International Centre for Allied Health Evidence

A review of the evidence on barriers and enablers to improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer and their families

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Executive Summary

Objective of the systematic literature review	The objective of this systematic literature review was to synthesise the evidence on barriers and enablers to improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer and their families. This review also examined approaches or strategies that have been used to improve the knowledge and experience in this population including key success factors associated with effective interventions.
Review questions	1. What are the barriers and enablers to improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer and their families? 2. What existing strategies or approaches are currently in place to improve their knowledge and experience, and what are their outcomes? 3. What is the evidence of effectiveness of interventions and approaches for improving their knowledge and experience following a cancer diagnosis? 4. What are the key features or characteristics (such as parameters) of effective interventions and approaches (i.e. key success factors)? 5. What are the barriers (e.g. health literacy) to the effectiveness and uptake of interventions aimed at improving the experience and knowledge of Aboriginal and Torres Strait Islander people with cancer? 6. What innovative and/or technological approaches have been used to effectively engage Indigenous Australians? 7. What are the literature and knowledge gaps in improving the experiences and knowledge of Aboriginal and Torres Strait Islander people with cancer and their families?
Methodology	A systematic, step-by-step approach, underpinned by best practice in reviewing the literature, was utilised as part of the methodology of this systematic literature review.
Evidence sources	Interrogation of the literature identified 41 relevant publications. Of these, six were systematic reviews, nine were quantitative studies, 22 were qualitative studies and four studies used mixed methods.
Answers to review question	The literature provides insights into a number of barriers and enablers to improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer and their families. The barriers identified in the literature can be grouped into key categories including individual, health provider, health system and environmental barriers. Commonly reported "*individual*" barriers were related to health literacy, attitude, culture, access, social, economic and communication issues. Within the category "*health-provider*", barriers related to their knowledge, attitude, culture and communication were described. Barriers reported to exist within the "*health system*" were issues associated with available resources, quality of services, and the nature and culture of the health environment. "*Environmental*" barriers referred to overcrowding and unsafe housing. Some of these barriers were particularly amplified for those from rural and remote areas. Few enablers were reported and they could be considered potential strategies to address the aforementioned barriers. The enablers identified from the literature could be broadly

classified into the following categories: *individual, health-provider, health service, and health system*. Within the category *"individual",* enablers such as culturally appropriate and targeted education, and use of bush medicine and other services which align and support individuals' cultural beliefs were reported. Health literacy support such as timely and relevant access to information about cancer and its treatment, and targeted media advertisements were also identified as enablers. Within the category *"health-provider",* enablers such as health providers with experience and relationships with Aboriginal communities, established working relations with local Indigenous health workers, health provider's mannerisms and adaptability to local contexts and availability of gender appropriate staff were reported. Within the category *"health service",* enablers such as use of an Aboriginal health worker or Indigenous liaison officer, engaging with family, and support for social workers (for counselling services) were described. Financial support such as funding for access to health services (such as transport, accommodation etc.) was also recognised as an enabler. Within the category *"health system"*, the role of cancer council services in providing access to Indigenous staff member, delivering professional training and development for staff, and facilitating improvements in Indigenous community engagement were reported as enablers. Other enablers such as previous experience of cancer and cancer care, previous interaction with health providers, and familiarity with cancer care strategies (such as screening) were also described.

A range of strategies were reported at improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer. Some of these strategies had an *"individual"* focus such as use of technology (such as free access to telephones and laptop to connect with their families), use of personal approach to facilitate engagement and collaboration, establishment of support groups to promote individual and community partnerships, culturally appropriate resources, and acknowledged and respected use of alternative and traditional medicine. Strategies targeted to *"health-providers"* were also described including education and training opportunities, and ongoing professional support; these strategies led to positive experiences of Aboriginal and Torres Islander people with cancer. Key learnings for health care providers in order to improve the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer include: respect for cultural diversity and respect of Indigenous Australian people and their wishes, recognizing that Indigenous patients and their families have different perspectives (such as use of alternative and traditional medicine), and ensuring a person-centred care approach (such as collaborative decision making with Aboriginal patients and families, addressing their concerns and misunderstandings, using plain language to communicate and using information materials which are culturally appropriate). Some strategies also had a *"health-system"* focus including implementation of new models of care (such as teleoncology), and use of dedicated Aboriginal health workers or Indigenous liaison officers who could act as a conduit between health providers and Indigenous people. The use of multifaceted initiatives, which recognised local barriers and implemented enabling strategies and were underpinned by collaborative partnership approaches between sectors (such as generic and aboriginal-centric health services) were also described.

In terms of evidence of effectiveness of interventions and approaches for improving knowledge and experience of Aboriginal and Torres Strait Islander people following cancer diagnosis, there is some evidence to indicate that this can be achieved for the *"individual"* and *"health-provider"* levels. For *"individual",* there is evidence to indicate that positive outcomes can be achieved in terms of knowledge, experience, satisfaction, participation, compliance, screening and access for the Aboriginal and Torres Strait people. For *"health-provider",* there is evidence to indicate that positive outcomes can be achieved in terms of awareness, confidence and knowledge. Evidence also indicates that these positive outcomes for the individual and health-provider could be underpinned by respect for, recognition of, and engagement with Aboriginal and Torres Strait Islander people and their communities in their cancer care.

With regards to the key features and characteristics of effective interventions, no single study focused exclusively on this question. Overall, the literature highlights that there is no *"one size fits all"* and a range of fundamental success factors need to be taken into consideration if interventions to improve the knowledge and experience Aboriginal and Torres Strait Islander people following a cancer diagnosis are to be successful. These include *health system structural factors* (such as access to Aboriginal health workers or Indigenous liaison officers, training and cultural awareness for health providers), *health service process factors* (such as respect for and culturally relevant care, acknowledgement of traditional healing) and *functional factors* (such as communication and cooperation with and engagement of ATSI people and their communities).

When viewed from an individual stakeholder point of view, the literature reports on a range of success factors from an *"individual"* and *"health-provider"* perspective. From an *"individual"* perspective, success factors include ready access to care which acknowledges the role of traditional healing, respects Indigenous culture/belief systems/perspectives and, utilises health workers who have a specific Aboriginal focus. From a *"health-provider"* perspective, success factors include access to training in cultural awareness, and regular communication, cooperation and engagement with Aboriginal and Torres Strait Islander people and/or their representatives. These finding highlight the complexities of entwined factors which currently exist, and hence the need for a system-wide focus when addressing this issue, rather than singular, stand-alone strategies.

There was a small body of literature reporting the barriers to effectiveness and uptake of interventions aimed at improving the experience and knowledge of Aboriginal and Torres Strait Islander people with cancer. These can occur at *"individuals"* (Aboriginal and Torres Strait Islander people and health providers), *"health service"* (in terms of resources and time) and *"health system"* levels. Examples of barriers include historical processes (resistance to change), medico-legal constraints, meagre resources and limited timeframes. There was limited literature on innovative and/or technological approaches have been used to effectively engage Indigenous Australians. These include small scale pilot initiatives trialing teleoncology using videoconferencing and a new model of care based on a holistic patient treatment model which addressed social, cultural and treatment needs of Indigenous Australians. Emerging evidence from these initiatives shows promising results. It is likely with emerging technologies, such as use of smart phones and tablets, applications (apps) and electronic health records, the evidence base will continue to evolve and further research may provide unique solutions to effectively engaging with Indigenous Australians in cancer care in the future.

	There were a number of literature and knowledge gaps in improving the experiences and knowledge of Aboriginal and Torres Strait Islander people with cancer and their families. Collectively, these gaps exist in the areas of service provision, funding, data availability, workforce, research and knowledge/information. The literature, however, also provides examples of strategies that could be used to address these gaps. Evaluation of research on barriers and enablers to improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer and their families pose numerous difficulties. Several publications within Aboriginal and Torres Strait Islander people with cancer span a wide spectrum of levels of evidence. Much of the literature on improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer and their families use research methodologies which could be considered as low level of evidence such as descriptive, observational and case studies. This may be appropriate in some instances as the focus on the research may be about describing or showcasing a resource, model of care or partnership approaches. However, what is lacking is high level evidence which have demonstrated a causal link between interventions and approaches targeted at Aboriginal and Torres Strait Islander People and/or health providers and improvements in outcomes. This evidence gap persists in the literature and requires ongoing further research to address it.

Introduction

Background

Changes to healthcare service delivery have been witnessed in recent times, both nationally and internationally. A number of factors have driven this change, including the increasing recognition that healthcare should be underpinned by key principles of quality; namely safety, effectiveness, patient centeredness, timeliness, efficiency and equity.[1] The need for healthcare to be underpinned by these integral quality principles has led to a quality and safety movement in Australia and around the world. An integral element of quality health care is the engagement by, and involvement of, patients as active participants and consumers in health care service delivery rather than mere passive recipients.

However, while there is widespread recognition of the importance of engaging with patients as active consumers within health care service delivery, how best to actually achieve this in clinical practice continues to face a number of challenges. There is a growing body of evidence which highlights numerous barriers in putting patient at the centre of care. Generally, these barriers cluster around the issues of time (such as limited time during consultations), intention-behaviour gap (while many health care professionals may have good intentions to engage with patients, due to workload pressures, tiredness, lack of time, they revert back to the historical paternalistic approach which they may be more familiar with), knowledge (lack of knowledge about how to translate theoretical and scientific knowledge into consumable form) and training (lack of formal and ongoing training of health professionals in patient-centred care).

Australia's ageing population, along with an increasing incidence of cancer and the growing cost of cancer care, necessitate the efficient use of resources, implementation of best practice standards, and shared decision making with clients. However, for the benefits to be shared across all health care settings and contexts, all people with cancer, including Indigenous Australians, need to be effectively engaged with the changes. There are many reasons why Indigenous Australians have poor outcomes from cancer when compared to their non-Indigenous peers. One of these reasons can be attributed to poor or ineffective consumer engagement as a result of low health literacy among Aboriginal and Torres Strait Islander patients and low cultural literacy among health professionals and the health care system.

Cancer is the second leading cause of death among Indigenous Australians, with an average of 424 deaths per year between 2006 and 2010, which is 1.4 times higher than the mortality rate for their non-Indigenous counterparts.[2] In 2010-11, 4,689 cancer-related hospitalisations for Indigenous people were identified in New South Wales, Victoria, Queensland, Western Australia, South Australia and the Northern Territory.[3] Information relating to Indigenous people's utilisation of cancer care is limited. What is available tends to focus on Indigenous women's involvement in cancer screening programs (particularly breast and cervical screening), and the barriers to accessing these services.[4] These barriers include limited knowledge about cancer and its management, remoteness of their homes, culturally specific reasons and personal issues.[4] It seems, therefore, that low health literacy in Aboriginal and Torres Strait Islander and low cultural

	literacy among health professionals and healthcare system in general contribute to ineffective consumer engagement. Despite calls for improvements in healthcare quality and safety, it is clear that cancer remains to be an important health issue for Indigenous Australians. While the patterns of cancer incidence and mortality can be largely explained by higher prevalence of risk factors in this population,[5] the need to address the barriers Indigenous Australians face in accessing cancer services requires urgent attention. These issues have serious implications to the Australian health system, which must ensure that high quality cancer detection and management is accessible to and appropriate for both Indigenous and non-Indigenous Australians.
Objective of the systematic review	The objective of this systematic literature review was to synthesise the evidence on barriers and enablers to improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer and their families. This review also examined approaches or strategies that have been used to improve the knowledge and experience in this population including key success factors associated with effective interventions.
Review questions	1. What are the barriers and enablers to improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer and their families? 2. What existing strategies or approaches are currently in place to improve their knowledge and experience, and what are their outcomes? 3. What is the evidence of effectiveness of interventions and approaches for improving their knowledge and experience following a cancer diagnosis? 4. What are the key features or characteristics (such as parameters) of effective interventions and approaches (i.e. key success factors)? 5. What are the barriers (e.g. health literacy) to the effectiveness and uptake of interventions aimed at improving the experience and knowledge of Aboriginal and Torres Strait Islander people with cancer? 6. What innovative and/or technological approaches have been used to effectively engage Indigenous Australians? 7. What are the literature and knowledge gaps in improving the experiences and knowledge of Aboriginal and Torres Strait Islander people with cancer and their families?

