, Weipa, Kowanyama, Aurukun and Cloncurry Marital status: Not reported Employment status: Not reported Socio-economic status: Not reported	Cancer type: Breast cancer Cancer stage: Not reported Comorbidities: Not reported Treatments: Not reported In rural and remote, treatment services are limited and women are generally referred to large and regional hospitals	Sampling: Purposive Setting: Urban, rural and remote settings QLD. Interviews and focus groups were conducted in women's homes	n = 194 (interview and focus group data)	Qualitative	Time points: 1 Dates: 1998-1999 (study conducted over a period of 9 months)	Tools: Semi-structured interviews Case histories Focus groups (triangulated with community feedback and discussions with steering committee) Reliability & validity: Not reported
Meiklejohn et al., 2017	The purpose of this study was to explore Indigenous Australian cancer survivors' perspectives of follow-up cancer care and management	Sample size: n = 21 Mean age: Range: 45-64 years Gender: Female: n = 13 (62%) Male: n = 8 (38%)	Education: Primary: n = 7 Junior high: n = 8 Senior high: n = 0 TAFE: n = 5 University: n = 1 Language: English Geographical group: Major city: n = 12 Inner regional: n = 3 Outer regional: n = 1 Remote: n = 0 Marital status: Very remote: n = 5 Single: n = 3 Married/de facto: n = 11 Separated/widowed/divorced: n = 7 Employment status: Full/part time: n = 6 Retired: n = 7 Centrelink: n = 7 Home duties: n = 1 Socio-economic status: Not reported	Cancer type: Breast: n = 9 Blood related: n = 3 Head and neck: n = 2 Brain: n = 2 Other: (thymus, lung, skin, female genital organ and male genital organ): n = 5 Cancer stage: Not reported Comorbidities: Not reported Treatments: Not reported	Sampling: Convenience Setting: Primary healthcare service or large tertiary hospital follow-up care	100%	Qualitative (Yarning methods) None	Time points: 1 Yarn', between 6 months to 5 years post-cancer diagnosis	Tools: Recorded interview Reliability & validity: Strengths and limitations: Audio recorded and transcribed Mentioned trustworthiness and credibility were not discussed but appeared implicit in the data collection

TABLE 1 (Continued)

Author and year	Purpose	Sample size, mean age (SD, years) and gender	Participants	Clinical information	Sampling/setting	Response rate	Design and theoretical model	Time points (number of time points and dates)	Data collection tools
Meiklejohn et al., 2018	Explores cancer survivorship perceptions of Indigenous cancer survivors, their support people and healthcare workers (This study builds upon work previously conducted by the authors; Meiklejohn et al., 2017)	Sample size: n = 22 Mean age: Not reported Gender: Female: n = 14 Male: n = 8	Education: Primary School: n = 5 Grade 10: n = 12 Grade 12: n = 1 TAFE/Trade: n = 1 University: n = 3 Language: Not reported Geographical location: Major city: n = 3 Inner regional: n = 0 Outer regional: n = 11 Very remote: n = 8 Marital status: Married/partner/de facto: n = 11 Single: n = 6 Separated/divorced/widow: n = 5 Employment status: Full time: n = 5 Part time: n = 1 Home duties: n = 0 Centre link support: n = 11 Retired: n = 5 Socio-economic status: Not reported	Cancer type: Breast: n = 6 Thyroid: n = 3 Gyna: n = 2 Other: n = 3 Cancer stage: Not reported Comorbidities: Not reported Treatments: Not reported	Sampling: Not stated Setting: Large tertiary QLD hospital when returning for follow-up cancer care and 2 remote primary healthcare services	Not reported	Qualitative None	Time points: 1 Dates: May 2015–September 2016	Tools: Focus groups Reliability & validity: Verbatim transcription, NVivo analysis, Inductive thematic analysis, Team member cross-checking for validity
Meiklejohn et al., 2020	Explore Indigenous Australian cancer survivor's perspectives of cancer survivorship	Sample size: n = 19 Mean age: 25–44 years: n = 2/19 (10%) 45–64 years: n = 10/19 (53%) >65 years: n = 7/19 (37%) Gender: Female: n = 13/19 (68%) Male: n = 6/19 (32%)	Education: Primary: n = 6/19 (32%) Junior high: n = 8/19 (42%) Senior high: n = 0/19 (0%) Technical and further education: n = 4/19 (21%) University: n = 1/19 (5%) Language: English speaking was a requirement of participation Geographical location: QLD Major city: n = 11/19 (58%) Inner regional: n = 3/19 (16%) Outer regional: n = 1/19 (5%) Very remote: n = 4/19 (21%) Marital status: Single: n = 3/19 (16%) Married/de facto: n = 10/19 (53%) Separated/widowed/divorced: n = 6/19 (31%) Employment status: Full/part-time: n = 6/19 (31.5%) Retired: n = 6/19 (31.5%) Centre link support: n = 9/19 (47.4%) Home duties: n = 1/19 (5%) Socio-economic status: Not reported	Cancer types: Breast: n = 9/19 (47%) Blood related: n = 3/19 (16%) Head and neck: n = 2/19 (11%) Brain: n = 1/19 (5%) Other: n = 4/19 (21%) Cancer stage: All post-treatment and 'disease free' Comorbidities: Not reported Treatments: Not reported	Sampling: From tertiary hospital and remote primary health services Setting: Location of interviews was convenient for the participants. They could also choose to have a support person present	n = 19/21 (90.5% eligible)	Qualitative description Social construction framework	Time points: 1 Dates: Interviews conducted between May 2015 and April 2016	Tools: Interviews and semi-structured interview guides are given in tables: No formal tools Reliability & validity: Not reported

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TABLE 1 (Continued)

Author and year	Purpose	Sample size, mean age (SD, years) and gender	Participants	Clinical information	Sampling/setting	Response rate	Design and theoretical model	Time points (number of time points and dates)	Data collection tools
Mool et al., 2012	To assess the level of satisfaction and the responses of Indigenous patients, their families and healthcare workers (HWs) to video conferencing (VC) and such teleoncology service	Sample size: Patients: n = 23 (participated in VC) N = 9 interviews Family: n = 2 interviews HWs: n = 6 interviews (doctor: n = 1; CNC: n = 1; RN: n = 2; Indigenous liaison: n = 1; senior support officer: n = 1) Mean age: Patients: 59.3 years (range 44–69; SD not reported) Family: not reported HWs: not reported Gender: Patients Female: n = 6/9 (66%) Male: n = 3/9 (33%)	Education: Not reported Language: Not reported Geographical location: From place of residence to Townsville: 800 km (65–1286) From place of residence to nearest VC unit: 9 km (1–383) Geographical group: Aboriginal: n = 7/9 (77%) Torres Strait Islander: n = 2/9 (22%) Marital status: Not reported Employment status: Not reported Socio-economic status: Not reported	Cancer type: Not reported Cancer stage: Not reported Comorbidities: Not reported Treatments: Not reported	Sampling: Purposive (identified via Townsville Cancer Centre's oncology information database) Setting: Face-to-Face via telephone or VC according to feasibility and interviewee preference	Patients: n = 9/23 (39%) Family: not reported HWs: 6/6 (100%)	Qualitative None	Time points: 1 Dates: Patients had used a VC service between January 2007 and July 2011	Semi-structured interviews using a mix of open-ended and graded-response questions
Newman et al., 2017	Describe the experiences of Aboriginal people with cancer diagnosis and care. It is a part of the Aboriginal Patterns of Cancer Care (APOCC) project funded by National Health and Medical Research Council	Sample size: Total: n = 23 Men with cancer: n = 6 Carers: n = 12 Clinicians: n = 5 Mean age: Aboriginal men with cancer: 1940s: n = 1 1950s: n = 1 1960s: n = 2 1970s: n = 1 Year of birth not provided: n = 1 Carers: 1940s: n = 0 1950s: n = 1 1960s: n = 5 1970s: n = 2 Year of birth not provided: n = 4 Clinicians: Not reported Gender: Men with cancer: n = 6 Carer: Female: n = 11 Male: n = 1 Clinicians: Females	Education: Not reported Language: Not reported Geographical group: Men with cancer – Aboriginal Carers – 10 Aboriginal Clinicians – 3 urban services 2 – rural or regional areas Marital status: Not reported Employment status: Aboriginal men with cancer Unknown – 2 Full time – 1 Receiving disability benefit – 2 Unemployed – 1 Socio-economic status: Not reported	Cancer type: Prostate cancer: n = 3 Leukaemia: n = 1 Liver: n = 1 Testicular: n = 1 Cancer stage: Not reported Comorbidities: Not reported Treatments: Not reported	Sampling: Purposive sampling Setting: Done in NSW exact setting not mentioned	Not applicable	Qualitative study Secondary analysis of qualitative interviews None	Time points: 1 Dates: Not specified	Tools: The interviews were semi structured and open ended Interviews with Aboriginal men and women explored their understandings and experiences of cancer risk, symptoms, diagnosis and care, including treatment decisions Interviews with carers or clinicians explored their personal and/or professional views on and experiences of Aboriginal people with cancer Reliability & validity: Not reported

TABLE 1 (Continued)