METHODOLOGY

Approach	The systematic literature review was underpinned by transparent, rigorous and methodical processes, which systematically interrogated, accessed, retrieved, appraised and synthesised current best available literature evidence on barriers and enablers to improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer and their families. The systematic literature review approach taken to address each question used the most appropriate methodology, reflecting the original purpose of the question, the nature of the best available evidence, and its quality. The scientific assessment followed the National Health and Medical Research Council's framework for appraising and synthesising the existing quantitative research. For qualitative research, the scientific assessment followed best practice in the field of meta-synthesis. The approach to this systematic literature review was unique, as it drew upon evidence from a number of diverse but equally relevant sources and methodological designs. In order to successfully and comprehensively answer the objectives of this initiative and provide answers to all questions posed, a comprehensive approach to literature interrogation was required which systematically identified, gathered, appraised and synthesised primary (quantitative and qualitative research), secondary (systematic reviews) and grey literature.
Criteria for considering research in the review	The criteria for considering studies in this review were defined using the PICO framework – **P**articipants, **I**ntervention, **C**omparison and **O**utcomes. The type of studies considered is also described below.
Type of studies	***Included*** • Any existing systematic reviews, meta-analyses, guidelines or relevant reports from relevant organisations • Any quantitative or qualitative publications from peer-reviewed journals ***Excluded*** • Opinion, commentary and unstructured literature reviews • Non-English language literature
Type of participants	***Included*** • Aboriginal and Torres Strait Islander people with cancer, including their families ***Excluded*** • Aboriginal and Torres Strait Islander children and adolescents
Type of intervention	***Included*** • Any intervention for improving knowledge and experience of Aboriginal and Torres Strait Islander people diagnosed with cancer • Studies which reported about barriers and enablers to improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer and their families

Type of comparators	Usual care, control or no care
Type of outcomes	***Including*** but not limited to • Clinical outcomes (e.g. physiologic and functional) • Psychosocial outcomes • Knowledge • Quality of life • Healthcare cost • Health service use • Patient experiences ***Excluded*** • Specific to outcomes from interventions from cancer
Peer-reviewed databases	Informit (health, Indigenous peoples) OVID (Medline, AMED, EMBASE, PsychINFO), IPortal Indigenous Studies portal, EBSCOhost (Academic Search Premier, Australian and New Zealand Reference Centre, CINAHL, HealthSource), PubMed, Cochrane library, Scopus, Web of Science; Core Collection, ERIC.
Targeted researchers and other evidence sources	Independent validation of the search process was sought from the Cancer Australia team and their feedback was incorporated in the final methodology. The search strategy was also reviewed by an independent librarian at University of South Australia and feedback was incorporated in the final methodology. Key Australian and international researchers' publications were identified, in collaboration with Cancer Australia team, as a means of validating the search processes implemented by the *i*CAHE technical team. Pearling and manual searching was also conducted (secondary searching). The final list of included publications was then submitted to and independently validated by the Cancer Australia team.
Pearling	Reference lists of retrieved articles were also searched to maximise the retrieval of relevant publications.
Grey literature	As a means of avoiding publication bias, and to improve the overall reach and spread of this systematic literature review, a targeted streamlined grey literature search was undertaken. Sources such as Australian Indigenous HealthInfonet, Cooperative Research Centre for Aboriginal & Tropical Health, Australian Institute of Aboriginal and Torres Strait Islander Studies and Australian Indigenous Health Bulletin were interrogated for any relevant publications. A scoping search of an internet search engine (Google) was conducted to identify any additional websites which can contribute to this systematic literature review.
Key words	A combination of search terms from concepts 1-7 was used to identify potentially relevant publications from the included databases. Synonymous terms and related MESH headings were used to expand the search as appropriate.

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<tr><td>concept 1</td><td>Aborigin* or Torres Strait or ATSI Or Indigenous or Oceanic Ancestry Group or</td></tr>
<tr><td>concept 2</td><td>cancer or malignanc* or tumo$r* or oncology or neoplasm*</td></tr>
<tr><td>concept 3</td><td>Barrier* or obstacle* or hurdle* or limit*</td></tr>
<tr><td>concept 4</td><td>Enabler* or facilitator* or support* or enhance* or succe*</td></tr>
<tr><td>concept 5</td><td>Health</td></tr>
<tr><td>concept 6</td><td>Literac* or educat* or information or knowledge or perspect* or decision$making or empower* or patient experience or consumer experience</td></tr>
<tr><td>concept 7</td><td>Northern Territory or Queensland or South Australia or Western Australia or Tasmania or ACT or Australian Capital Territory or New South Wales or Victoria or Austral*</td></tr>
</table>
<p>Appropriate truncation symbols and Boolean operators (AND, OR, NOT) were used for relevant databases.</p>
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<td>Literature selection</td>
<td>The titles generated by the electronic databases were scanned to identify potentially relevant papers and where the titles did not allow determination of relevance to the topic, abstracts were reviewed. Full text copies of eligible publications (based on title or abstract) were retrieved for full examination. During this process, the complete papers were examined against the inclusion criteria. Publications which met all the inclusion parameters were included in the review and those which did not meet the inclusion criteria were not considered.</td>
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<td>Allocation of hierarchy of evidence</td>
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<p>As each study design inherently carries various methodological biases, ranking publications based on study designs assisted in categorising studies according to the level of bias within their methodologies. This is an important first step in assessing the quality of the evidence base. For the purpose of this systematic literature review, for all quantitative research, <i>i</i>CAHE technical team used the National Health and Medical Research Council’s (NHMRC) Level of Evidence (Intervention stream). Two independent reviewers allocated a ranking to the study design of every included publication.</p>
<p>As there are is no agreed hierarchy of evidence for qualitative research, this process of allocating a hierarchy level was not implemented for qualitative research studies. The National Health and Medical Research Council (NHMRC) acknowledged this as a limitation of the current ‘NHMRC additional levels of evidence and grades for recommendations’ which explicitly stated that ‘<i>There are some types of evidence that have not been captured in this new grading approach, specifically qualitative studies</i>’[6] For this review, therefore, <i>i</i>CAHE technical team described the specific qualitative methodology used for the individual studies (e.g. phenomenology, grounded theory, ethnography), rather than allocate a ranking to the study design.</p>
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Critical appraisal	Two *i*CAHE reviewers independently examined the methodological quality of included publications. For primary quantitative and qualitative studies, the modified McMaster Critical Appraisal tools[7,8] were used. *i*CAHE has chosen the Modified McMaster Quantitative (**Appendix 1**) and Qualitative (**Appendix 2**) Critical Appraisal tools for this systematic literature review because these tools are generic by design (that is, they are not specific to individual research designs) and as such can be used across multiple research designs. They provide a common framework for evaluating different research designs within a systematic literature review. For primary mixed-method studies, methodological quality was assessed using the MMAT- Mixed Methods Appraisal Tool[9] (**Appendix 3**). The *i*CAHE technical team has a long history of using these tools successfully across a number of systematic literature reviews. For secondary research studies, such as systematic reviews, the Critical Appraisal Skills Program (CASP) tool[10] (**Appendix 4**) was used. The *i*CAHE technical team chose this tool as it is a published and widely used tool across the world. The *i*CAHE technical team has a long history of using this tool successfully across a number of systematic literature reviews. For grey literature, such as government reports, due to the nature of these publications (non-scientific and as such there are no critical appraisal tools available for such publications), no formal critical appraisal process was undertaken. Ratings for individual publications were compared between reviewers and discrepancies were resolved by discussion. The quality of evidence was reported narratively for this systematic review, rather than providing a summary score. The use of scores to distinguish high and low quality studies is questionable because of the degree of subjective judgement, and hence, not recommended. For this review, therefore, it was preferable to describe aspects of methodological quality (e.g. blinding, inadequate sample) and their potential impact on the review findings.
Data extraction	Customised data extraction forms were developed for this systematic review; key elements considered pertinent to address the objectives and questions of this project were extracted. Comprehensive data extraction tables are attached in the Appendix of this report **(Appendix 5).**
Body of evidence framework	As this systematic literature review considered quantitative and qualitative research paradigms, and aimed to answer a number of critical and comprehensive questions, a meta-analysis was not considered an appropriate methodological process to synthesise the evidence from the literature. **Quantitative research synthesis** The *i*CAHE technical team utilised the NHMRC FORM methodology[11] to grade and provide a framework to synthesise the evidence from the literature. While the NHMRC FORM

methodology is mostly used in the development of clinical guidelines, the *i*CAHE technical team used this methodology as a unique way of summarising the quantitative research findings. This framework considers all evidence dimensions for all studies, which are then used in the development of a specific recommendation. There are five key components, which make up the body of evidence for each recommendation. The first component relates to the evidence base, which is assessed in terms of quantity of evidence (number of studies), level of evidence and quality of evidence (risk of bias). The second component relates to whether the findings across included studies, which may encompass a range of populations and study designs, are consistent. These first two components provide an overview of the internal validity of the study. The third component relates to the clinical impact, which is a measure of possible benefits of applying the findings to a population, while taking into account a number of factors including the balance of risks and benefits. The fourth component relates to generalisability, which takes into account how well the subjects and settings of the included studies represent the population and settings of interest for the review. The fifth and final component relates to applicability and this relates to whether the evidence base (included studies in the review) is relevant to and appropriate for Australian health care settings.

Each component was then rated according to the NHRMC Body of Evidence matrix (a copy of which is provided in **Appendix 6**) which contains four distinct categories (A-D). Category A is classified as *"Excellent"* and denotes an excellent evidence base (several high level studies with local risk of bias), with findings across studies being consistent, with very large clinical effects, and with excellent generalisability and applicability. Category B is classified as *"Good"* and indicates a good evidence base (some high and low level studies with low risk of bias), with findings from most studies being consistent (inconsistences explainable), with substantial clinical impact, and with good generalisability and applicability. Category C is classified as *"Satisfactory"* with satisfactory evidence base (high level studies with moderate risk of bias or low level studies with low risk of bias), with some inconsistencies in findings across studies (reflecting genuine uncertainty) but with moderate clinical impact and satisfactory generalisability and applicability. Category D is classified as *"Poor"* with poor evidence base (high level studies with high risk of bias and low level studies), inconsistent findings, slight or restricted clinical impact, and poor generalisability and applicability.

Qualitative research synthesis

Currently there is no universally agreed process for reviewing qualitative research, and approaches to synthesising qualitative evidence are still emerging. However, for this review, *i*CAHE utilised an established method of synthesising qualitative evidence through systematic comparison of individual studies, examination of the consistency/inconsistency of findings, and employing a meta-ethonographic approach. This approach is systematic and involves a rigorous process of taking analysis from first-order concepts and second order themes to third order of interpretation. The first level of analysis involves breaking down and rigorously examining findings from individual studies. The second order analysis involves identifying common themes (which can be colour coded), which are then grouped together and main themes are developed pertinent to the topic under investigation. The third-order interpretation involves linking

	relationships between concepts. This meta-synthesis framework has been used previously in the literature[12] and builds on the work by Noblit and Hare.[13] **Systematic reviews and mixed methods research synthesis** The findings from systematic reviews and mixed methods were synthesised descriptively and emergent findings reported. As there is no universally agreed process for synthesising findings from systematic reviews and mixed methods, descriptive reporting provided a useful and practical means of summarising this body of research.
Evidence snap shots	A summary of the evidence base underpinning the response is provided as “Evidence snap shots”, which acts as a precursor to the complete findings. An evidence snap shot provides a succinct summary of the evidence base and key findings from the literature. It also contains the NHMRC Body of Evidence matrix for quantitative evidence and narrative summaries for secondary, qualitative and mixed methods.