Author and year	Purpose	Sample size, mean age (SD), years and gender	Participants	Clinical information	Sampling/setting	Response rate	Design and theoretical model	Time points (number of time points and dates)	Data collection tools
Page et al., 2016	To survey the level of lung cancer awareness in rural and remote Aboriginal and Torres Strait Islander communities and discover perceived barriers to timely diagnosis and treatment of lung cancer	Sample size: n = 67 Community members: n = 51 Indigenous Health Workers: n = 14 Patients: n = 2 Mean age: Community members: <30 years: n = 8 31–50 years: n = 21 >51 years: n = 22 Indigenous Health Workers: <30 years: n = 3 31–50 years: n = 7 >51 years: n = 4 Gender: Community Members Female: n = 65% Male: n = 35% Indigenous Health Workers Female: n = 57% Male: n = 43%	Education: Community Members: <Grade 10: n = 31% Grades 10–12: n = 49% >Grade 12: n = 20% Indigenous Health Workers: Not reported Language: English, no Indigenous language spoken at home Geographical location: Three Queensland outer regional and remote communities and one urban setting Marital status: Community members Married or de facto: n = 61.5% Single: n = 29% Divorced: n = 8% Indigenous Health Workers Not reported Employment status: Community members Full time: n = 51% Part time/casual: n = 16% Not working: n = 33% Socio-economic status: Community members only answered this question <20k: n = 40% 20–40k: n = 31% >40k: n = 28% Declined to answer: n = 6	Cancer type: Lung Cancer awareness: Not reported Comorbidities: Not reported Treatments: Not reported	Sampling: Purposive & snowballing technique Setting: Queensland outer regional and remote communities and one urban setting	Variable response rate to some questions	Mixed Methods None	Time points: 1 Dates: Not specified	Tools: Questions were sourced from a lung cancer awareness survey conducted in the UK, surveys used in a study on respiratory diseases and remaining questions were developed by the research team. The interview schedules were tested in Brisbane by Indigenous elders and Indigenous project officers Reliability & validity: Not reported
Pilkington et al., 2017	To examine perspectives on breast screening among Aboriginal women in Western Australia, exploring the factors which impact on their participation in breast screening. It also sought to identify potential initiatives that could consolidate existing efforts to increase participation	Sample size: n = 65 Mean age: Range: 24 years to 64 years (mean and SD not reported) Gender: Female: n = 59/65 (91%) Male: n = 6/65 (9%)	Education: Not reported Language: Not reported Geographical location: Metropolitan, rural and remote locations in Western Australia (screening services located in Perth Metropolitan area, a regional service based in Bunbury and four mobile vans visiting almost 100 rural towns) Marital status: Not reported Employment status: Not reported Socio-economic status: Not reported	Cancer type: Breast cancer screening Cancer stage: Not reported Comorbidities: Not reported Treatments: Not reported	Sampling: Networking, snowballing Setting: Various (most convenient for the research participants)	N = 65/67 (97%) *2 individuals who attended a session but participated by indicating agreement with others rather than expressing their own views have not been classified as research participants*	Qualitative descriptive None	Time points: 1 Dates: Not reported	Tools: Semi-structured interviews, focus groups and yarning circles Semi-structured interview questions were given Reliability & validity: Not reported
Prior, 2009	Exploration of why Aboriginal women participate in cancer screening but are reluctant to follow up results or accept medical advice about treatment	Sample size: n = 48 Mean age: Not reported Gender: Not clearly described	Education: Not reported Language: Not reported Geographical location: 2 Aboriginal communities in QLD Marital status: Not reported Employment status: Not reported Socio-economic status: Not reported	Cancer type: Not reported Cancer stage: Not reported Comorbidities: Not reported Treatments: Not reported	Sampling: Purposeful Setting: 2 Aboriginal communities QLD in	Not stated	Qualitative descriptive	Time points: Multiple time points (1–2 weeks in communities over 2 year period)	Tools: Community observations, interviews Reliability & validity: Data-driven reflexivity

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TABLE 1 (Continued)

Author and year	Purpose	Sample size, mean age (SD), years and gender	Participants	Clinical information	Sampling/setting	Response rate	Design and theoretical model	Time points (number of time points and dates)	Data collection tools
Reilly et al., 2018	This study sought to understand how care coordination influences Aboriginal people's experiences of cancer treatment	Sample size: Total: n = 62 Aboriginal patients or cancer survivors: n = 29/62 (47%) Cancers: n = 11/62 (18%) Service providers: n = 22/62 (35%) Mean age: mean and SD not reported Range: 19 years to 75 years Patients 18–25 years: n = 5/29 (17%) 26–45 years: n = 2/29 (7%) 46–65 years: n = 13/29 (45%) 66+ years: n = 6/29 (21%) Carers 18–25 years: n = 1/11 (9%) 26–45 years: n = 5/11 (45%) 66+ years: n = 0/11 (0%) Service Providers Not reported Gender: Patients Male: n = 16/29 (55%) Female: n = 13/29 (45%) Carers Male: n = 4/11 (36%) Female: n = 7/11 (64%) Service Providers: Male: n = 5/22 (23%) Female: n = 17/22 (77%)	Education: Not reported Language: Participants were proficient in English as a first or additional language (no interpreters used) Geographical location: South Australia Patients Urban: n = 11/29 (38%) Regional: n = 3/29 (10%) Remote: n = 15/29 (52%) Carers Urban: n = 2/11 (18%) Regional: n = 5/11 (45%) Remote: n = 4/11 (36%) Service providers: Urban: n = 5/22 (23%) Regional: n = 3/22 (14%) Remote: n = 6/22 (27%) Marital status: Not reported Employment status: Not reported Socio-economic status: Not reported	Cancer type: Cancers of concern to patients and carers: Respiratory: n = 6 GI: n = 4 Breast: n = 4 H&N: n = 3 Reproductive: n = 4 Haem: n = 7 Other: n = 3 Cancer Stage: Not reported Comorbidities: Not reported Treatments: Not reported	Sampling: Convenience and snowball Setting: Participants nominated their preferred interviewer and location (with a view to maximizing cultural safety)	Not reported	Qualitative None	Time points: 1 Dates: January 2015–July 2016	Tools: Face-to-face semi-structured interviews Reliability & validity: Narratives entered into 'cancer pathway mapping tool' Thematic analysis via NVivo with iterative cycles of revision with Aboriginal cultural advisors
Shahid, Finn, & Thompson, 2009	To report Aboriginal patients' views about effective communication between Aboriginal people and health service providers in Western Australian hospital settings	Sample size: n = 30 Aboriginal patients with cancer: n = 14/30 (47%) Family members: n = 16/30 (53%) Mean age: mean and SD not reported Age groups: 30–39 years: n = 4/30 (13%) 40–49 years: n = 18/30 (60%) 50–59 years: n = 5/30 (17%) ≥60 years: n = 3/30 (10%) Gender: Female: n = 23/30 (77%) Male: n = 7/30 (23%)	Education: Not reported Language: All participants spoke English Geographical location: Urban: n = 11/30 (37%) Regional: n = 19/30 (63%) Marital status: Not reported Employment status: Not reported Socio-economic status: Not reported	Cancer type: Not reported Cancer Stage: Not reported Comorbidities: Not reported Treatments: Not reported	Sampling: Purposive with limited snowball recruitment in rural settings Setting: Interviews were conducted in a setting of the participants' choice	n = 30 interviews conducted	Qualitative (thematic analysis) Social ecological Model	Time points: 1 Dates: 01 March 2006–30 September 2007	Tools: In-depth, semi-structured interviews Reliability & validity: Interviews were audio recorded, transcribed verbatim and coded independently by two researchers Feedback sessions with available participants clarified whether emerging themes were an accurate reflection of participants' experiences
Shahid, Finn, & Thompson, 2009	This paper reports the first comprehensive Australian study of Aboriginal beliefs about cancer (This was a qualitative study in which the 'meaning of cancer' was explored among Aboriginal people in WA)	Sample size: n = 37 Aboriginal participants Cancers/survivors: n = 14/37 (38%) Family members (of those who had died from cancer): n = 16/37 (43%) Health Service Providers: n = 7/37 (19%) Mean age: 30–39 years: n = 5/37 (14%) 40–49 years: n = 19/37 (51%) 50–59 years: n = 9/37 (24%) 60+ years: n = 4/37 (11%) Gender: Female: n = 29/37 (78%) Male: n = 8/37 (22%)	Education: Not reported Language: All spoke English Geographical location: Various geographical areas within W.A. Urban: n = 15/37 (41%) Regional: n = 22/37 (59%) Marital status: Not reported Employment status: Not reported Socio-economic status: Not reported	Cancer type: Not reported Cancer stage: Not reported Comorbidities: Not reported Treatments: Not reported	Sampling: Not reported Setting: Not reported	Not reported	Qualitative Social constructionist framework	Time points: 1 Dates: Interviews conducted between March 2006 and September 2007	Tools: Semi-structured interview (participants were encouraged to introduce topics of importance to them) Reliability & validity: Thematic analysis – coded independently by two researchers To maximize reflexivity and rigour, all stages were discussed within the research team. Interpretation was assessed by consultation with members and rigorous debriefing and feedback sessions via at-pack and original Aboriginal

TABLE 1 (Continued)