RESULTS

Search results

The search strategy identified a total of 749 peer-reviewed and one grey literature which were reviewed by *i*CAHE researchers (as shown in Figure 1). Please refer to **Appendix 7** for an example of database hits (Medline and Embase). After removal of duplicates (396), review of titles and abstracts resulted in the exclusion of 218 publications. Reasons for exclusion were: (a) opinion, commentary and unstructured literature reviews, or conference abstracts or summary of forum, (b) Aboriginal and Torres Strait Islander children and adolescents, (c) interventions for cancer, (d) specific to outcomes from actual interventions for cancer, (e) not relevant to the review objectives, (f) not specific to Aboriginal population and (g) not specific to cancer. Key Australian and international researchers' publications were identified and cross-referenced with the retrieved literature from the systematic search. This process demonstrated good congruence between publications identified from the systematic search and those identified from the targeted researchers. One hundred thirty eight (136) publications were retrieved for full examination. After scrutiny, 95 were further excluded, leaving 41 literatures for inclusion in the review. The reference lists of the included publications were carefully examined for additional literature (i.e. pearling). No further publications were found eligible.

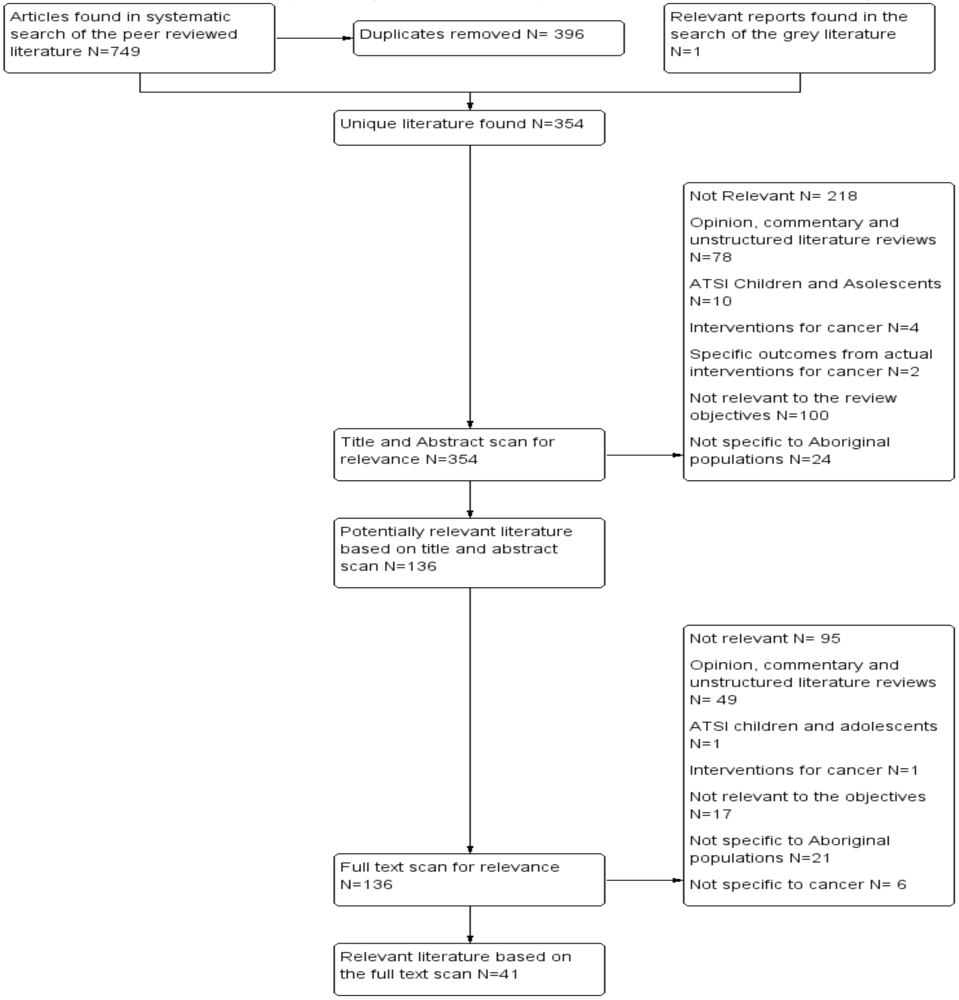

Figure 1 Flowchart of article selection process

Characteristics of included studies

Publication year and country

All studies included in this review were published in Australia between 1997 and 2014. Two publications were from the year 2014,[14,15] seven publications were from the year 2013;[16-22] followed by six publications in 2012[23-28] and five in 2011. [29-33] Three publications were from 2010, [34-36] four from 2009,[37-40] four in 2008[39,41-43] and one in 2007.[44] The year 2006 has three publications included,[45-47] two publications from the year 2000,[48,49] one in the year 1999,[50] two in the year 1998[51,52] and finally, one in 1997.[51]

Indigenous group

Nineteen of the included studies focused on both Indigenous groups of Australia i.e. Aboriginals and Torrens Strait Islanders[14,16,18,23,24,26-28, 31-33,41,43-48,51] Eighteen studies focused only on Aboriginals.[15, 17, 19, 20, 22, 30, 36-39,42, 49, 50, 52-55] One addressed cultural subgroups living in Australia including Indigenous population,[24] two studies explored Indigenous groups of Australia, New Zealand, Canada and United States of America [21,56] and one paper reported about Indigenous health professionals.[33]

Cancer type

Of the included studies, 17 covered all types of cancers [14,15,17,19,20,22,27-29,31,36,38-40,56] while seven focused on cervical cancer [42,46,48,50,52,53,51] and three on colorectal cancer.[23,24,32] There was one study each on breast,[49] lung,[16] bowel[34] and gynaecological cancers.[33] Two studies were about palliative care but did not specify which cancer they focused on.[44,54] One study reported on both cervical & breast cancers.[43] One study covered a number of cancers such as lung, colon, rectum, breast, cervical and non-Hodgkins lymphoma.[45] Finally, six studies did not specify which cancer they focused on.[19,26,35,37,40,47]

Research type

There were six studies included that were secondary evidence. [16,17,21,31,34,56]

Thirty one of the included studies were primary evidence of which nine were quantitative ,[18,23,27,28,35,45,48,51,53] 22 were qualitative [14,15,19,20,22,24,29,30,33,36-41,44,46,47,49,50,52,54] and four were mixed method[26,32,42,48] research designs.

Research design

The secondary evidence comprised five systematic reviews[16,21,29,34,56] and one rapid review.[17]

Primary evidence was divided as follows:

- The primary quantitative research designs consisted of one survey,[23] two cohort observational,[45,55] two cross-sectional observational, [18,28]one pre post study,[35] one randomised trial,[51] one descriptive study[27] and one study did not report the specific research design.[48]
- The primary qualitative research designs comprised of one descriptive study, [41] one ethnographic study,[46] one interpretive ethnography,[37] three phenomenology studies, [38,40,47] one grounded theory[19] , one community participation model[50] and 14 studies did not report on the specific study design.[14,15,20,22,24,29,30,33,36,39,44,49,52,54]
- The mixed methods included four studies.[26,32,42,50]

Critical appraisal

Secondary research

There were six secondary research papers[16,17,21,31,34,56] included in this report which were appraised using the Critical Appraisal Skills Programme tool. A summary of the critical appraisal scores is provided in **Appendix 8**.

All studies asked a clearly focused question, searched for relevant papers, included the appropriate studies and combined results to provide a narrative synthesis. Three papers [16,17,56] assessed the quality of the included studies, however Shahid and Thompson (2009) and Van Schaik and Thompson (2012) made no mention of the appraisal process and one paper was not clear on the appraisal method.[34] Of the six reviews, only two[17,34] reported that the benefits were worth the harms and costs while for the other reviews this quality appraisal item was not applicable to report. All reviews considered all important outcomes and their findings can be applied to local populations.

Primary quantitative research

There were nine primary quantitative studies[18,23,27,28,35,57,45,48,55] which were appraised for quality using the McMaster critical appraisal tool. A summary of the critical appraisal scores is provided in **Appendix 9**.

All nine studies stated a clear purpose, described relevant background literature, had a design appropriate to the research question and described the sample and intervention in detail. All their analysis methods and conclusions were appropriate given the study methods and results. Informed consent was obtained in three studies.[23,27,28] Outcome measures were valid and reliable in four studies,[18,48,55,57] not valid and reliable in one study,[35] not addressed in three,[23,27,28] and this criterion was not applicable in one study.[45]

Results were reported in terms of statistical significance in all studies except for one[27] which reported results narratively. Participant drop outs were found in two studies[55,57] , not reported in one[35] and the criterion was not applicable in the remaining six studies.[18, 27, 28,23, 45, 48] Between group significance was clinically meaningful in four[18,48,55,57] studies, it was not meaningful not in one study[35] and this criterion was not applicable in the other four studies.[23,27,28,35]

Primary qualitative research

There were 22 primary qualitative studies[14,15,19,20,22,24,29,30,33,36,37,38,39,40,41,44,46,47,49,50,52,54,55] which were appraised for quality using the McMaster Critical Appraisal tool for Qualitative studies. A summary of the critical appraisal scores is provided in **Appendix 10**.

All studies had a clearly stated purpose, reviewed relevant background literature, selected a design appropriate to the study question, described the process of purposeful selection, enabled a meaningful picture of the study to emerge, made conclusions that were appropriate to the study findings and had findings that contributed to theory development and future research.

Ten of the studies identified a theoretical perspective,[15,19,22,29,36,37,38,40,46,54] only four did sampling until redundancy was reached,[14,37,38,40] and informed consent was obtained in all except for five studies.[41,49,50,52,24]

There was a clear and complete description of the site in eight studies[14,15,19,20,22,37,52,54] and of the participants in all except for eight studies.[22,33,39,41,44,47,50,52]

There was a description of the role of the researcher & relationship with participants in nine studies[19,37,41,44,46,47,49,50,52] and the identification of assumptions and biases of the researcher was given in only two of the included studies.[19,50] Procedural rigor was used in data collection strategies in all except three studies,[41,50,52] data analysis was inductive in all except five studies,[30,39,41,50,52] findings were consistent with and reflective of data in all except three studies,[39,46,50] decision trial was developed in seven of the included studies[20,22,29,36,37,38,40] and the process of analysis the data was adequately described in all except seven studies.[30,33,41,49,50,39,52]

Evidence of the four components of trustworthiness in the included studies was as follows:

- Credibility: All included studies satisfied this criterion
- Transferability: Six studies did not satisfy this criterion.[22,33,41,44,47,52]
- Dependability: Five studies did not satisfy this criterion. [24,30,41,50,52]
- Confirmability: Three studies did not satisfy this criterion. [24,39,52]

Primary mixed methods research

Four of the included studies[24,26,32,42,43] were mixed methods study design and they were appraised for methodological quality using the MMAT- Mixed Methods Appraisal Tool. A summary of the critical appraisal scores is provided in **Appendix 11**.

All papers had a clear research question, collected data which answered the research question, had data sources that met the research objective, used a process of analysis that met the research objective, gave appropriate consideration given to how findings related to the context, had a sampling strategy that allowed for answering the research question and had a sample representative of the population under study. In addition, use of the mixed methods design and integration of the qualitative and quantitative data allowed for answering of the research question in all the studies. However, none of the studies gave appropriate consideration to the limitations associated with this integration of data.

None of the studies gave appropriate consideration to how findings relate to the researchers' influence. Details of methodology were not available for one study as they were reported to have been provided in another publication but were not accessible at the time of this review.[43]

1. What are the barriers and enablers to improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer and their families?

EVIDENCE SNAPSHOT OF BARRIERS

<table>
<tr>
<td>Secondary evidence</td>
<td>Five systematic reviews[16,21,25,31,34] and one rapid review[17] reported a range of barriers to improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer (and their families). Barriers were described at different levels, including those related to individual patients, health provider, health system, and environment.

Individual patient barriers range from issues relating to health literacy, cultural issues, social issues, access issues and economic barriers. Health provider-related barriers include issues related to the lack of understanding of the cultural needs of Indigenous people. Health system-related barriers relate to the lack of, or limited culturally appropriate resources. Environment-related barriers refer to poor environment conditions and unsafe housing.</td>
</tr>
<tr>
<td>Primary evidence (Quantitative)</td>
<td>Seven quantitative studies reported barriers to improving the knowledge and experience of Aboriginal and Torres Strait Islander patients diagnosed with cancer.[18,23,28,45,48,51,53]

<table>
<tr><th>Component</th><th>Evidence Grading</th></tr>
<tr><td>Evidence base
<i>The evidence base is assessed in terms of the quantity, level and quality (risk of bias) of the included studies.</i></td><td>D
(Poor)</td></tr>
<tr><td>Consistency
<i>The consistency component of the ‘body of evidence’ assesses whether the findings are consistent across the included studies.</i></td><td>B
(Good)</td></tr>
<tr><td>Clinical impact
<i>Clinical impact is a measure of the potential benefit from application of the findings to a population.</i></td><td>D
(Poor)</td></tr>
<tr><td>Generalisability
<i>This component covers how well the subjects and settings of the included studies match those of the recommendations.</i></td><td>B
(Good)</td></tr>
<tr><td>Applicability
<i>This component addresses whether the evidence base is relevant to the Australian healthcare setting generally.</i></td><td>B
(Good)</td></tr>
</table>

The majority of barriers reported for individual patient level relate to the inadequate knowledge of and negative attitudes to cancer and its treatment, past experiences and health history, social issues, and access issues. On a health provider level, lack of their</td>
</tr>
</table>

	understanding about culture, language barriers, and failure to establish ongoing relationships with patients, and differences in communication style affect patients' uptake of cancer services. Health system-related barriers include the lack of, or limited culturally appropriate resources such as Indigenous staff and Indigenous-specific cancer services (e.g. culturally appropriate design of screening services), limited practical support (e.g. transport, financial assistance, accommodation) and funding.
Primary evidence (Qualitative)	Twenty one qualitative studies[15,19,20,22,24,29,30,33,36,37,38,39,40,41,44,46,47,49,50,52,54,55] identified barriers to improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer and their families. These studies identified barriers which occur at various levels such as individual, health provider and health system levels. Individual patient barriers range from issues relating to health literacy, attitudes & perception, cultural issues, social & economic issues, and access issues. Health provider-related barriers refer to health care workers' lack of understanding of, or false assumptions about Aboriginal and Torres Strait Islander people's culture (e.g. values, customs, traditions, etc.) and their inability to adapt the services to Indigenous culture. Health system-related barriers include unsympathetic health service environments, lack of flexibility in appointment times, lack of support for extended family visits, lack of Indigenous staff support, limited access to services and lack of coordination between services.
Primary evidence (Mixed methods)	One mixed methods study reported health system-related barrier to colorectal screening participation.[32] Language barriers, lack of knowledge about cancer and limited awareness of preventive strategies such as screening were cited as major barriers to participation in a screening program.

EVIDENCE SNAPSHOT OF ENABLERS

<table>
<tr><td>Secondary evidence</td><td>Only one systematic review described an enabler for improving the experience of Aboriginal and Torres Strait Islander patients with cancer.[31] The involvement of an Indigenous health worker/liaison officer/staff was found helpful during the process of diagnosis and treatment and in facilitating better relationships between patients and health service provider/system.</td></tr>
<tr><td>Primary evidence (Quantitative)</td><td>Three quantitative studies reported enablers to improving the knowledge and experience of Indigenous patients with cancer. [18,23,51] The use of mass media for increasing awareness about cancer and its treatment was described; other enablers include previous experience with the medical system, culturally-sensitive approach to health services, a dedicated Indigenous Liaison, and provision of practical support (e.g. accommodation, transportation).
<table>
<tr><th>Component</th><th>Evidence Grading</th></tr>
<tr><td>Evidence base
<i>The evidence base is assessed in terms of the quantity, level and quality (risk of bias) of the included studies.</i></td><td>D
(Poor)</td></tr>
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(Good)</td></tr>
<tr><td>Applicability
<i>This component addresses whether the evidence base is relevant to the Australian healthcare setting generally.</i></td><td>B
(Good)</td></tr>
</table></td></tr>
<tr><td>Primary evidence (Qualitative)</td><td>Eight qualitative studies[19,24,36,37,41,47,49,52] identified enablers to improving the experience and knowledge of Aboriginal and Torres Strait Islander people. Enablers include use of Indigenous health service providers or Indigenous Liaison Officers, assistance from cancer support groups, services which respect significance of family support, counselling services, provision of information regarding cancer and its treatment, and cost-free services (i.e. screening). The informal meetings and discussions between non-Indigenous service providers and their Indigenous counterparts were also reported as enablers, as they can increase cultural awareness and facilitate cross cultural relationships.</td></tr>
<tr><td>Primary evidence</td><td>Two mixed methods studies reported enablers to improving the knowledge and</td></tr>
</table>

(Mixed methods)	experience of Aboriginal and Torres Strait Islander patients with cancer.[32,43] Both studies reported enablers for screening participation. Factors such as culturally appropriate service provision, use of Indigenous health workers, Aboriginal and Torres Strait Islander community involvement in program delivery, previous experience with screening, flexible appointments, and practical support were described to facilitate participation in screening programs.

BARRIERS to improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer and their families

Secondary evidence	Five systematic reviews[16,21,25,31,34] and one rapid review[16] reported a range of barriers to improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer (and their families). Barriers were described at different levels, including those related to individual patients, health provider, health system, and environment. **Individual patient barriers** range from issues relating to health literacy, cultural issues, social issues, access issues and economic barriers. *Health literacy* Many Aboriginal and Torres Strait Islander people have little understanding of cancer as a disease[21,25,34] and have poor awareness of the benefits of screening prevention services[34] and other cancer treatment.[25] Poor health literacy as a result of inadequate education and low socioeconomic background was reported as a barrier to receiving optimal cancer care[16,17] and accessing early detection programs (e.g. screening). [34] Several misconceptions about cancer were reported in the literature. There is a belief that cancer was a death sentence[16,25,31,34] and that treatment was mostly futile.[31] This perception and fatalistic view is strongly related to poorer survival and a major factor explaining why people ignore early symptoms and do not access treatment.[16] There are concerns about the toxicity, side effects, and potential disfigurement of cancer treatment, and these beliefs explain why Aboriginal and Torres Strait Islander people are less likely to receive aggressive cancer treatment.[31] *Cultural issues* There is also a perception that cancer is a 'white man's disease' and that it therefore requires 'white man's medicine'. [21,25,31] There is a reluctance by Aboriginal and Torres Strait Islander people who had survived or were dealing with cancer to talk about cancer and therefore the community generally see only the dark side of cancer and the reality that cancer can be treated with timely Western medicine is largely hidden.[21] Some believe that cancer is a form of payback or punishment and is put on a person for unlawful activity or wrongdoing.[16,21,25,31]There is also a belief that patients bear the pain on behalf of the family or the community member and thus, their suffering secures the safety and well-being of other members.[21] Some believe that cancer is contagious, which can lead to social and emotional isolation for the person who has been diagnosed with cancer.[16,21] Some others believe that cancer only affects Aboriginal and Torres Strait Islander people and as such it needed to be cured by a traditional healer.[31] *Social barriers* In some instances, relocating to a hospital which is far from home gave a feeling of emotional distance and isolation from one's community.[31] For some patients, this means not being able to fulfil community social obligations or that they will have limited social network.[31] As advanced technology is located in major urban centres, Aboriginal and Torres Strait Islander people experience social and cultural dislocation if they are required to relocate from remote communities.[16]

Access barriers

Several barriers related to access were described including poor coordination of services from screening programs to follow-up and treatment, lack of transportation, family responsibilities, difficulties communicating with health providers and health organisations due to language or literacy or cultural differences[25,34] and remoteness or distance barriers.[16,25,34]

Economic barriers

Many Aboriginal and Torres Strait Islander people do not have private health insurance or any income protection,[16] and costs associated with seeing a general practitioner including follow-up and treatment, travel to hospital and accommodation were also reported as barriers.[34]

Other individual barriers

One review reported other individual barriers related to cancer screening uptake including previous experience of racism and distrust in medical institutions, discomfort with mainstream services (e.g. hospital environment), presence of co-morbidities, negative attitude, low perceived risk of cancer, and worry or fear of cancer.[34]

Health provider-related barriers include issues related to the lack of understanding of the cultural needs of Aboriginal and Torres Strait Islander.[16, 34] The lack of cultural competency of the health practitioner may hinder communication between the practitioner and patient.[16] Patient-provider relationship can be prone to miscommunication and such miscommunication is especially an issue for Aboriginal and Torres Strait Islander patients. There is no Indigenous word for cancer, which is also one of the reasons for miscommunication.[16,21,31] Health practitioner communication and patient understanding of their condition and treatment is often difficult to achieve for both linguistic and cultural reason.[31] Communication issues can compound a pre-existing lack of trust in the Western medical establishment and can also lead to 'unrealistic expectations' of cancer treatment.[31] The differences in cultural background between the health practitioner and patient also increase the likelihood of misdiagnosis and non-cooperation with treatment and disease management.[16]

Health system-related barriers include the lack of, or limited culturally appropriate resources. There is a lack of culturally sensitive public health campaign, lack of health promotional materials in Indigenous languages,[34] limited cancer-specific information and ineffective preventive strategies by the health community.[16] There are limited specialist cancer services in regional Australia and few, if any, Indigenous cancer specialists[16] and staff.[34]

Environmental factors which can be attributed to poor socioeconomic status including low income, low level of education, high rates of unemployment, greater risk of being involved with the legal system and poor or substandard housing (e.g. overcrowding and inadequate facilities and structures) have also been identified as barriers to improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer and their families.[16] Poor environmental conditions and unsafe housing expose patients to

	environmental tobacco smoke or other sources of diseases.[16]
Primary evidence (Quantitative)	Seven quantitative studies reported barriers to improving the knowledge and experience of Aboriginal and Torres Strait Islander patients diagnosed with cancer. Four studies specifically examined factors which influence participation in screening programs,[23,48,51,53] one study investigated factors that determine compliance to radiotherapy treatment,[18] another study described cancer support services for Aboriginal and Torres Strait Islander patients,[28] and one other study investigated why Aboriginal and Torres Strait Islander people have more advanced cancer and lower cancer survival.[45] Barriers were reported at the individual patient level, health provider level and health system level. The majority of barriers reported for **individual patient level** relate to the knowledge of and attitudes to cancer and its treatment. Low levels of education,[48] and inadequate knowledge and understanding of bowel cancer[34] were reported as barriers to participating in a screening program. The fear of finding out something is wrong was also described as a barrier to screening participation.[34] People who do not have symptoms and no family history of bowel cancer are less likely to participate in a screening program.[34] Aboriginal and Torres Strait Islander people with cancer are also less likely to receive treatment because of lack of awareness or knowledge about existing services.[28] Knowledge of and attitudes to cancer symptoms and treatment, social and cultural distance from mainstream health services,[45] and costs associated with accessing support services[28] were reported as barriers to accessing cancer treatment. Communication difficulties were also identified as a major impediment for Indigenous people with cancer.[45] In a study which examined radiation treatment compliance in the Aboriginal and Torres Strait Islander population, toxicity grade was shown to be a predictor for compliance, with those who suffer worse toxicity having poorer compliance rates because of abandonment of treatment.[18] On a **health provider level**, lack of their understanding about culture, language barriers, and failure to establish ongoing relationships with patients and differences in communication style affect patients' uptake of cancer services.[28] **Health system-related** barriers include the lack of, or limited culturally appropriate resources including Indigenous staff[28] and health workers.[53] In a study aimed at describing the availability of cancer support services, no Indigenous-specific cancer services were identified and only a handful of services were 'Indigenous friendly' and most did not have Indigenous staff.[28] Few services offered practical support such as transport, financial assistance, and accommodation[28] to Aboriginal and Torres Strait Islander patients with cancer. In another study, the financial insecurity faced by many medical services is a frequent barrier to the smooth running of projects and services provided to patients with cancer.[51] For example, because of a funding crisis, Indigenous health workers had less time available to follow up women for screening and had to reduce health promotion activities.[51] Concerns about lack of client follow-up and inadequate staffing were also raised by one other study.[53] Barriers to participation in bowel cancer screening were related to the design of of the