Author and year	Purpose	Sample size, mean age (SD, years) and gender	Participants	Clinical information	Sampling/setting	Response rate	Design and theoretical model	Time points (number of time points and dates)	Data collection tools
Shahid et al., 2010	An overview of the use of bush medicine and traditional healing among Aboriginal Australians for their treatment of cancer and the meaning attached to it and argues for health service providers to recognize its importance in the life of Aboriginal people, especially during consultation	Sample size: (part of another study n=37) Aboriginal participants who made mention about bush medicine (focus of this paper) n=11 Patients: n=4/11 (36%) Family: n=4/11 (36%) HCPs: n=3/11 (27%) Mean age: Not reported for the sample represented in this paper Gender: Not reported Female: n=9/11 (82%) Male: n=2/11 (18%)	Education: Not reported Language: English Geographical location: Western Australia Urban: n=6/11 (55%) Rural: n=3/11 (27%) Remote: n=2/11 (18%) Marital status: Not reported Employment status: Not reported Socio-economic status: Not reported	Cancer type: Reported for 9/11 patients Breast: n=3/11 (27%) Cervical: n=2/11 (18%) Head and neck: n=1/11 (9%) Lung: n=2/11 (18%) Unknown: n=1/11 (9%) Cancer stage: Not reported Comorbidities: Not reported Treatments: Not reported	Sampling: Purposive Setting: Not reported Interviews were conducted in Perth (urban), one rural and two remote areas of Perth, WA	Not reported (only used interviews relevant to the study aim n=11)	Qualitative (thematic analysis) None	Time points: 1 Dates: March 2006 and September 2007	Tools: In-depth, open-ended interviews Reliability & validity: Interviews were audio recorded and transcribed verbatim. Transcripts were reviewed by two researchers, independently
Shahid et al., 2011	An explicit aim of the research was to explore differences in experiences for Aboriginal people based on their residence in urban, rural or remote settings This paper focuses on what could be considered as infrastructure necessities for Aboriginal patients on their cancer journey including transport, accommodation, preparation for hospital-based cancer treatment, service affordability and support services	Sample size: n=30 Mean age: Adults Gender: Not reported Remote area: n=2 (0.07%) Marital status: Not reported Employment status: Not reported Socio-economic status: Not reported	Education: Not reported Language: English Geographical location: Western Australia Urban: n=11 (37%) Rural: n=9 (30%) Remote area: n=2 (0.07%) Marital status: Not reported Employment status: Not reported Socio-economic status: Not reported	Cancer type: Not reported Cancer stage: Not reported Comorbidities: Not reported Treatments: Not reported	Sampling: Not reported Setting: Rural, remote and urban areas of WA	Not reported	Qualitative description None	Time points: 1 Dates: One interview between March 2006 and September 2007	Tools: Semi-structured interview, no specific tools reported Thematic analysis independent coding by two researchers and use of N-Vivo7 software Yarning methodology Reliability & validity: Interviews were audio-recorded, transcribed verbatim and coded independently by two researchers before members of the team conferred Feedback sessions with available participants assisted clarification of whether emerging themes were an accurate reflection of participants' experiences
Shahid et al., 2013	To report on cancer service providers' views about the factors impacting communication & offering practical strategies to improve communication with Indigenous Australian cancer patients in WA	Sample size: n=62 Mean age: Not reported Gender: Female: n=51 Male: n=11	Education: Not reported Language: Not reported Geographical group: Western Australia Urban: n=33 Rural: n=29 Marital status: Not reported Employment status: Not reported Socio-economic status: Not reported	Cancer type: Not reported Cancer stage: Not reported Comorbidities: Not reported Treatments: Not reported	Sampling: initially, information sheet sent to service managers, requesting interested staff to contact. Others purposive recruited Setting: WA (Perth +6 remote/rural regions of WA)	Not reported	Interviews Social ecological framework	Time points: 2 Dates: March 06-September 07 April-October 2011	Tools: Semi-structured interviews Reliability & validity: Digitally recorded, transcribed verbatim, NVivo inter-coding reliability checks by members of the research team coding and re-checking of coding

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TABLE 1 (Continued)

Author and year	Purpose	Sample size, mean age (SD, years) and gender	Participants	Clinical information	Sampling/setting	Response rate	Design and theoretical model	Time points (number of time points and dates)	Data collection tools
Shahid et al., 2016	Examine factors contributing to delayed diagnosis of cancer among Aboriginal Australians from patient and service providers' perspectives	Sample size: Cancer survivors n = 14 Family: n = 16 HSP: n = 62 Mean age: Not reported Gender: Not reported	Education: Not reported Language: English Geographical location: All from Western Australia Survivors and Family 19 (63%) were from rural/remote communities and 11 were from urban areas For the HSP, about equal proportions of all HSPs were recruited from urban and rural settings Marital status: Not reported Employment status: The HSPs (62 in total) comprised general practitioners (GPs)/clinic nurses (29.0%), oncologists (3.2%), Aboriginal health workers (19.3%), cancer nurse coordinators (8.1%), palliative care providers (17.7%), social workers (11.3%) and others (11.3%). Socio-economic status: Not reported	Cancer type: Not reported Cancer stage: Not reported Comorbidities: Not reported Treatments: Not reported	Sampling: Purposive and snowball Setting: Rural, remote and urban areas of WA	Not reported	Qualitative Social constructionist	For cancer sufferers and families: not reported For HSP: interview 1 between March 2006 and September 2007; interview 2 between April and October 2011	Tools: No standardized tools used Reliability & validity: Data were rechecked by at least two members of the research team to examine how the codes can be linked to form coherent themes
Tam et al., 2018	To explore the cancer care experiences of Indigenous Australians diagnosed with cancer	Sample size: n = 12 Mean age: 20–44 years old: n = 4 (33%) 45–64 years old: n = 3 (25%) 65+ years: n = 5 (42%) Gender: Female: n = 9 (75%) Male: n = 3 (25%)	Education: Primary school: n = 1 (8.5%) Year 10 or equivalent: n = 6 (50%) Year 12 or equivalent: n = 1 (8.5%) Vocational education or university: n = 4 (33%) Language: Not reported Geographical location: Major city: n = 8 (68%) Inner regional: n = 2 (16%) Outer regional: n = 2 (16%) Marital status: Not reported Employment status: Full-time paid work: n = 2 (16%) Part-time or casual paid work: n = 3 (25%) Centrelink: n = 5 (42%) Home duties: n = 1 (8.5%) Retired: n = 1 (8.5%) Socio-economic status: Not reported	Cancer type: Breast cancer: n = 5 (42%) Lymphoma: n = 4 (33%) Other (lung, thymus, head and neck): n = 3 (25%) Primary cancer: n = 10 (84%) Recurrence or metastatic cancer: n = 2 (16%) Cancer stage: Not reported Comorbidities: Not reported Treatments: Surgery: n = 8 (68%) Chemotherapy: n = 10 (84%) Radiotherapy: n = 6 (50%) Other (hormone therapy, stem cell transplant): n = 3 (25%)	Sampling: Convenience sampling Setting: Large tertiary public hospital (QLD)	12/19 (63%) response rate	Qualitative None	Time points: 1 Dates: June 2012–January 2014	Tools: Semi-structured interviews Duration of interviews between 14 and 98 min Reliability & validity: Inductive thematic analysis Reliability: independent analysis of the interview transcripts by two researchers until consensus was reached Validity: Systematic comparison of existing data with new data Reporting: COREQ checklist used to guide the reporting of findings

TABLE 1 (Continued)

Author and year	Purpose	Sample size, mean age (SD, years) and gender	Participants	Clinical information	Sampling/setting	Response rate	Design and theoretical model	Time points (number of time points and dates)	Data collection tools
Thewes et al., 2016	This study describes patient and staff attitudes towards the acceptability and feasibility of the SCNAT-IP in routine care. Additionally, this study aimed to identify refinements needed to prepare the SCNAT-IP for use in clinical settings	Sample size: Indigenous pts: n = 34 Health prof: n = 22 Conducted assess: 10/22 (45%) Conducted interviews: 12/22 (55%) Mean age: Indigenous pts: 34–76 years (54.4 years; SD 11.0) Health prof: 25–62 years (42 years; SD 11.4) Gender: Indigenous pts: Female: n = 23/34 (68%) Male: n = 11/34 (32%) Health prof: Female: (100%)	Education: Jnr/high or below: n = 21/34 (62%) Senior high: 5/34 (15%) Dipl/trade/degree: 8/34 (12%) Language: English: n = 19/34 (56%) Indigenous language: n = 15/34 (44%) Geographical location: City: n = 4/34 (12%) Regional: n = 24/34 (71%) Remote: n = 6/34 (18%) Marital status: Single: n = 10/34 (29%) Married/de facto: n = 18/34 (53%) Widowed/separated/divorced: n = 6/34 (18%) Employment status: Not reported Socio-economic status: Not reported	Cancer type: Breast: n = 12/34 (35%) Colorectal: n = 6/34 (18%) H&N: n = 6/34 (18%) Lung: n = 3/34 (9%) Gyne: n = 2/34 (6%) NHL: 1/34 (3%) Haem: n = 1/34 (3%) Other: n = 3/34 (9%) Cancer stage: Local: n = 11/34 (32%) Regional: n = 1/34 (15%) Distal mets: 12/34 (35%) N/A: n = 3/34 (9%) Unknown: n = 3/34 (9%) Comorbidities: Diabetes: n = 8/34 (24%) CVD: n = 9/34 (27%) Resp: 9/34 (27%) Other: 15/34 (44%) Treatments: Chemo: Yes – n = 22/34 (65%) No – n = 12/34 (35%) RT: Yes – n = 21/34 (62%) No – n = 13/34 (62%) Other: Yes – n = 13/34 (38%) No – n = 21/34 (62%)	Sampling: Convenience Setting: Participants were recruited from one of four sites (1) NT: tertiary cancer centre servicing outer regional and remote areas (2) Victoria: large metro tertiary cancer centre (3, 4) NSW: 2 regional cancer clinics	Patients: Eligible: n = 89 Invited: n = 45/89 (51%) Agreed: n = 36/45 (80%) Recruited into study: n = 34/36 (94%)	Qualitative None	Time points: 1 Dates: November 2013–March 2014	Tools: Face-to-face or telephone interview (following the completion of SNAT-IP clinical visit) Reliability & validity: Interviews were audio recorded and transcribed. Used thematic analysis. 10% of transcripts were double coded
Thompson et al., 2011	Identify what helped or impeded Aboriginal participation in cancer care. This research paper responds to question posed by planners committed to establishing a Cancer Unit to meet the needs of Aboriginal people	Sample size: n = 30 Mean age: Adults Gender: Female: n = 23 Male: n = 7	Education: Not reported Language: English Geographical group: Urban (11) and rural (19) Marital status: Not reported Employment status: Not reported Socio-economic status: Not reported	Cancer type: Not reported Cancer stage: Not reported Comorbidities: Not reported Treatments: Not reported	Sampling: snowball recruitment of participants Setting: survivors of cancer or family members of cancer sufferers	NA	Qualitative None	Time points: 1 Dates: March 2006 and September 2007	Tools: Unclear, interview process lacks specific detail Reliability & validity: Feedback sessions with available participants assisted clarification of whether emerging themes were an accurate reflection of participants' experiences. Not reported how many participants verified their content

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TABLE 1 (Continued)