	screening program and test method including the postal distribution, storage of samples, and lack of privacy in which to do the test.[34] Home visits to discuss Pap smear screening were viewed as culturally inappropriate by Indigenous Health Workers.[51]
Primary evidence (Qualitative)	Twenty one qualitative studies[15,19,20,22,24,29,30,33,36,37,38,39,40,41,44,46,47,49,50,52,54,55] identified barriers to improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer and their families. The literature reports on a multi layered range of individual patient, health provider and health system findings. Individual patient barriers range from issues relating to health literacy, attitudes & perception, cultural issues, social & economic issues, and access issues. *Health literacy issues* Indigenous Australians were found to have limited understanding of biomedical concepts and physiology associated with cancer.[20,47,49] Poor understanding of the purpose and advantages of cervical screening was reported by Manderson and Hoban[46] and Shahid, Finn and Thompson[38]. Lack of awareness of colorectal cancer and the National Bowel Cancer Screening Program led to anxiety and confusion for Indigenous adults who received a test kit and mistakenly concluded they were at high risk.[24] Low levels of understanding about cancer and the medical system were considered a significant impediment to communication between cancer service providers and patients.[20] Limited knowledge led to lack of participation and control.[49] Lack of symptoms and absence of cancer in family history were reported as reasons for non-participation in cancer screening processes[24,49]; *"If I hadn't of found a lump there I would have been like anybody else (sic), I wouldn't have worried about mammograms, I wouldn't have worried about screening later in my life."* (McMichael et al. 2000, p 517). McMichael et al[49] found that women under 40 years were generally better informed in knowledge of breast cancer symptoms than older women, however they also believed they were at lower risk (a belief reinforced by Breast Screen promotional material encouraging mammography for women aged 50 to 69 years). Manderson and Hoban[46] found that some females considered themselves as either too young or too old to be at risk of or to test for cervical cancer. Health workers in Prior's study reported that older women did not consider themselves at risk of cervical cancer if they were sexually inactive. Understanding of cancer reportedly varied with cancer type where visible signs of illness increased comprehension of the disease process; *"I think it depends on the type of cancer; one lady died quite suddenly with leukaemia and people have found that very difficult to understand*.[47] Aboriginal and Torres Strait Islander patients and their families, especially those from rural and remote regions, lacked understanding of the importance of adhering to oncology treatment regimes, including the need to attend follow up appointments on time,

complete length of stay for treatment, stay close to the place of treatment and to abstain from smoking and consuming alcohol.[20]

Lack of knowledge of cancer type, treatment options and outcomes, and a common perception amongst Indigenous Australians that there was only one type of cancer and therefore outcomes were the same regardless of the site or stage of growth were reported by Prior[37] and Shahid, Finn and Thompson.[38]

Attitudes and perceptions

Perceived lack of self-efficacy influenced cancer screening participation. Lack of confidence to adequately perform breast self-examination and recognise symptoms, was reported by Aboriginal and Torres Strait Islander women in one study.[49] Similarly, Javanparast et al[24] found that Indigenous participants indicated they would like assistance from a support worker to complete colorectal screening tests.

Distrust of health service facilities and staff was identified as an important barrier to health service provision in several studies. [15,22,46,49,40,54] Placed into historical context by some authors, distrust of health services emanates from a broader distrust of the institutions of mainstream society, and a shared experience of racism and marginalisation, which invokes fear of further negative treatment. [22,54] Shahid [54] pointed out that Aboriginal and Torres Strait Islander patients remain disempowered and marginalised within the medical system while non-Indigenous service providers' control the structure, purpose, topic and language of communication surrounding treatment. Home visits concerned some families who feared judgement of their living conditions.[37]

Preference for health workers of the same gender was reported in several studies.[33,46,52,54] Gender preference influenced Aboriginal and Torres Strait Islander women's presentation for first and subsequent screening for breast cancer.[46] Shahid et al[54] reported that older Aboriginal and Torres Strait Islander men and women experienced shame, embarrassment and loss of dignity when cared for by the opposite gender.

Cultural issues

Indigenous story telling traditions did not include the concept of cancer, and this influenced Aboriginal and Torres Strait Islander peoples' readiness to accept the' cancer story', exacerbated by strong local cultural rules that govern which stories can or cannot be told."[47]

Manderson and Hoban[46] reported a variety of perspectives of health amongst Aboriginal and Torres Strait Islander people, depending upon a person's involvement in traditional settings and exposure to biological medical concepts. A holistic view of self and health which incorporates spiritual links to one's land and community is held by some Aboriginal and Torres Strait Islander women in traditional cultural environments:
"Health is very holistic, your identity, where you belong, where you belong in the community, where your country is" [46, pp79-80]

For others, including those living in urban settings, health has a different basis:
"In some places Aboriginal people are still hooked to the land, but a lot of people are like

me who are naïve about those things. Not everyone thinks in Aboriginal ways . . . I think the upcoming women don't really care about women's business" (remote woman). [46, pp 79-80]

The women's perspective of health as feeling well and capable of caring for children and grandchildren can influence treatment adherence. For example, women may not be prepared to endure side effects from chemotherapy and radiation therapy such as nausea, vomiting, fatigue and impaired arm movement, as they do not fit with this view of health. [49]

Preventative health measures were found to be a low priority for Indigenous Australian women who tend to respond to personal health needs when poor health hinders their usual activities.[46,49] Female Indigenous Australians in another study indicated that their participation in cancer screening was largely motivated by obligation to an authority, rather than self.[37]

The notion of "shame", also described as "shyness" and an avoidance of "embarrassment" for oneself within one's community, emerged as a barrier to health service provision in several papers.[24,29,37,40,41,46,49,52] Indigenous Australians associated "shame" with several cancer screening practices. Cervical cancer screening promoted feelings and experiences of shame for women who reported embarrassment about the Pap smear procedure.[46] Many believed cervical cancer screening was associated with the detection of sexually transmitted disease.[46,52] Older women without partners or husbands were afraid to be seen attending women's clinics, should members of their community believed they had behaved inappropriately.[37] Similarly, breast cancer screening processes were associated with shame as women were embarrassed to reveal their bodies for examination. [49] Women were uncomfortable about being examined by male staff[37] and clinic staff from their own community.[33] Exposing one's body to a white male health service worker and divulging information about personal sexual practices was viewed as shameful and contradictory to women's' private business.[37] Colorectal cancer self- test kits were equally regarded as "shameful" because they involved faecal collection and "some Indigenous participants used the term "*shame job*" to describe them .[24]

Lack of privacy in busy, full homes inhibited participation in personal screening practices including self-breast examination.[49] Lack of neighbourhood privacy within small and remote communities, with intimate postal services meant mailed colorectal cancer testing kits and samples could be a potential source of embarrassment.[24]

Shame and embarrassment associated with invasion of privacy inhibited peoples' communication with medical professionals and ward rounds and teaching sessions within the hospital environment added to their discomfort.[40]

Post –surgery, breast cancer survivors may be too shy to present for an assisted bra fitting.[49]

Cultural values surrounding the 'sacredness of a woman's body' and her position with her community influenced non-participation in cancer screening and surgical treatment decisions.[37] Dissection and amputation of the physical body is viewed as a violation of a woman's identity, and the risk this represents to one's womanliness and relationship with her partner, is perceived as a greater risk than the cancer itself.[37] Examples were provided in the literature of women who declined surgery or chose more conservative options for reasons of cultural identity. Prior cites one woman who chose lumpectomy over mastectomy in order to retain her "womaness", and another who declined bowel surgery as she feared a colostomy bag would negatively impact on her relationship and self-image.

"I don't want them cutting me up leaving me to be half a women. My breasts are my womaness." [37,p 284]

"I don't want them cutting me inside, leaving me in a mess. I'm better off without that. So I came here to end my days back where my family live, and where my parents lived." [37,p 284]

Christian beliefs surrounding the sacredness of the human body similarly influenced treatment choices.[37]

Many Indigenous women equated abnormal screening results and cancer diagnosis with a prognosis of death,[37,49]

"It is a killer to me. A lot of people say that they can treat and get rid of it but they can't…"I think cancer is one thing that they can't find treatment for". (rural woman) [49,pp 517-518]

"When I hear the word cancer I feel fear. it's the big C, you know, frightening, means you're going to die (Rita).Well cancer is terminal it can't be cured; it's a bad disease (Aunty Sylvia) What can be done about it [cancer]? It can't be cured can it? No one can stop it (Maria)" [37, p 283.]

This fatalistic perspective was reinforced by limited evidence of healthy cancer survivorship within the containment of rural communities, [37] including the reluctance of cancer survivors and patients to share their cancer stories with others. [21]

Deep fear and the expectation that cancer was fatal influenced treatment decisions and Indigenous Australians often chose to either ignore symptoms and forgo treatment or to endure it until side effects became too difficult to manage as the physical distress associated with treatment was view as unjustifiable.[37,38] Fear of cancer prevented effective communication about the purpose of screening and treatments. [22]

The belief that cancer is contagious can lead to "social and emotional isolation" for a person diagnosed with the disease.[47]

"If someone gets it [cancer] people stay away, there're afraid of it, they might think you can catch it or something" [37,p 283]

Cancer is viewed by sections of the Indigenous Australian population as a system of punishment or "payback" for a wrongdoing committed.[37,38,46,47,52]

"…Aboriginal people they think different way. Frightened someone put that cancer in their body someone trying to curse them. Second voice: Might have cursed that rock and chucked it at that person. Yeah. Where went is where the cancer is." [47, p 245]

This belief has implications for treatment as a person with cancer may keep their diagnosis secret[37] or delay seeking treatment in the belief that their suffering on behalf of the family or community secures safe passage for others. [21] Open communication about the disease may be hindered by fear and the strong emotional and cultural implications associated with “black magic”;[47]

“[It] …is essential for health care workers to fully appreciate the impact on patients' physical symptoms and their fear and 'great terror' associated with being 'sung'. An understanding of that fear must accompany clinical strategies “[47, p 252]

They may also believe Western medicine can do little to change their circumstances,[52] and accept the disease as their spiritual destiny;

“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. So what if I have whatever wrong with me, you know, that's just a part of life in many cases ... the spiritual side of health is often seen as more important than the physical side ...” [47, p 246]

The belief that cancer afflicts Indigenous Australians exclusively was reported by McGrath et al.[47]

“And let them know that balandas, they get cancer too, (name location) people won't believe ... won't believe ... (that) balanda (get) cancer…”[47]

Some Indigenous Australians believe cancer is a curable disease;

'…they don't understand the sickness is not curable and they believe they'll get better'. [47, p 247]

Unwillingness to talk about cancer prevented people diagnosed with the disease from connecting with other people with cancer and cancer survivors[19];

“Some don’t want to talk about cancer because of what other people will think. They might think it is a dirty disease or they caught it [cancer] from mucking around, you know not having a clean life. So they don’t want to get a bad reputation, they keep it [cervical cancer] to themselves until it’s too late.” (p 283)

“Well no one wants to talk about cancer; they shy away from the topic. You get frightened. I think talking about it [cancer] can bring it on” [37, p 283]

While some health service providers perceived death and dying preferences as sensitive topics within Indigenous Australian communities, Shahid et al 2013b refer to data, which illustrates that this is not always the case, and emphasises that there is diversity between individuals, and that family arrangements have sometimes already been organised.