Author and year	Purpose	Sample size, mean age (SD, years) and gender	Participants	Clinical information	Sampling/setting	Response rate	Design and theoretical model	Time points (number of time points and dates)	Data collection tools
Treloar et al., 2013	This study examined individual, social and cultural aspects of health literacy relevant to cancer among Aboriginal patients, carers and their health workers in New South Wales	<p>Sample size: Patients: n = 22/22 (100%) identified as Aboriginal Carers: n = 18/14/18 (78%) HCWs: n = 16/8/16 (50%) identified as Aboriginal</p> <p>Mean age: Patients born in: 1940s: n = 3/22 (14%) 1950s: n = 9/22 (41%) 1960s: n = 4/22 (18%) 1970s: n = 2/22 (9%) 1980s: n = 1/22 (4%) Not reported: n = 3/22 (14%)</p> <p>Gender: Patients: Female: n = 16/22 (73%) Male: n = 6/22 (27%) Carers: Female: n = 16/18 (89%) Male: n = 2/18 (11%) HCWs: Female: n = 11/16 (69%) Male: n = 5/16 (31%)</p>	<p>Education: Not reported Language: Not reported Geographical location: NSW (urban/rural not reported for patients) Marital status: Not reported Employment status: Full/part time: n = 8/22 (36%) Sick benefits: n = 4/22 (18%) Not working: n = 4/22 (18%) 1960s: n = 4/22 (18%) Socio-economic status: Not reported</p>	<p>Cancer type: Not reported Cancer stage: Not reported Comorbidities: Not reported Treatments: Not reported</p>	<p>Sampling: Purposeful (initial recruitment) Snowball (additional recruitment via referral from participants and existing contacts of researchers) Setting: Interviews were conducted at a location convenient to the participant</p>	Not reported	Qualitative None	<p>Time points: 1 Dates: Interviews conducted between 2008 and 2011</p>	<p>Tools: Semi-structured in-depth interviews (0.5–2 h in length) conducted with three different groups (cancer patients; carers; and HCWs) Reliability & validity: Audio recorded, transcribed and checked for accuracy. Cultural liaison was used to clarify language and terms Codes were developed from the literature. Analysis informed by interpretive description</p>
Treloar et al., 2013	Explore the cancer care experiences of Aboriginal people in NSW using a social inclusion lens The aim of this paper was to examine accounts of cancer care for processes that exclude Aboriginal people in NSW from the everyday aspects of care and concomitantly, for processes that could be employed to enhance social inclusion among Aboriginal people in this context	<p>Sample size: n = 56 Aboriginal persons with cancer: n = 22 (39%) Carers: n = 18 (32%) HCWs: n = 16 (29%) Meatage: Patient Range: born in 1940s to 1980s (highest prevalence in 1950s) Carer Range: born from 1940s to 1980s (highest prevalence 1960s) HCWs Not reported Gender: Patient Female: n = 16/22 (73%) Male: n = 6/22 (27%) Carer Female: n = 16/18 (89%) Male: n = 2/18 (11%) HCW Female: n = 11/16 (69%) Male: n = 5/16 (31%)</p>	<p>Education: Not reported Language: Interviews appear to be in English, some translation of Aboriginal language and terms was needed for interview transcripts Geographical location: Eastern NSW both metropolitan and non-metropolitan Marital status: Patient: not reported Carer: n = 5 reported caring for a spouse or partner HCW: not reported Employment status: Patient Working full or part time: n = 8/22 (36%) Sickness benefits: 4/22 (18%) Not working: 4/22 (18%) Not reported: 6/22 (27%) Carers Not reported HCW 3 2 educators, 4 liaison workers, 2 dietitians, 1 health services manager, 1 GP and 1 men's health worker Socio-economic status: Not reported</p>	<p>Cancer type: Not reported Cancer stage: Not reported Comorbidities: Not reported Treatments: Not reported</p>	<p>Sampling: From AMS (Aboriginal Medical service) and oncology wards at hospitals. Flyers with toll free number given to staff to distribute (Purposeful) Some snowball from people known to participants in community Setting: location of interviews was convenient for the participant</p>	Not reported	Qualitative descriptive Social inclusion theory	<p>Time point: 1 Dates: Interviews conducted between 2008 and 2011</p>	<p>Tools: Interviews. No further information was given Reliability & validity: Not reported</p>

TABLE 1 (Continued)

Author and year	Purpose	Sample size, mean age (SD, years) and gender	Participants	Clinical information	Sampling/setting	Response rate	Design and theoretical model	Time points (number of time points and dates)	Data collection tools
Valery et al., 2017	To describe changes over time in the prevalence of unmet supportive care needs of Indigenous Australians newly diagnosed with cancer and to identify factors associated with greater needs at diagnosis	Sample size: n = 82 Mean age: <50: n = 32/82 (39%) >50: n = 50/82 (61%) SD not reported Gender: Female: n = 43/82 (52%) Male: n = 39/82 (48%)	Education: Primary school or less: n = 57/82 (70%) High school: n = 24/82 (30%) Language: Not reported Geographical location: Major cities: n = 32/82 (39%) Regional: n = 33/82 (40%) Remote/Very remote: n = 17/82 (21%) Geographical group: Aboriginal descent: n = 65/82 (79%) Torres Strait Islander descent: n = 13/82 (16%) Both: n = 4/82 (5%) Marital status: Married/de facto: n = 98/82 (46%) Divorced/widowed/separated: n = 44/82 (54%) Employment status: Not reported Socio-economic status: Most advantaged/advantaged: n = 14/82 (17%) Low/intermediate disadvantage: n = 42/82 (51%) Most disadvantaged: n = 26/82 (32%)	Cancer type: Breast: n = 18/82 (22%) Digestive organs: n = 13/82 (16%) Respiratory and intrathoracic organs: n = 13/82 (16%) Head and neck: n = 13/82 (16%) Cancer stage: Local: n = 19/82 (23%) Regional: n = 26/82 (32%) Distant: n = 18/82 (22%) N/A: n = 11/82 (13%) Comorbidities: Chronic respiratory disease: n = 24/82 (29%) Diabetes: n = 19/82 (23%) Cardiovascular disease: n = 13/82 (16%) Charlson comorbidity index CCI = 0 N = 35 (43%) CCI = 1+ N = 47 (57%) Treatments: Surgery plus adjuvant therapy: n = 39/82 (48%) Surgery only: n = 19/82 (23%) Adjuvant therapy: n = 24/82 (29%) Recent* n = 69/82 (84%) Over 30 days n = 13/82 (16%) *Recent cancer treatment is defined as surgery, chemotherapy and/or radiation therapy received for cancer treatment in the 30 days prior to interview	Participants were identified by hospital cancer care staff or Indigenous liaison officers through daily appointments lists Initial interviews were face-to-face and follow ups were either face-to-face or via telephone Actual location not mentioned. Sample was recruited from 4 public hospitals in Queensland	396 participants were identified 248/396 (63%) were initially interviewed 207/248 (83.5%) were interviewed 3 months post enrolment 165/248 (66.5%) were interviewed 6 months post enrolment 82/248 (33%) were interviewed at both time points and hence this was the data that were analysed	Quantitative None	Time points: 3 (each at 3 months apart) T1: Recruitment (on average 4-4 days post-diagnosis SD 27) T2: 3 months after enrolment T3: 6 months after enrolment (min 120 days - max 274 days) Dates: Between November 2010 and December 2012	Tools: Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP) ARIA (for remoteness) IRSAD (for socio-economic advantage) Clinical details extracted from medical records using a standardized form Reliability & validity: SCNAT-IP Validated but requires accurate self-reporting to an interviewer

Abbreviations: AHW, Aboriginal Health Worker; ARIA, Accessibility/Remoteness Index of Australia; ARG, Aboriginal Reference Group; CAM, Complementary and Alternative Medicine; CCI, Charlson Comorbidity Index; COREQ, Consolidated Criteria for Reporting Qualitative Research; CSP, cancer service providers; CWC, Cancer Worry Chart; DT, Distress Thermometer; GI, Gastrointestinal Cancers; Haem, Haematological Cancers; HCP, healthcare provider; HCWs, healthcare workers; H&N, head and neck cancers; IHLO, Indigenous Health Liaison Officers; IPN, Indigenous Patient Navigator; IRG, Indigenous Reference Group; IRSAD, Index of Relative Socio-economic Advantage and Disadvantage; KAP, knowledge, attitudes and practices survey; NICA, National Indigenous Cancer Network; R-I-CAM-Q, Revised International Questionnaire to Measure Use of Complementary and Alternative Medicines; SCNAT-IP, Supportive Care Needs Assessment Tool for Indigenous People; SCNS-SF34, Supportive Care Needs Survey-Short Form (34 item); IEIFA, Socio-economic Indexes for Areas; SLA, Statistical Local Areas; TM, traditional medicine; T&CM, Traditional and Complementary Medicine; VC, video conferencing.

TABLE 2 Results of quality appraisal of primary studies.

Qualitative study	Item number of checklist						
	S1.	S2.	1.1.	1.2.	1.3.	1.4.	1.5.
Cuesta-Briand et al., 2015	Y	Y	Y	Y	Y	Y	Y
Cuesta-Briand et al., 2016	Y	Y	Y	Y	Y	Y	Y
Dembinsky, 2014	Y	Y	Y	Y	Y	U	U
Green et al., 2018	Y	Y	Y	Y	Y	Y	Y
Lyford et al., 2018	Y	Y	Y	Y	Y	Y	Y
McGrath et al., 2006	Y	Y	Y	U	Y	Y	U
McGrath & Rawson, 2013a	Y	Y	U	Y	U	Y	U
McGrath & Rawson, 2013a	Y	Y	Y	Y	U	U	U
McGrath et al., 2015	Y	Y	Y	Y	Y	Y	Y
McMichael et al., 2000	Y	Y	Y	U	U	Y	Y
Meiklejohn et al., 2017	Y	Y	Y	Y	Y	Y	Y
Meiklejohn et al., 2018	Y	Y	Y	Y	Y	Y	Y
Meiklejohn et al., 2020	Y	Y	Y	Y	Y	Y	Y
Newman et al., 2017	Y	Y	Y	Y	Y	Y	Y
Pilkington et al., 2017	Y	Y	Y	Y	Y	Y	Y
Prior, 2009	Y	Y	Y	Y	Y	Y	Y
Reilly et al., 2018	Y	Y	Y	Y	U	Y	Y
Shahid, Finn, & Thompson, 2009	Y	Y	Y	Y	Y	Y	Y
Shahid, Finn, & Thompson, 2009	Y	Y	Y	Y	Y	Y	Y
Shahid et al., 2010	Y	Y	Y	Y	Y	Y	Y
Shahid et al., 2011	Y	Y	Y	Y	Y	Y	Y
Shahid et al., 2013	Y	Y	Y	Y	Y	Y	Y
Shahid et al., 2016	Y	Y	Y	Y	Y	Y	Y
Tam et al., 2018	Y	Y	Y	Y	Y	Y	Y
Thewes et al., 2016	Y	Y	Y	Y	Y	Y	Y
Thompson et al., 2011	Y	Y	Y	Y	Y	Y	Y
Treloar et al., 2013	Y	Y	Y	Y	Y	U	Y
Treloar et al., 2013	Y	Y	Y	Y	Y	Y	Y

Item number checklist key*: S1. Are there clear research questions, S2. Do the collected data allow us to address the research questions, 1.1. Is the qualitative approach appropriate to answer the research question and 1.2. Are the qualitative data collection methods adequate to address the research question, 1.3. Are the findings adequately derived from the data, 1.4. Is the interpretation of results sufficiently substantiated by data, 1.5. Is there coherence among qualitative data sources, collection, analysis and interpretation.

Quantitative non-randomized controlled trials	Item number of checklist						
	S1.	S2.	3.1.	3.2.	3.3.	3.4.	3.5.
Bernardes et al., 2018	Y	Y	U	U	N	U	N
Dorrington et al., 2015	Y	Y	U	U	Y	U	Y

Item number checklist key*: S1. Are there clear research questions, S2. Do the collected data allow to address the research questions, 3.1. Are the participants representative of the target population, 3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure), 3.3. Are there complete outcome data, 3.4. Are the confounders accounted for in the design and analysis, 3.5. During the study period, is the intervention administered (or exposure occurred) as intended.

Quantitative descriptive studies	Item number of checklist						
	S1.	S2.	4.1.	4.2.	4.3.	4.4.	4.5.
Adams et al., 2015	Y	Y	N	U	U	U	U
Bernardes et al., 2012	Y	Y	Y	Y	Y	Y	Y

TABLE 2 (Continued)

Quantitative descriptive studies	Item number of check list						
	S1.	S2.	4.1.	4.2.	4.3.	4.4.	4.5.
Bernardes et al., 2014	Y	Y	Y	U	Y	Y	U
Bernardes et al., 2019	Y	Y	Y	U	Y	U	U
Christou & Thompson, 2012	Y	Y	Y	N	Y	N	Y
Diaz et al., 2016	Y	Y	Y	N	Y	Y	Y
Garvey et al., 2016	Y	Y	N	U	U	Y	U
Garvey et al., 2018	Y	Y	U	U	U	Y	Y
Mooi et al., 2012	Y	Y	Y	Y	U	Y	Y
Valery et al., 2017	Y	Y	Y	Y	Y	Y	Y

Item number checklist key*: S1. Are there clear research questions, S2. Do the collected data allow us to address the research questions, 4.1. Is the sampling strategy relevant to address the research question, 4.2. Is the sample representative of the target population, 4.3. Are the measurements appropriate, 4.4. Is the risk of non-response bias low, 4.5. Is the statistical analysis appropriate to answer the research question.

Mixed methods	Item number of checklist						
	S1.	S2.	5.1.	5.2.	5.3.	5.4.	5.5.
Gall et al., 2019	Y	Y	N	Y	Y	U	Y
Page et al., 2016	Y	U	N	U	U	N	U

Item number checklist key*: S1. Are there clear research questions, S2. Do the collected data allow us to address the research questions, 5.1. Is there an adequate rationale for using a mixed methods design to address the research question, 5.2. Are the different components of the study effectively integrated to answer the research question, 5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted, 5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed, 5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved.

*Three levels of assessment quality scores

Yes (Y)
Unclear (U)
No (N)

the surgery while all the white people were seen to. Aboriginal people would sit there for a whole day and wait. ... Even if it was freezing cold. (family member) (Shahid, Finn, & Thompson, 2009)

In the words of one patient, '... [my doctor] treated me like a drug addict'. The direct consequences resulted in a breakdown in therapeutic relationship and respect with the treating doctor (Gall et al., 2019). Many articulated that they felt unheard and that their concerns did not matter to healthcare providers (Gall et al., 2019). These experiences have caused a breakdown in trust for First Nations people with healthcare professionals. As a result, people have disengaged with cancer services for screening, diagnosis and treatment.

Thewes et al. (2016) have attributed cultural factors, such as being 'shy' and 'a reluctance to talk about problems or articulate their needs', as a reason for people to delay seeking cancer care; however, other authors (Newman et al., 2017; Shahid, Finn, & Thompson, 2009) saw this reticence as 'resilience or lowered expectations' resulting from the abhorrent historical experience by First Nations people within existing health services. People reported fearing a diagnosis of cancer because hospitals and health

services are associated with racism, trauma and death (Cuesta-Briand et al., 2015; Gall et al., 2019; Garvey et al., 2018; Green et al., 2018; Newman et al., 2017; Reilly et al., 2018; Shahid, Finn, & Thompson, 2009; Thompson et al., 2011; Treloar et al., 2013; Valery et al., 2017).

A lack of interpreter services and the use of technical jargon by health professionals have further alienated some First Nations people:

Pitjantjatjara, Yankunytjatjara, Pitjantjatjara - that's their first language ... they don't understand what the doctor's saying because you haven't got a lot of people that speak our language in the hospital here ... A lot of them go-go back and they end up passing on because they don't really understand it. (Patient) (Reilly et al., 2018)

Shame and embarrassment about their invasion of privacy also contributed to some people feeling uncomfortable communicating with medical professionals. Ward rounds and teaching sessions added to this discomfort.

You wake up all you see these doctors there, all these white coats watching over you. I found that a bit

TABLE 3 Synthesis findings.

Theme	Sub-themes	Quotes as data	References
1	Breakdown in trust	'I went down to have x-rays and there was a whole heap of orderlies sitting there around their waiting area. And I heard a racist remark by one of the orderlies. And I ended up in tears.... It's like, oh Jesus, you are here crook and you hear a racist joke'. (Patient) (Reilly et al., 2018)	Cuesta-Briand et al., 2015; Gall et al., 2019; Garvey et al., 2018; Green et al., 2018; Newman et al., 2017; Reilly et al., 2018; Shahid, Finn, & Thompson, 2009; Thompson et al., 2011; Treloar et al., 2013; Valery et al., 2017
	Resilience and lower expectations	'...a lot of people will not speak up because they do not want to go through all that rigmorole of the name calling and all that sort of stuff...so they shut up, they stay quiet, and they do not talk unless it's to one of their own...they know is going to listen'. (Carer) (Reilly et al., 2018)	Shahid, Finn, & Thompson, 2009; Newman et al., 2017; Thewes et al., 2016
	Fear of racism	'Just that fear of being treated differently and not wanting to put yourself in a position for that. (patient). Every time [my partner] goes into the hospital, he is treated like a piece of dirt. And then he ends up discharging himself because he does not get proper treatment. (Non-Aboriginal carer) (Treloar et al., 2013)	Cuesta-Briand et al., 2015; Gall et al., 2019; Garvey et al., 2018; Green et al., 2018; Newman et al., 2017; Reilly et al., 2018; Shahid, Finn, & Thompson, 2009; Thompson et al., 2011; Treloar et al., 2013; Valery et al., 2017
	Communication	'Physicians' use of jargon and technical terms also caused frustration: ... with the remote Aboriginals in the community. ... they go home and take this medication and they have not got a clue what they are taking or what it is for anything. If you do not understand why you have to do something, sometimes you do not do it'. (Rural female family member) (Shahid, Finn, & Thompson, 2009)	Bernardes et al., 2012; Bernardes et al., 2018; Dembinsky, 2014; Gall et al., 2019; Garvey et al., 2016; Garvey et al., 2018; Green et al., 2018; Newman et al., 2017; Pilkington et al., 2017; McGrath & Rawson, 2013a; Meiklejohn et al., 2017; Reilly et al., 2018; Shahid, Finn, & Thompson, 2009; Shahid et al., 2013; Shahid et al., 2016; Thewes et al., 2016; Thompson et al., 2011; Treloar et al., 2013
	Health system	'Aboriginal patients need to feel welcomed when they access services and only an Aboriginal staff can do that effectively because they'd understand the cultures, the land and spirituality of it, we do not. I mean we can read stuff, but we do not feel it'. (Rural non-Aboriginal HSP) (Shahid et al., 2016)	Bernardes et al., 2012; Bernardes et al., 2018; Cuesta-Briand et al., 2016; Diaz et al., 2016; Dorrington et al., 2015; Green et al., 2018; Lyford et al., 2018; McGrath & Rawson, 2013a; Meiklejohn et al., 2017; Mooi et al., 2012; Page et al., 2016; Prior, 2009; Reilly et al., 2018; Shahid et al., 2011; Shahid et al., 2013; Shahid et al., 2016; Thompson et al., 2011
	Holistic view of health	'Western science and medicine define the world in all those little parts and non-people related. And (name location) see everything as kin. Kin, kinship, everything is kin, all people, the world'. (McGrath et al., 2006)	Adams et al., 2015; Bernardes et al., 2014; Dembinsky, 2014; Garvey et al., 2018; McGrath et al., 2006; Meiklejohn et al., 2020; Prior, 2009; Reilly et al., 2018; Shahid, Finn, & Thompson, 2009; Tam et al., 2018
	Community responsibilities	'Coming to town to have someone look at their private parts is not a priority'. (McGrath & Rawson, 2013a)	Bernardes et al., 2018; Bernardes et al., 2019; Meiklejohn et al., 2017; McGrath & Rawson, 2013a; Reilly et al., 2018; Shahid, Finn, & Thompson, 2009
	Men and woman's business	'The prostate thing with the Aboriginal men is... like I say is a 'taboo'... area. They will not go and get a simple test done by the doctor... they feel very 'funny' about it, and so they usually leave it until the last minute, and sometimes that's just too late'. (Shahid, Finn, & Thompson, 2009)	Bernardes et al., 2012; Cuesta-Briand et al., 2016; McGrath & Rawson, 2013a; Newman et al., 2017; Shahid et al., 2009; Thewes et al., 2016
	Concerns about confidentiality	'Some patients felt uncomfortable having an indigenous person as an IPN - did not like to share condition with someone known in their community'. (Health worker) (Bernardes et al., 2018)	Bernardes et al., 2018; Cuesta-Briand et al., 2015
	Attributed to sorcery or payback	'They believe cancer is caused by other agents, so if someone's been sung - it's payback for something they or their family have done in the past'. (McGrath et al., 2006)	McGrath et al., 2006; Prior, 2009
2	Incongruent	'Cancer surgery is a violation of their cultural identity and threatens to undermine their place in society'. (McGrath & Rawson, 2013a)	Adams et al., 2015; Bernardes et al., 2014; Dembinsky, 2014; Garvey et al., 2018; McGrath et al., 2006; Meiklejohn et al., 2020; Prior, 2009; Reilly et al., 2018; Shahid, Finn, & Thompson, 2009; Tam et al., 2018
	Shame	'too ashamed and frightened to tell' so kept it a secret... 'feeling lost and alone with no one to talk to about the problems they were having'. The women described the experiences as 'lonely, sad, hurt' and that they felt 'isolated' and 'unable to share the story'. (McGrath & Rawson, 2013a)	McGrath & Rawson, 2013a; Newman et al., 2017; Shahid, Finn, & Thompson, 2009
	Cultural well-being of the community	'It's hard for a lot of people. So, they prefer to either go for bush medicine or not take the treatment, because they know that they are going to be away for a while from their family'. (Shahid et al., 2010)	Adams et al., 2015; Bernardes et al., 2019; Cuesta-Briand et al., 2016; Dembinsky, 2014; Garvey et al., 2018; Green et al., 2018; McGrath et al., 2006; McGrath & Rawson, 2013a; Meiklejohn et al., 2020; Prior, 2009; Shahid, Finn, & Thompson, 2009; Treloar et al., 2013
	Spiritual	'The healing is by accepting, and I think that is where (name location) are, it's not the medical intervention it's the closeness. It's the accepting; well, this is my life, I am a person, I - the ultimate goal is to have that close kinship with people... the spiritual side of health is often seen as more important than the physical side'. (McGrath et al., 2006)	Gall et al., 2019; Shahid, Finn, & Thompson, 2009; Shahid et al., 2010; Tam et al., 2018; Thompson et al., 2011; Bernardes et al., 2019; Dembinsky, 2014; Garvey et al., 2018; Meiklejohn et al., 2020; Prior, 2009
	Psychological/social/emotional	'I feel it is getting out to them and reaching them and bringing them in and meeting other women with these problems but not only cancer. They come and talk about all the other problems, whether their child has been molested or they have been abused. That all ties in when we get together as a women's group'. (Network member) (Cuesta-Briand et al., 2015)	Bernardes et al., 2018; Bernardes et al., 2019; Cuesta-Briand et al., 2015; Dembinsky, 2014; Garvey et al., 2018; Green et al., 2018; Meiklejohn et al., 2020; McGrath & Rawson, 2013a; Reilly et al., 2018; Shahid et al., 2010; Tam et al., 2018; Thompson et al., 2011; Valery et al., 2017
	Interpersonal/intimacy	'Indigenous women will only discuss vulvar cancer with small select number of family members. They preferred to talk to female members of the family (would sometimes confide in their husbands)'. (McGrath & Rawson, 2013a)	Shahid, Finn, & Thompson, 2009; Tam et al., 2018; McGrath & Rawson, 2013a