Large city-based hospitals were described as feared and disempowering places for Indigenous Australian people from rural and remote areas in several studies; [19,29,30,41,44,]

“For Aboriginal people from the rural and remote areas, the metropolitan city and the biomedical hospital is an alien place and they do not want to die there.” [44, p267]

“how petrified they are when they go down to Perth and see these big hospitals, and they say they are not going back.” [IWCSG member][41, p 9]

Hospitals were perceived as symbolising white dominance, without recognition of, nor provision for Indigenous Australian peoples’ cultural needs.[30] Shahid et al [29] described fear and disorientation experienced by rural and remote people who travelled to an urban centre for cancer treatment. This was heightened by lack of formal welcome or invitation into Noongar country, navigational difficulties including inability to read signs, disempowering hospital regimes and dependency issues.[29] Indigenous Australians also experienced fear of entering hospitals where loved ones had died .[19]

Preference for traditional medicine was highlighted by four studies.[19,30,37,47] Thompson et al[30] described Aboriginal and Torres Strait Islander patients employing Indigenous medicine and healers alongside Western medical treatment. Newman et al[19] cites an urban-based Indigenous medical service general practitioner who explains;
"We are always looking for non-drug ways to look after ourselves . . .that's our culture is to connect with the land and with the ancestors and to look after our spirits in order to make our body stronger and part of that is bush medicines, use of herbs and . . .hand healing sort of work, massage, physio, sitting down under a tree and listening." (Evelyn) p 440[19]
In contrast, Prior[37] reported that female participants expressed reluctance to state their preference for traditional healing while in hospital, fearing ridicule from staff.

Social and economic issues
Priorities can be viewed within the context of socio-economic and structural circumstances ,[19] where attending appointments and screening tests are regarded as a low priority amidst greater concerns of making ends meet, while faced with poverty, poor housing conditions, high food costs, and limited access to transport.[19,52] Due to reduced socio-economic status and security Indigenous Australian people may have fewer resources to draw on as a buffer to cope with the issues surrounding cancer treatment.[15]

"Our people are worse off by just about any social index you can measure, whether its poverty, imprisonment, housing, so all of those issues don't go away just because you've got cancer . . . [Some] are only just coping already with the care that they have to give [to]family members and then the diagnosis is another burden that they really were not prepared to cope with . . .and you have all the consequences of higher degrees of mortality and morbidity that our people face and if you are living with cancer in those conditions, it's going to be a lot harder. So things like getting to appointments, getting yourself fed . . . because a lot of us don't have decent employment condition[s]. And when you're sick, that doesn't change, it just gets worse." (Aboriginal General Practitioner, urban Aboriginal medical service) (p 439).[19]

The expense of cancer treatment and long waiting lists within the public health system were barriers to adequate treatment provision.[29,30] Indigenous Australians have comparatively less access to specialist medical care and private medical facilities due to significantly lower rates of private health insurance.[29] Lack of access to the mainstream economy contributes to vulnerability and inequitable access to health care for many Indigenous Australians.[15]

Family and community responsibilities were afforded a higher priority than personal health needs and women were therefore reluctant to attend follow up appointments or treatment which involved being away from family and home for long periods of time.[29,33,46,49]

"If a person who has cancer has to go away for treatment, it not only affects the person, but the whole family. There are a lot of factors then impacting on that decision to go away to Brisbane for a week of treatment – looking after elderly people in the family, looking after other people in the family with problems" (remote woman)(p 518)[49]

Women, particularly from rural and remote areas, indicated they would decline reconstructive surgery, despite the perceived benefits to their self-esteem and image, in order to minimise the time spent away from their community and family.[49]

Complexities that surround the identification of appropriate family support for a home-based cancer patient were discussed in three papers;[44,46,54]
“Most of the issues we deal with are actually with family members and cultural issues regarding who can actually help us in that family, care for that person . . . not appropriate for certain people to do certain things for the client” (p 267).[46] Indigenous Australian families may not be able to care for a terminally ill cancer patient due a range of factors including difficulty in managing medications and home care, the absence of local home-based services and hospitals, poverty, and other priorities such as multiple children, other sick family members, and ongoing grief and loss from family bereavement.[54]

Access issues
Travel to city hospitals for treatment meant leaving family and community support networks;[37,49]
“I think it is scary for an Indigenous person to go down to the city and have no one there supporting them ... sometimes the doctor can speak to them and they would not understand what they had been told ... I mean they will probably really want someone from their family (rural woman).[49]

Long distance travel was a deterrent for Aboriginal and Torres Strait Islander cancer patients, particularly older and more traditional people, from leaving their community to access the treatment they needed.[29]

Some patients were inexperienced with various aspects of travel, such as using toilets on planes or pay telephones along the way. [29]

Remote residents were often ignorant about the distance and expense involved in travelling to and around the city, and additional expenses rapidly reduced the amount of money available for food or accommodation. [29] Confusion and difficulty using the Patient Assisted Travel Scheme was reported by a significant number of Aboriginal and Torres Strait Islander people. [29]

Cost and availability of ‘safe’ and Aboriginal and Torres Strait Islander friendly support was important for rural patients.[30] Rural-based cancer patients reported inadequate referral and booking arrangements, and difficulties locating accommodation on arrival in a city. Treatment was often aborted with unsuccessful accommodation arrangements. [29]

Lack of access to Indigenous counselling services, for cancer patients and their families, contributed to experiences of emotional isolation and burden amongst those affected by cancer;[49]
“A lot of people mourn in silence. They have got no-one to go to and no-one to talk to and there is quite a few that are really quiet and they don’t know how to get around. And they get sicker I reckon if they can’t talk” (remote woman) (p. 519).[49]

"She had a support worker but she was white and she didn't want to ring her, didn't want to talk to her. She wanted someone that was from the same culture. There was no-one up here. I tried looking for someone and there was nothing" (urban woman) (p. 519).[49]

Health provider-related barriers

'Health care workers' misunderstanding of Aboriginal and Torres Strait Islander peoples' views were problematic, and negatively impacted upon their ability to effectively work with Indigenous patients and their families, to promote access to available health care services".[47]

The inability of health service providers to adapt their model of care to incorporate Indigenous cultural values, provides a barrier to improved experiences for Indigenous patients who wish to be treated "as a whole person within their sociocultural context" (p3). [54]

"*Western science and medicine define the world in all these little parts and non-people related. And (name location) see everything is kin. Kin, kinship, everything is kin, all people, the world."* (p247). [47]

Service oriented teams with prescribed strategies for treating the disease were recognised as inappropriate for Indigenous patients, [30,54] who are more concerned with why the person has been afflicted, than how the disease affects them. [47] A 'narrative of equal treatment', adopted by health service providers, ignores the complexities of cultural difference[19];

'*All our patients pretty much get treated the same . . .So it would be no different what goes on and how we refer and how we manage them'* (Non Aboriginal Cancer Care Coordinator)(p 438)[19]

Cancer patients in Thompson's[30] study felt that health service staff did not listen to their personal and family concerns.

The literature revealed a lack of understanding of Aboriginal and Torres Strait Islander peoples' values, customs, and socio-economic circumstances amongst hospital and community health service staff. [39,40,52,54] Inability of non-Indigenous health service providers to accommodate cultural rituals and practices within their services were reported by.[19]

Many mainstream palliative care providers reported having minimal experience with Aboriginal and Torres Strait Islander patients, due to small Indigenous patient numbers, and they believed this lack of experience impacted upon staff skills in communication with Indigenous patients;

"It's difficult because clearly if we're not seeing many, then our skill set as a team is not fully developed and optimal" (urban, non- Aboriginal palliative care provider) (p3). [54]

Inability to establish rapport with Indigenous Australians stemmed from underlying false assumptions, and missed opportunities to develop trust, including adjusting practice to accommodate cultural difference.

Newman et al[19] identified an underlying false assumption amongst non-Indigenous health

workers of commonality with English speaking Indigenous Australians;
"…when you walk into a home of someone who was born and raised [in Australia] and was here before your ancestors even came and they speak English, I think there's an expectation that you're going to be able to build a rapport and understand one another . . .But in fact that's not correct, [and] I don't know that we really get that sometimes. " (p 441)[19]

Furthermore, Newman et al[19] identified that this assumption of commonality led health workers to be comparatively more willing to adjust their practices to accommodate the specific needs of overseas born culturally and linguistically diverse people than for Indigenous Australians.

Shahid et al [54] found that palliative care providers experienced difficulty providing holistic support and developing relationships with patients referred in later stages of disease, who required emergency symptom management. They identified a lack of recognition amongst palliative care providers, of the importance of gaining trust by establishing an ongoing relationship with their Indigenous community and addressing community specific cultural concerns.

Cancer is a Western concept and for which no word exists in Indigenous Australian languages. [47] While patients understood what cancer was, biomedical jargon used by health service staff created a barrier to communication with Indigenous Australians who found it frustrating; [20,30,40,47,49]
'They sit down, they talk to you, but the words that they say to you, you know, they don't put it in terms how I'd understand' (rural woman) (p 517). [49]
Limited understanding of medical terminology and treatment procedures meant that some Indigenous Australians were unclear about available treatment options and their efficacy. [49]

McMichael et al [49] cite the case of a woman who received a mastectomy "but said she had not understood her treatment options and recognised neither the term 'mastectomy' nor 'prosthesis" (p 517).

Health system-related barriers
Unsympathetic health service environments were outlined in four papers. [30,40,46,49] Hospitals were described as "cold", "indifferent", "intimidating" and "inflexible". [30,40,49] Negative experiences including uncompassionate staff interactions[40] and racist and disrespectful treatment by staff [49] were reported by Indigenous Australians who felt their needs and preferences were overlooked [40]. Alienation was experienced most severely by people from rural and remote areas. [30]

Fixed appointment times were highlighted as a major barrier to health service provision by several studies. [20,46,49,54] Cancer service providers had difficulty adjusting to a different concept of time and found it challenging to meet the needs of Aboriginal and Torres Strait Islander patients who did not function within a time schedule. [54] Palliative care providers reported an inability to provide more flexible arrangements or additional time with their patients due to caseload time frames;

"They don't understand that we're not there just to look after that particular person. We're there to look after that person at that particular time because after we've finished here we have to go somewhere else and somewhere else …. So that's taken a while for people to learn and that's always going to be an ongoing issue so we are quite inflexible about times." (Rural, non-Aboriginal palliative care provider). [54]

Aboriginal and Torres Strait Islander people expressed confusion around appointment procedures and dissatisfaction with inflexible appointment times. [46] A fixed appointment schedule was viewed as inconsistent with 'Aboriginal time', and it prevented impromptu visits for cancer screening. [49]

The importance of extended family was underappreciated and often ignored and unsupported by some health service providers. [40] Aboriginal and Torres Strait Islander patients encountered lack of hospital flexibility around extended families wanting to provide ongoing patient support, and visitor policies discouraged large family visits by placing restrictions on the maximum number of visitors at a time.[29,30] Similarly, hospital buildings are not designed to accommodate this. [30]

Discontinuity of care due to health service staff turnover and referrals to regional hospitals for remote and rural residents impacted on the ability for patients to develop important relationships with the persons caring for them and left them feeling disappointed, disjointed and disorientated. [30,40,49]
"Doctors can diagnose, but they don't follow up with it properly. Or they refer you on to someone else and you don't have time to build up a rapport with anyone. You don't know where you are, you're confused, you've got low self-esteem because you're feeling bad about yourself, all this fear comes into it (remote man)" (p 518). [49]

Lack of Indigenous language interpreter and liaison services during the journey from remote areas to city hospitals, and within hospitals, provided a barrier to communication for cancer patients whose first language was not English.[29,39,40] Indigenous Australian English is different from standard Australian English in pronunciation and meaning and can also be a source of misunderstanding between staff and patients. [20] Indigenous Liaison Officers provide a supportive role for Aboriginal and Torres Strait Islander patients who may be leaving their community and without family for the first time.