TABLE 3 (Continued)

Theme	Sub-themes	Quotes as data	References
3	Inaccessible	'We get down there and we have got nowhere to stay. My niece, she lives in Perth, and she is an hour away from Charlies, so we do not even bother going there. ... too far'. (Rural, female family member) (Shahid et al., 2011)	Bernardes et al., 2014; Dembinsky, 2014; Shahid et al., 2011; Thompson et al., 2011
	Health literacy	'A lot of Indigenous people...I suppose 70 to 80 per cent, would not really know properly ...I do not think they understand it. They do not understand about prevention. They do not understand about early detection and screening. Really, I felt that - from working there - some of their experiences or their understanding is so simple, it is very childlike'. (Healthcare worker) (Shahid, Finn, & Thompson, 2009)	Bernardes et al., 2014; Christou & Thompson, 2012; Newman et al., 2017; Pilkington et al., 2017; Shahid, Finn, & Thompson, 2009; Treloar et al., 2013
	Leaving home	'Especially a lot of people when they come from the community, they do not know what they are gonna face. Yeah, like ... where are they gonna stay, how they are gonna support themselves for six weeks, and if their family is gonna come. ...' (Remote, male patient). (Shahid et al., 2011)	Bernardes et al., 2014; Dembinsky, 2014; Shahid et al., 2011; Thompson et al., 2011
	Fear of dying	'Frightened, frightened. Cancer bad, make people die quickly'. (McGrath et al., 2006)	Bernardes et al., 2014; Dembinsky, 2014; Lyford et al., 2018; McGrath et al., 2006; Meiklejohn et al., 2020; Pilkington et al., 2017; Shahid, Finn, & Thompson, 2009
	Cognitive	'It would be good to have more info, more widespread information about cancer. We've got so much health promotion brochures on "What's Diabetes?" or "What does Speed, or Cocaine do to the Body?" you know all those kinds of ... but there's nothing ... I do not think I've seen one thing on what cancer does to the body or what you can do, or what causes cancer, those kind of ... health promotion materials would be useful'. (Treloar et al., 2013)	Christou & Thompson, 2012; Shahid et al., 2016; Treloar et al., 2013
	Daily living	'Daily living needs included help with household chores, bathing, home support and mobility access'. (Bernardes et al., 2018, McGrath & Rawson, 2013a)	Bernardes et al., 2019; Bernardes et al., 2018; McGrath & Rawson, 2013a
	Physical	'72.6% accessed allied health workers, most common being the dietitian' (Bernardes et al., 2012)	Garvey et al., 2018; Bernardes et al., 2012; Bernardes et al., 2018; Dembinsky, 2014; Gall et al., 2019; Page et al., 2016; Meiklejohn et al., 2020; Shahid et al., 2010
	Practical	'Especially a lot of people when they come from the community, they do not know what they are gonna face. Yeah, like ... where are they gonna stay, how they are gonna support themselves for six weeks, and if their family is gonna come. ... A lot of support should come from within the hospital as well, especially social workers'. (Remote, male patient). (Shahid et al., 2011)	Bernardes et al., 2018; Bernardes et al., 2019; Cuesta-Briand et al., 2015; Cuesta-Briand et al., 2016; Diaz et al., 2016; Dembinsky, 2014; Garvey et al., 2016; Green et al., 2018; Lyford et al., 2018; Lyford et al., 2018; McGrath & Rawson, 2013a; Meiklejohn et al., 2017; Meiklejohn et al., 2020; Mooi et al., 2012; Page et al., 2016; Reilly et al., 2018; Shahid, Finn, & Thompson, 2009; Shahid et al., 2011; Thompson et al., 2011; Valery et al., 2017
	Family related	'Close family members were often unsure about what was happening to relatives and felt they could have helped more had they been better informed' (Shahid, Finn, & Thompson, 2009)	Bernardes et al., 2019; Dembinsky, 2014; Green et al., 2018; Lyford et al., 2018; Newman et al., 2017; Reilly et al., 2018; Shahid, Finn, & Thompson, 2009

et al., 2016; Green et al., 2018; McGrath & Rawson, 2013b; Meiklejohn et al., 2020; Shahid et al., 2011, 2013, 2016; Thompson et al., 2011).

... their understanding of Aboriginal culture, Aboriginal history, and just living circumstances is extraordinarily poor among hospital staff. (Patient) (Green et al., 2018)

It was clear across many of the included studies (Bernardes et al., 2012, 2018; Cuesta-Briand et al., 2016; Diaz et al., 2016; Dorrington et al., 2015; Green et al., 2018; Lyford et al., 2018; McGrath & Rawson, 2013a; McMichael et al., 2000; Meiklejohn et al., 2017; Mooi et al., 2012; Page et al., 2016; Prior, 2009; Reilly et al., 2018; Shahid et al., 2011, 2013, 2016; Thompson et al., 2011) that Australian First Nations peoples had a clear understanding about their preferences for care to overcome discrimination, racism and trauma to improve the health system. These strategies included (1) patient-led approaches, (2) access to Aboriginal health workers and (3) inclusion of culturally safe practices. Participants articulated that having a flexible and patient-led approaches was important to them as illustrated in this quote:

If we have got to go and start structuring it too much, those women are going to turn around and say: "It is getting too much whitefella way now" and they are going to back off. (Support Worker) (Cuesta-Briand et al., 2015)

It was paramount that people affected by cancer had access to Aboriginal health workers (including innovative models like patient navigators and family escorts), and emphasized the importance that compulsory cultural safety training was mandated for all cancer care staff and trauma informed care:

Aboriginal patients need to feel welcomed when they access services and only an Aboriginal staff can do that effectively because they'd understand the cultures, the land and spirituality of it, we don't. I mean we can read stuff, but we don't feel it. (non-Aboriginal support worker) (Shahid et al., 2016)

Finally, participants emphasized the need for inclusion of culturally safe practices (such as yarning, bush medicine, smoking ceremonies, gender appropriate services, larger rooms for families, access to garden spaces, flags and artwork) within existing hospital environments (Green et al., 2018):

Ritual cleansing of physical spaces where death has occurred is needed (smoking ceremonies through which negative energies can be removed – leaving them in the room contributes to another person's inability to overcome disease). (Patient) (Dembinsky, 2014)

5.2.2 | Theme 2: Cultural ways of knowing, being and doing are fundamental to how First Nations people engage with cancer care services

Many participants across the studies (Adams et al., 2015; Bernardes et al., 2014; Dembinsky, 2014; Garvey et al., 2018; McGrath et al., 2006; McMichael et al., 2000; Meiklejohn et al., 2020; Prior, 2009; Reilly et al., 2018; Shahid, Finn, Bessarab, & Thompson, 2009; Tam et al., 2018) described a holistic understanding of health shared by many First Nations people.