Communication failings between primary care providers and tertiary hospitals led to inconvenience for cancer patients. Tertiary hospital appointments for treatment and follow up were arranged with insufficient consideration of patient location and associated travel time and cost. [29] Poor communication between primary care providers and palliative services contributed to late referrals. [54]

Access to services in remote areas was problematic and patients needed to wait for specialist's visits to remote communities and larger rural towns.[33] Lack of access to public or private transport limited access to services and reinforced the need for mobile services to be offered in accessible locations. [49] Lack of infrastructure and facilities in rural and remote areas contributed to delayed palliative care referrals. [54] Limited availability of prosthesis fitting services existed in rural and remote areas. [49]

	Other barriers Inadequate access to appropriate information was a barrier to cancer patients' knowledge and experience. [15,38,40,52] Ad hoc information acquisition via informal networks, and confusion surrounding financial assistance programs contributed to a lack of uptake of transport, temporary accommodation and housing support by cancer patients and their carers.[15,29] While there are members committed to addressing Indigenous concerns, there are no Indigenous Australians on any board of the Cancer Councils. [14] Thompson et al [14] report that Cancer Councils have difficulty in finding Indigenous staff and in achieving partnerships with Indigenous health services. Furthermore, Cancer Council staff are largely unaware of links to Indigenous-specific resources and do not maintain records of the status of Indigenous Australian clients. [14] The absence of Aboriginal and Torres Strait Islander faces in public health campaigns, rendered the campaigns as meaningless to Indigenous Australians.[22]
Primary evidence (Mixed methods)	One mixed methods study reported **health system-related** barrier to colorectal screening participation.[32] Low knowledge, and hence lack of awareness of high prevalence or mortality rates from colorectal cancer, in addition to potential for prevention through screening, was cited as a major barrier to participation in screening. This was considered a system barrier, as much more can be done within and outside the health care system to increase knowledge and awareness of these issues. Language barriers were considered a key issue for the majority of non-English-patients. Not being able to read in English and to follow the instructions on sample collection delayed or prevented people completing the screening test, in spite of their willingness to participate in screening.

ENABLERS to improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer and their families

Secondary evidence	Only one systematic review described enablers for improving the experience of Aboriginal and Torres Strait Islander people with cancer.[31] This review paper examined the literature associated with Indigenous beliefs about cancer treatment, both 'bush medicine' and biomedical, in order to provide recommendations to healthcare providers about accommodating Indigenous beliefs when treating cancer. Aboriginal and Torres Strait Islander people with cancer expressed feelings of isolation and cultural alienation, and the presence of Indigenous health workers or Indigenous liaison officers, of the same gender as the patient and who have survived cancer themselves, was reported to be especially helpful during the process of diagnosis and treatment.[31] An Indigenous health worker can play multiple roles in providing care within the health service environment and in facilitating better linkages with primary and community-based care.[31] They can also help facilitate obtaining informed consent which is important to undertake prior to commencing any form of treatment.[31]
Primary evidence (Quantitative)	Three quantitative studies reported enablers to improving the knowledge and experience of Aboriginal patients with cancer. [18, 34,51] Two studies examined factors associated with participation in screening programs.[34,51] In one study, having seen media advertising on bowel cancer screening was significantly associated with greater awareness and higher overall bowel cancer knowledge.[34] This suggests the important role of mass media for public education and raising the profile of bowel cancer.[34] Other factors significantly associated with bowel cancer knowledge were also reported, including previous participation in cancer screening, seeing a doctor more often, having a family or personal experience with cancer, greater levels of perceived self-efficacy and perceived susceptibility.[34] In another study which focused on Pap smear screening, a personal approach by Indigenous Health Workers can encourage women to attend for Pap smears, provided the health workers are able to make contact with the women.[51] The most appropriate and feasible means of encouraging participation in Pap smear for Aboriginal and Torres Strait Islander women is by opportunistically promoting and conducting Pap smears, and by using a holistic and culturally sensitive approach to providing women's health services. [51] Compliance to radiotherapy treatment of Indigenous patients was the focus of one study.[18] Funded transportation, accommodation, meals and transfers from health care services to lodging for the patient and escorts were reported to have a positive impact on compliance rates. Dedicated Indigenous Liaison Officers who provide support in the practical aspects of treatment were believed to be an essential component of patient care.
Primary evidence (Qualitative)	Eight qualitative studies[19,24,36,37,41,47,49,52] identified enablers to improving the experience and knowledge of Aboriginal and Torres Strait Islander people. Aboriginal and Torres Strait Islander health service providers were perceived as better able to manage sensitive issues regarding shyness and the need for privacy and to avoid

shame, by their non-Indigenous counterparts and Indigenous cancer support group participants. [41] They contributed to an experience of safety and trust for Indigenous Australian people and this facilitated access to treatment and screening processes.[19,41,49]

Non-Aboriginal Health Service Providers acknowledged;

"… at the end of the day I am not Indigenous…I will never be able to relate and communicate as well as they can to each other." [41]

"Aboriginal people can say things to Aboriginal people that we can't and often things that aren't easy to say like 'get off your butt and get that lump check out'. Like, no other white person could ever say that and not, probably quite rightly, get punched." [41]

One Indigenous Australian person described the comforting experience of care from an Indigenous Australian worker as; "*Sometimes you just really need to see a black face . . .To make that heart to heart connection"*.[19]

Indigenous Support Liaison Officers coordinate support, subsidised transport and accommodation and provide treatment option information and mediation and liaise with staff on behalf of the patient. McMichael et al[49] reported that women assigned Indigenous Hospital Liaison Officers indicated that their support was 'invaluable'.

Assistance with housework, childcare and shopping, beds and bedding was provided by an Indigenous women's cancer support group during illness and treatment periods.

"*Coming out of hospital …and I didn't know who to talk to. When I was introduced to the group I just felt like I wanted to cry because this was like a saviour. Like I could talk to them. If I was too sick and I couldn't clean, they would come and do that too."* [41]

Indigenous Australian patients appreciated members from a women's cancer support group accompanying them to medical appointments, screening facilities and hospitals. [41]

Respect for the significance of family, and services which embrace their presence and involvement in patient support are perceived as beneficial to the experience of Aboriginal and Torres Strait Islander cancer patients;

"All the family want to be there, and they will do shifts so the patient is never alone, no one should die alone. Someone will cook the meals and bring this up to the hospital and everyone will carry on laughing and joking like normal. We all get to talk about the good times, also do some remembering about those good times, they like that" (Aboriginal health worker).[37]

Continuity in counselling services from the time of diagnosis through to the post-operative period, and inclusive of time during travel for away from home treatment, helps to minimise stress and isolation.[49] While Indigenous counsellors were appreciated for their understanding of cultural issues and communication styles, rapport with and connection to one's community and respect for confidentiality were equally important values sought in counselling staff. [49] Counselling and support for families supporting cancer patients was perceived as additionally beneficial. [49]

	Indigenous Australian women indicated a preference for female health workers for screening processes and educational sessions for reasons of cultural privacy. [49,52] Women indicated they would appreciate information regarding cancer treatment and efficacy when learning about self-examination. "*We just know about how to find lumps in the breast, not about surgery. They don't go into that. I'd like to find out now though so I know what to expect. I think one of the reasons that women leave check-ups too late is because they don't know these things*" (rural woman). [49] Participation in self-administered colorectal screening tests was facilitated by their cost-free availability.[24] Informal meetings and discussions between Non-Indigenous service providers, their Indigenous counterparts and Aboriginal and Torres Strait Islander people can increase cultural awareness by providing insight into the daily experiences, challenges and grief experienced by Aboriginal and Torres Strait Islander people. They present the opportunity to develop cross-cultural relationships, to learn from Indigenous counterparts and to contextualise the reasons why Aboriginal and Torres Strait Islander people may not access their cancer services. [41] Group meetings provided opportunities for informal discussion and for service providers to build relationships with the Aboriginal and Torres Strait Islander women attending the group and this led to insights into the realities of daily life for Indigenous Australian people including the difficulties and grief that Indigenous people too often face in a number of domains of their life. This helps contextualize why Aboriginal and Torres Strait Islander people may not focus on their health, even in the face of a life-threatening illness." *"…the opportunity to tap into Indigenous input into the care and support of Aboriginal women with cancer, and to learn about some of the issues underpinning the reasons why Indigenous people may not have been accessing cancer support services* (p9). Early diagnosis is reported to aid acceptance of bio-medical explanations for the disease (McGrath 2006). This is in comparison to diagnosis later in the dying trajectory, which is more likely to be linked to black magic; *"…I've spoken to a few members of the community and they are actually quite happy that these deaths - a lot of the deaths aren't black magic or the ones we've had of late because they've been pre-diagnosed. So if white people can give an explanation for the illness and the death they accept that. If not, if it's like picked at very, very end stage anyway before we actually see these people and can treat these people, they're usually the ones they put it down to as black magic*" (p 248). [47]
Primary evidence (Mixed methods)	Two mixed methods studies reported enablers to improving the knowledge and experience of Aboriginal and Torres Strait Islander patients with cancer.[32,43] One study reported strategies for improving early detection and management of breast and cervical cancer in Aboriginal and Torres Strait Islander women. [43] Strategies such as Indigenous Australian community involvement in planning and delivery of programs, employment and training of Indigenous people, and gender sensitive provision of

	culturally appropriate, holistic services by general practitioners was shown to facilitate cervical and breast screening. [43] Flexible appointments and transport assistance enhanced access to services. Recruitment of a female doctor was also reported to increase the attendance of Indigenous Australian women at cervical screening clinic during the project. [43] Women felt more comfortable when Indigenous health workers used locally appropriate health promotion resources in the screening clinics. [43] The involvement of Indigenous health workers was found to facilitate exchange of insights between Indigenous and mainstream health services. [43] Another study reported on enablers for colorectal cancer screening participation.[32] Culturally appropriate and clear, understandable instructions were valued by English speaking Indigenous Australian patients.[32] The decision to participate in colorectal screening was highly influenced by a doctor's recommendation so that people who were seen by their doctors and encouraged to undergo screening were likely to participate.[32] Familiarity with the bowel screening test and having done the test before was also identified as an enabler for participation.[32]

2. What existing strategies or approaches currently in place to improve the knowledge and experience of Aboriginal and Torres Strait people with cancer, and their outcomes

EVIDENCE SNAPSHOT

Primary evidence (Quantitative)

Four quantitative studies[18,27,35,51] reported existing strategies aimed at improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer. These four studies reported strategies such as an innovative cancer education course for Indigenous Health Professionals in Western Australia, use of a personal approach in improving attendance for Pap smears, a new model of care and its impact on compliance with radiotherapy in Darwin, and use of teleoncology for rural cancer care in North Queensland. Outlined below is the NHMRC Body of Evidence matrix for primary quantitative research.

Component	Evidence Grading
Evidence base *The evidence base is assessed in terms of the quantity, level and quality (risk of bias) of the included studies.*	**D (Poor)**
Consistency *The consistency component of the 'body of evidence' assesses whether the findings are consistent across the included studies.*	**B (Good)**
Clinical impact *Clinical impact is a measure of the potential benefit from application of the findings to a population.*	**D (Poor)**
Generalisability *This component covers how well the subjects and settings of the included studies match those of the recommendations.*	**B (Good)**
Applicability *This component addresses whether the evidence base is relevant to the Australian healthcare setting generally.*	**B (Good)**

Primary evidence (Qualitative)

Five qualitative studies[14,36,38,39,41] reported existing strategies aimed at improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer. Collectively, these five studies discussed the importance of *respect for, recognition of, and engagement with, Aboriginal and Torres Strait Islander people, their perspectives, experiences and values in their cancer care.* This could be achieved through establishment of support groups, dedicated resources which are culturally appropriate, training opportunities for health providers (such as cultural awareness), and acknowledging and respecting use of alternative and traditional medicine.