Health is not just the physical well-being of an individual but the social, emotional, and cultural well-being of the whole community. This is a whole-of-life view and includes the cyclical concept of life-death-life. (Bullinah Aboriginal Health Service, 2023)

In keeping with this world view of health, participants (Bernardes et al., 2018, 2019; McGrath & Rawson, 2013b; Meiklejohn et al., 2017; Shahid, Finn, Bessarab, & Thompson, 2009) identified the expectation to prioritize community responsibilities over individual cancer care needs for screening or treatment. Due to the cultural belief of men's and women's business, special consideration was needed for cancers of the reproductive system. Three studies (McGrath & Rawson, 2013b; Newman et al., 2017; Shahid, Finn, Bessarab, & Thompson, 2009) identified the impact of social stigmas associated with vulva cancer. Feelings of shame, sadness, isolation, hurt and loneliness were shared by people with these cancers, who showed a reluctance to talk about their diagnosis or to access treatments.

...too ashamed and frightened to tell... so kept it a secret ... feeling lost and alone with no one to talk to about the problems (Patient) (McGrath & Rawson, 2013b)

Privacy was highly valued, and participants expressed concerns about confidentiality, the 'bush telegraph' was viewed as a barrier which stopping people from seeking care:

You will get some people that may not want to access the [Indigenous health service], you know, because they say, 'It is not confidential. It is not the paper side of it. It is because people see them going in, you know, and that is their sort of broken confidentiality. (Support worker) (Cuesta-Briand et al., 2015)

For some First Nations people, the 'why', rather than the 'how', was more important in making sense of a cancer diagnosis and for restoring community well-being. For these people, a cancer diagnosis or death could be attributed to sorcery and/or transgressions from social norms with 'payback', black magic or being 'sung' viewed as

the reason for the cancer diagnosis or death (McGrath et al., 2006; Prior, 2009). For this reason, some Aboriginal health workers did not want to be involved at the time of death for fear of being blamed (McGrath et al., 2006).

Many participants identified an incongruence between some First Nations peoples' cultural values and recommended cancer care (Adams et al., 2015; Bernardes et al., 2014; Dembinsky, 2014; Garvey et al., 2018; McGrath et al., 2006; McMichael et al., 2000; Meiklejohn et al., 2020; Prior, 2009; Reilly et al., 2018; Shahid, Finn, Bessarab, & Thompson, 2009; Tam et al., 2018). For example, testing (especially genomic testing) and removing organs conflicted with the spiritual beliefs of some First Nations people who view the body as indivisible (Bernardes et al., 2014; Garvey et al., 2018; Prior, 2009). Dying in hospital or palliative care services also caused problems for some patients who believed dying at home was necessary to allow the passing on of sacred information (Dembinsky, 2014; Shahid, Finn, Bessarab, & Thompson, 2009). Many participants expressed a profound spiritual connection to land, culture and community and its role in healing (Bernardes et al., 2019; Dembinsky, 2014; Gall et al., 2019; Garvey et al., 2018; McMichael et al., 2000; Meiklejohn et al., 2020; Prior, 2009; Shahid et al., 2010; Shahid, Finn, Bessarab, & Thompson, 2009; Tam et al., 2018; Thompson et al., 2011).

Healing is not just physical; it's mental, emotional, and spiritual as well. (Patient) (Shahid, Finn, Bessarab, & Thompson, 2009)

First Nations people spoke of the importance of a strong spirit and hope for the future (Bernardes et al., 2019). Some participants were given a 'healing gemstone' or a 'healing bracelet' by family members that they kept with them throughout their cancer journey (Gall et al., 2019). A few participants reported on the use of visualization.

... [I was] going through the bush, and I just sit there, imagined myself in there walking around ... like walking in I was struggling, and then as soon as I walked into the bush it was like "I'm free" ... just imagined myself like that. (Patient) (Gall et al., 2019)

Bush medicines were used either sequentially or concurrently with Western medicines. For some nations, healers with supernatural powers (Marrngiti – Yolngu; Ngangkere – Anangu) were important for restoring social order and healing not just for the patient but the whole community (McGrath et al., 2006; Prior, 2009).

There is something in it ... that is good for your insides, just as a cleanser. Makes all your body organs healthy and strong, it gets rid of all your internal stress. (Patient) (Shahid, Finn, & Thompson, 2009)

Garvey et al. (2018) (Garvey et al., 2018) found that 70% of First Nations people with cancer had unmet supportive care needs, mostly in the psychological/social/emotional domains. Many studies (Bernardes et al., 2018, 2019; Christou & Thompson, 2012; Dembinsky, 2014; Garvey et al., 2018; Green et al., 2018; McGrath & Rawson, 2013b; Meiklejohn et al., 2020; Reilly et al., 2018; Shahid et al., 2010; Tam et al., 2018; Thompson et al., 2011; Valery et al., 2017) identified unmet psychological and interpersonal/intimacy needs including feelings of loneliness, sadness, shame and disempowerment (especially noted in patients with reproductive system cancers (McGrath & Rawson, 2013a); and fear of hospitals, cancer re-occurrence or spread and of dying, particularly 'off-country'. Six months after diagnosis, Garvey et al. (2018) (Garvey et al., 2018) found clinically significant levels of stress in 33% of patients associated with older patients, those undergoing surgery, those who were married/separated/divorced and those who had to travel away from home to access services. Being 'on-country', bush medicine and yarning with family and friends – including connecting with others who had a cancer diagnosis, opportunities to express difficult emotions, counselling and support from Aboriginal health workers and autonomy – were all identified as helpful strategies in managing these psychological needs (Cuesta-Briand et al., 2015; Dembinsky, 2014; Green et al., 2018; McMichael et al., 2000; Reilly et al., 2018; Shahid et al., 2010; Tam et al., 2018; Thompson et al., 2011).

5.2.3 | Theme 3: First Nations people need culturally safe person-centred cancer care services that address practical needs

Cancer healthcare services were often inaccessible to people in rural and remote locations. Travel (distances, road conditions and a lack of transport), accommodation needs (for the patient and family), appropriate clothes (if there are climate differences), associated financial costs and inflexible health service delivery models all made services less accessible (Bernardes et al., 2014; Dembinsky, 2014; Diaz et al., 2016; McMichael et al., 2000; Thompson et al., 2011).

People think "no I don't want to go down because I've got no way of getting there, going to the hospital, or I don't have any family down there," so they choose not to. (Patient) (Shahid et al., 2011)

In the real world we can't order MRIs and things like that, and most of these things do attract an excess. CAT scan and most X-ray people, there is quite an extra amount of money you have to pay which our patients can't afford. (family member) (Shahid et al., 2011)

Leaving home for cancer tests and treatments was associated with sadness and loneliness.

... they come down and they feel isolated. They are out of their environment, lonely, and never been into a big hospital, so they feel isolated, scared, and frightened. (Patient) (Shahid, Finn, Bessarab, & Thompson, 2009)

Three studies (Newman et al., 2017; Shahid, Finn, Bessarab, & Thompson, 2009; Treloar et al., 2013) identified health literacy about cancer symptoms, screening services and treatment as barriers to early cancer detection.

I think probably just awareness, so being aware of what's involved, even before you get the bloody disease, so just having better knowledge of things, what's available, what's out there to be watchful for or fearful of and what you can do about it. (Patient) (Shahid, Finn, Bessarab, & Thompson, 2009)

Many participants expressed difficulty in navigating the healthcare system which was also problematic for many participants.

Aboriginal people...they are not into the system. If you don't know the system, which is hard to know, you got to take a lot of it in and you got to listen to a lot of things, if you can't take that on board ... you would be stuck. You would walk away and say "I can't do this, it's too much. (Patient) (Treloar et al., 2014)

While Bernardes et al. (2014) (Bernardes et al., 2014) reported family history as a known predictor of cancer risk, this did not translate into increased screening rates. For some, an absence of family history or symptoms negated the necessity to participate in screening services (Bernardes et al., 2014; Christou & Thompson, 2012). For others, family history became a barrier as they were frightened of finding out something was wrong. Many participants reported a fear of dying associated with a cancer diagnosis (Bernardes et al., 2014; Dembinsky, 2014; Lyford et al., 2018; McGrath et al., 2006; Meiklejohn et al., 2020; Pilkington et al., 2017; Shahid, Finn, Bessarab, & Thompson, 2009).

You think sometimes it might be because they are scared of finding that they have got breast cancer. I know some women still think that if you get breast cancer it is a death sentence. (Patient) (Pilkington et al., 2017)

Community relationship-building initiatives to promote trust in cancer services are recommended to meet First Nations people's

cognitive supportive care needs by supporting improved health promotion and literacy (Christou & Thompson, 2012; McMichael et al., 2000; Shahid et al., 2016; Treloar et al., 2013).

I feel it is getting out to them and reaching them and bringing them in and meeting other women with these problems but not only cancer. They come and talk about all the other problems, whether their child has been molested or they have been abused. That all ties in when we get together as a women's group. (Support worker) (Cuesta-Briand et al., 2016)

Many studies also highlighted the need for educational resources that were generically accepted, evidenced based and culturally appropriate (Christou & Thompson, 2012; McMichael et al., 2000; Shahid et al., 2016; Treloar et al., 2013) to help with self-management of pain management and palliation, allied health services particularly dietetics, reconstruction and prosthesis (Bernardes et al., 2012, 2018; Dembinsky, 2014; Gall et al., 2019; McMichael et al., 2000; Meiklejohn et al., 2020; Page et al., 2016; Shahid et al., 2010). Practical support was the most frequently identified need documented in this review (Bernardes et al., 2018, 2019; Cuesta-Briand et al., 2015; Dembinsky, 2014; Diaz et al., 2016; Garvey et al., 2016; Green et al., 2018; Lyford et al., 2018; McGrath & Rawson, 2013a; McMichael et al., 2000; Meiklejohn et al., 2017, 2020; Mooi et al., 2012; Page et al., 2016; Reilly et al., 2018; Shahid et al., 2011; Shahid, Finn, & Thompson, 2009; Thompson et al., 2011; Valery et al., 2017) and participants pointed to several strategies and preferences for care to overcome these barriers. First, First Nations people wanted ease of access to culturally safe practical assistance which included financial assistance, accommodation, practical clothing and home support (Bernardes et al., 2019; Cuesta-Briand et al., 2015; Diaz et al., 2016; Lyford et al., 2018; McGrath & Rawson, 2013a; Meiklejohn et al., 2017; Reilly et al., 2018; Shahid et al., 2011; Thompson et al., 2011; Valery et al., 2017).

They say in the information there's financial assistance available, but they don't explain that you'll be assessed ... I was never assessed and because I stayed working in the community sector ... I am one of the lucky ones too I suppose to have the knowledge. But you know, it's like you're begging for like financial help and them not listening. I think you just get stereotyped as like ...you know, it's not fair. (Patient) (Treloar et al., 2013)

Participants expressed that they needed more cancer care services in rural and remote areas (Bernardes et al., 2018; Cuesta-Briand et al., 2016; Lyford et al., 2018; McMichael et al., 2000; Meiklejohn et al., 2017; Page et al., 2021; Reilly et al., 2018; Shahid et al., 2011; Valery et al., 2017) including palliative care, with consideration given to innovative approaches such as telehealth. Mooi et al. (2012)

reported a preference for telehealth with reduced waiting time, cost, travel and separation from local supports. Research by Garvey et al. (2018) also found that patients who were living in remote areas were less likely than those in major cities to show clinical distress (Garvey et al., 2018). Finally, participants wanted to have improved care coordination including timely and comprehensive discharge care supported by greater linkage with primary healthcare services, community contacts and transitional care between services.

There needs to be a ... a person ... not necessarily a case worker but a, a support worker, ideally an Aboriginal person who has ... some awareness about cancer, has an awareness about the referral pathways, that they can support. So, I would like to see that there is someone ... who has the empathy or understanding about Aboriginal people and culture and that they can ... it's not the right kind of word but almost mentor you through that whole ... you know, that knows the journey ... often it's a journey you travel once and ... you don't know where you are going, you don't. (Patient) (Treloar et al., 2013)

There was a strong desire for family to be actively involved in the patient's care creating needs for family accommodation, school or tutoring assistance for patient's children, rooms in the hospital to accommodate family members and education and counselling for families enabling them to provide support at home (Bernardes et al., 2019; Dembinsky, 2014; Green et al., 2018; Lyford et al., 2018; McMichael et al., 2000; Newman et al., 2017; Reilly et al., 2018; Shahid, Finn, Bessarab, & Thompson, 2009). Family support was particularly important in assisting patients to return home to their country at the end of life.

6 | DISCUSSION

This systematic review was guided by Australian First Nations traditional custodians and knowledge holders to identify the needs and preferences for cancer care services for Australia's First Nations people affected by cancer. Many First Nations people affected by cancer grapple with their own health needs, but these are also inextricably linked to the well-being of the community. Existing Westernized cancer care models are not meeting the care needs and preferences of First Nations peoples in Australia living with cancer. This timely systematic review has underscored that policymakers, cancer services and Aboriginal Hospital Liaison Officers need to work in partnership with First Nations communities to deliver a healthcare system fit for purpose to address unmet needs identified in this review. It is centrally important that cancer services reflect First Nations people's concept of holistic health which is not just about physical well-being, but rather the social, emotional and cultural well-being of the whole community,

encompassing cyclical concept of life–death–life. Australia's First Nations people are often left with complex, multifaceted unmet supportive care needs that they have the resilience, Indigenous knowledges and strengths to address with support. These could be alleviated by strengthening stronger links to the community and embedding culturally safe practices.

Cancer and its associated treatments irrespective of cancer type have complex pathways requiring multiple healthcare professionals from various disciplines coming together to form multi-disciplinary teams (MDTs) across both private and public services (Askelin et al., 2021). While the clinical management of cancer is often the same (informed by evidence-based guidelines), this review has identified the urgent need for culturally safe care that recognizes Australian First Nations strengths, Indigenous Knowledges and resilience to co-create strategies to address the disparities, inequalities and injustices among existing cancer services. Acknowledging the development and national endorsement of the Optimal Care Pathway to guide the delivery of high-quality, evidence-informed and culturally safe care several years ago (Chynoweth et al., 2020) in Australia, this review has underscored that wider implementation is urgently needed across all cancer services and systems to address the distress, concerns and unmet needs identified. The Optimal Care Pathway (Cancer Australia, 2023) aims to complement existing cancer-specific pathways to deliver culturally safe and competent care which must show respect and an understanding of First Nations peoples culture.

However, many of the participants represented in this review continue to report discrimination, racism and trauma, resulting from colonization (Geia et al., 2020) which directly impacted First Nations cancer care experience. Australia has a shameful history since the landing of the First Fleet 234-years ago, and racism has become an accepted part of behaviour and language, still evident in the discourse of many of the participants affected by cancer represented in this systematic review. Patients expressed a direct lack of respect and dignity in their patient–clinician communication consultations which resulted in a breakdown in trust among First Nations people with cancer care providers. Australia's First Nations peoples are clear about what they want in the delivery of cancer services which includes: (1) being patient led, (2) easily accessible culturally safe care with practical assistance to include financial assistance, accommodation, practical clothing and home support, (3) more cancer care services in rural and remote areas encompassing palliative care (so individuals can remain on country), (4) consideration to design future innovative approaches such as telehealth for real-time remote care, (5) better access to Aboriginal health workers (including innovative models like patient navigators and family escorts) and finally, (6) compulsory cultural safety training for all cancer care staff and trauma-informed care. Future research is urgently needed to evaluate the implementation and evaluation of the Aboriginal and Torres Strait Islander's Optimal Care Pathway (Cancer Australia, 2023; Chynoweth et al., 2020) to establish if existing needs in this review are being addressed.

Further research should incorporate Indigenous research methods to ensure that the results arising from studies authentically

represent the views and perspectives of First Nations people. Moreover, it will be important to include and foster leadership among First Nations researchers within research teams to ensure that research about First Nations people is also respectfully designed and undertaken with their direct involvement and leadership, especially including traditional custodians and knowledge holders. Data sovereignty needs to be considered more fully so that data ownership and interpretation of results rests with First Nations people specifically.

We recommend a wider uptake of co-design with First Nations people aimed at strengthening research outcomes. This is likely to align the relevancy of results with improved culturally safe health outcomes for First Nations people. We have noted numerous gaps in the research landscape for cancer care for First Nations people. In particular, it is important to ensure that research attention matches the tumour-specific prevalence priorities occurring among First Nations people; the care needs of Australia's First Nations children affected by cancer; explore cultural competence among MDT cancer healthcare professionals; and explore how cultural practices and traditional healing practices can be facilitated, enabled and enacted within the clinical environment (Rooney et al., 2022). Barriers exist that compromise the integration of Western and Traditional models of care which will need further exploration (Rooney et al., 2022) and will require decolonizing restorative approaches to enable authentic representation of those most impacted. Culturally safe end-of-life care consideration should explore the need for *On Country* cultural and spiritual care that provides for individuals and families who experience geographical isolation (Rooney et al., 2022).

7 | LIMITATIONS

This systematic review was comprehensive and robust in design and execution in the review process. The research team included both First Nations people, non-First Nations researchers and healthcare professionals with expertise in cancer care. The researchers employed decolonizing restorative approaches to ensure voice, respect, accountability and reciprocity in this review work, a strength-based approach that privileges Indigenous voices and requires non-Indigenous researchers to practice cultural humility; (Tervalon & Murray-Garcia, 1998) however, it can be seen that decolonizing thinking and language to enable cultural safety is ongoing learning and, in this study, efforts to decolonize language and thinking even when guided by Aboriginal and/or Torres Strait Islander researchers can be challenging, and the non-Indigenous researchers continue to have much to learn to provide restorative justice and equity (Ramsden, 2002). There are, however, some limitations to note given the heterogeneity and the cross-sectional design of the included studies – it was not possible to identify the trajectory of unmet supportive care needs across the cancer care continuum (at the point of diagnosis, treatment, post-treatment, survivorship, end-of-life and bereavement). A further limitation is that some of the included studies are

clinically outdated by the year of publication and may not represent contemporary experiences of cancer care services. No studies were identified to give voice and expression (either through play or drawing) to Australia's First Nations children affected by cancer. Only one study (Meiklejohn et al., 2017) in this review employed the Indigenous research method (yarning) specifically, and while others acknowledged the merit of storytelling – this research technique seems to have been superficially incorporated into mainstream interview-based methodologies, rather than deployed as a primary methodological approach to research design. These research design limitations may impact the trustworthiness, and as such, the implications that arise for First Nations cancer care should be carefully considered.

8 | CONCLUSION/IMPLICATION FOR PRACTICE

Most participants experienced discrimination, racism and trauma, resulting from colonization, which directly negatively impacted Aboriginal peoples' cancer care experience. While the Optimal Cancer Pathway (OCP) was launched in Australia several years ago, people with cancer may continue to experience distressing unmet care needs. Cancer specialist nurses, members of the multidisciplinary team and policymakers are encouraged to reflect on these findings and to take proactive steps to stamp out and stand together with Indigenous and non-Indigenous cancer leaders to dismantle oppression in health and safely implement the OCP.

AUTHOR CONTRIBUTIONS

Catherine Paterson: Conceptualization, methodology, validation, screening, interpretation, writing original draft, writing–reviewing & editing and supervision. **Cara Roberts:** Screening, data extraction and writing–reviewing & editing. **Julie Blackburn:** Screening, data extraction and writing–reviewing & editing. **Natasha Jojo:** Screening, data extraction and reviewing. **Holly Northam:** Contribution to supporting development of methodology, cultural sensitivity aspects, screening and interpretation—especially around restorative approaches to First Nations health. **Emily Wallis:** Data analysis and interpretation and editing. **Alicia Hind:** Analysis and interpretation and reviewing. **Rebecca Caulfield:** Screening and validation. **Macey Barrett:** Data extraction and reviewing. **Kellie Toohey:** Screening, extraction, analysis and interpretation; writing–reviewing & editing. **Rachel Bacon:** Analysis and interpretation and writing of original draft, reviewing and editing. **Phillip Kavanagh:** Data analysis and interpretation and editing. **Rhonda Wilson:** Analysis and interpretation, writing–reviewing & editing and cultural supervision.

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The data that support the findings of this study are available in the Supplementary Material of this article.

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CONSENT TO PARTICIPATE

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