Primary evidence

Two mixed methods studies[26,43] reported on existing strategies aimed at improving the

(Mixed methods)	knowledge and experience of Aboriginal and Torres Strait Islander people with cancer. The teleoncology for Indigenous Australian patients and a multifaceted initiative aimed at early detection and management of breast and cervical cancer in Aboriginal and Torres Strait Islander women reported positive outcomes in terms of awareness and knowledge, community participation, improved screening and participation rates, and overall satisfaction.

Primary evidence (Quantitative)	Four quantitative studies[18,27,35,51] reported existing strategies aimed at improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer. Croager and colleagues[35] reported an innovative cancer education course which aimed to provide culturally relevant training in cancer control for Indigenous Health Professionals in Western Australia. The aims of this course were to increase cancer knowledge and awareness of resources available to help Aboriginal and Torres Strait Islander people with cancer and their families. The cancer education course was developed with help from the Cancer Council Western Australia's Aboriginal Advisory team and covered the continuum of cancer control from prevention through to palliation. The course content and materials had a particular emphasis on being culturally relevant, and were developed and delivered with acknowledgement of cultural issues including death and dying, shame, traditional bush medicine, and men's and women's business. Having two Aboriginal members from the Cancer Council's Aboriginal Advisory group ensured access to timely feedback and advice on the course's cultural relevance. The cancer education course was administered by experts in this field, (who were Non-Indigenous Australians with high levels of cultural awareness) and where possible, content was presented or co-presented by Indigenous people. The cancer education course was administered through a combination of classroom presentations, interactive sessions and visits to local cancer treatment centres. The findings from this research indicated positive outcomes, with participants reporting improvements in confidence and knowledge in some areas of cancer care. However, while these improvements were statistically significant at course completion, they were not necessarily sustained at follow up (approximately eight months). Hunt and colleagues[51] reported the results of a practice audit and an evaluation of recruitment strategies arising from a Pap smear recruitment intervention trial. In this study, 372 women were randomly allocated to personal approach, letter and control groups. For the personal approach, Indigenous Health Workers were asked to follow up women either in the community or in the clinic. Women in the letter group received a letter designed by Indigenous Health Workers, indicating that they were due for a Pap smear. The control group did not receive any intervention other than pre-existing file tags. At the end of a three-month follow-up period, files were examined to determine attendance at the clinic and whether Pap smears had been done. The findings from this study indicated that Indigenous Health Workers contacted only 22 of the 119 women in the personal approach group, with main barriers being workload and difficulty locating women. In the letter group, 37 of the 125 women's letters were undeliverable or returned to the sender. Overall, there were no marked differences in attendance among the three groups (7% of women in the personal approach group, 2% of women in the letter group and no women in the control group had Pap smears during the three-month follow up period). Le and colleagues[18] reported on a pilot study, conducted at the Alan Walker Cancer Care Centre in Darwin, which aimed to determine whether there is a difference in compliance with radiotherapy between Indigenous and non-Indigenous Australian patients. Furthermore, they determined which patient, disease and treatment factors affect treatment compliance in the Indigenous cohort. As part of this evaluation, 41 courses of treatment delivered to Indigenous Australian patients at the Alan Walker Cancer Care

	Centre were identified, as well as 224 courses in non-Indigenous Australian patients in the same centre. Interestingly, findings indicated that the compliance rates for Indigenous and non- Indigenous Australian patients were 83% and 81% respectively, and this was not statistically different. The findings from this pilot study do not support the perception that Indigenous Australians have overall poorer compliance with recommended radiation treatment courses. The authors offered some explanation for these findings. They highlighted that the Alan Walker Cancer Care Centre had implemented a holistic patient treatment model which addressed social, cultural and treatment needs of Indigenous patients. This model included funded transportation, accommodation, meals and transfers from health services to their lodgings. It also utilised Indigenous Liaison Officers who aided in the practical aspects of cancer treatment and hence were considered essential part of patient care. The model used additional innovative strategies such as complimentary telephone use and the provision of laptop computers to the patient and their families living afar for the duration of treatment, allowing communication via Internet applications. These multifaceted strategies may have ameliorated barriers to compliance resulting to positive findings. Sabesan and colleagues[27] reported the processes and outcomes associated with an innovative model of care involving telemedicine for rural cancer care in North Queensland. This descriptive study reported the establishment in 2007 of a teleoncology project between the regional tertiary centre of Townsville and rural towns in Townsville and Mt Isa health service districts. Medical oncologists from Townsville provided their services to rural sites via videoconferencing. In Mt Isa, rurally based doctors, chemotherapy-competent nurses and allied health workers accompanied patients during consultations. At other rural sites, either a doctor or a nurse accompanied patients because the consultations are for post-treatment reviews or follow-up visits. The findings from this study indicated 18 Indigenous Australian patients and their families from rural and remote communities were seen through Teleoncology clinics. Particular attention to cultural needs and community participation in patient care was facilitated by ensuring patients remain located within their immediate communities while still being able to access specialist advice and management. Ensuring attendance of local traditional healers and other family members with the patients ensured opportunities for education and acknowledgement of cultural values. The teleoncology model of care was able to demonstrate that the process of delivering care through videoconferencing had addressed an important barrier to cancer care, which is access for rural communities. Access to cancer care resulted in Indigenous cancer patients receiving specialist consultations and chemotherapy treatments closer to home.
Primary evidence (Qualitative)	Five qualitative studies[14,36,38,39] reported existing strategies aimed at improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer. Finn and colleagues reported the impact of the Indigenous Women's Cancer Support Group (IWCSG) which was established to support Indigenous Australians with cancer and their carers/relatives and to facilitate Aboriginal access to cancer screening and treatment. They conducted 22 interviews with Geraldton-based service providers, the coordinator of the IWCSG and 10 women who were linked to the IWCSG support. The authors also reflected on their observations of group meetings. The findings from the evaluation indicated that IWCSG group meetings provided an opportunity to share experiences, where Indigenous Australian

people with cancer and carers/relatives expressed their fears and difficulties. From a health service provider perspective, the IWCSG provided an opportunity to tap into Indigenous input into cancer care and support of Indigenous Australian women with cancer. Furthermore, it also provided an opportunity to learn about some of the issues underpinning the reasons why Indigenous Australian people may not have been accessing cancer support services. The IWCSG also acted as a “cultural bridge” in facilitating Indigenous people’s access to mainstream cancer services. The IWCSG’s impact also extended to communication issues, addressing and managing sensitive issues concerning Indigenous women’s shyness, need for privacy and shame regarding exposure of body parts, and assisting with domestic tasks as a result of cancer or treatment side effects. Several participants, including women with cancer and their carers, reported positive impact of the IWCSG such as the feeling of being connected with a caring and supportive community, access to ongoing support (practical and emotional), and the feelings of safety and trust. The importance of “heart” driving the IWCSG (with reference to heart/caring which had always been a part of Indigenous women’s culture, caring for and other community members) was also highlighted.

Shahid and colleagues contributed to three publications, all focusing on initiatives aimed at improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer. Shahid, Beckmann and Thompson [39] undertook an environmental scan within the state-based cancer councils to map activities in service provision in Indigenous cancer control. The findings from this mapping indicated that most state-based cancer councils had specific programs targeted at Indigenous Australian cancer issues. For example, in Queensland, the Queensland Cancer Fund had developed a cancer care course for Aboriginal Health Workers (AHWs) with assistance from an Indigenous advisory panel. The five-day program introduced various aspects of cancer treatment and care, and provided site visits to various cancer support services. Similarly, the Cancer Council Victoria (TCCV) since 2001 had been delivering training on cancer, screening and cervical cancer to Aboriginal Health Workers undertaking the Certificate 4 in Women’s and Babies’ health, delivered by the Victorian Aboriginal Community Controlled Health Organisation. The Cancer Council New South Wales (TCCNSW) had organised one-day training workshops for Aboriginal Health Workers covering basic information about cancer biology, prevention, early detection, treatment and end-of-life which were jointly delivered by two Aboriginal consultants. The state-based Cancer Councils had a focus on cultural awareness. While these cancer councils were found helpful, Shahid and colleagues acknowledged that these organisations faced difficulties in building and sustaining relationships with Indigenous Australian organisations due to a range of factors (such as lack of having Indigenous staff internally, few Indigenous-specific resources and few planned long term commitments). Thompson and colleagues have since updated this work in 2010. [14]

Since 2006, while there were some modest increases in activity within cancer councils, some gaps persisted. These include low Indigenous staff numbers (none in smaller cancer councils), lack of Indigenous representation at the Board level, capacity building directed outside cancer councils, and continued focus on partnership development with Indigenous organisations. This research did identify pockets of innovative strategies such as Telephone peer support for Aboriginal Health Workers currently operating in Northern Territory through Cancer Council Northern Territory and the establishment of Cancer Council

	Australia's National Aboriginal and Torres Strait Islander Subcommittee - a positive development which enhanced opportunities for sharing information and national coordination of activity. The authors provided a number of recommendations to improve the engagement of Indigenous Australian people with cancer councils and cancer control across a range of constructs. In two studies, Shahid and colleagues[36,40] reported the importance of recognising and taking into account Aboriginal and Torres Strait Islander peoples' beliefs and perspectives about cancer and its impact on access to cancer services. In one study, 37 Aboriginal people from various geographical areas within Western Australia with a direct or indirect experience of cancer[38] were interviewed. Key learnings for health care providers in order to improve the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer include: respect for cultural diversity and respect of Indigenous Australian people and their wishes, recognizing that Indigenous patient and their families have different perspectives (such as use of alternative and traditional medicine), ensuring the care that is provided is underpinned by person-centred care such as collaborative decision making with Aboriginal patients and families, addressing their concerns and misunderstandings, using plain language to communicate and using information materials which are culturally appropriate. Shahid and colleagues[36] explored the experiences of 11 people who had used bush medicine and traditional healing as part of cancer care in Western Australia. Findings from this study highlighted that for some Aboriginal and Torres Strait Islander people bush medicine and traditional healing were preferred because it helped them reconnect with their heritage, land and culture and the spirits of their ancestors, which brought them peace of mind. Bush medicine is seen as culturally safe, healthy and a means for healing the spirit, which is the Aboriginal way of being and doing. The authors recommended that Indigenous spiritual and holistic approach to health could play an important role in treatment choices for some patients.
Primary evidence (Mixed methods)	Two mixed methods studies[24,43] reported existing strategies aimed at improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer. Mooi and colleagues[26] reported the evaluation of teleoncology for Indigenous Australian patients, an overview of which was provided by Sabesan and colleagues. [27] This evaluation focused on the satisfaction levels of patients, their family members and Indigenous health workers about various aspects of the teleoncology service. Of the 23 Indigenous patients who participated in the teleoncology, nine were interviewed as part of this research. Furthermore, two family members were interviewed and six health workers (one doctor, one clinical nurse consultant, two registered nurses, one Indigenous liaison officer and one senior support officer) were also interviewed. Overall, all stakeholder groups indicated preference for teleoncology through videoconferencing over face to face consultation, due to a number of reasons including reduced waiting time, cost, burden of travel and removal from local supports. The health workers also highlighted benefits in terms of added educational value and fostering closer working relationships with the specialist team. Reath and Carey[43] reported a short-term evaluation of a project which focused on early detection and management of breast and cervical cancer in Aboriginal and Torres Strait Islander women. For this project, a partnership between local division of general practice

	and Aboriginal Community Controlled Health Service was required. Pilot sites from three states including one regional centre with a substantial Torres Strait Islander community (A), one capital city (B), and one rural centre (C) participated in this project. Each site received funding for a part time Indigenous worker and a female general practitioner. These personnel, in consultation and collaboration with local organisation and stakeholders, developed and implemented a multifaceted initiative which recognised barriers and implemented enabling strategies to improve general practitioners' early detection of breast and cervical cancer in Aboriginal and Torres Strait Islander women. The multifaceted initiative addressed barriers such as provider and patient knowledge, economic, logistic and cultural. Key activities at each site focused on the areas of service linkages/ cooperation, general practitioners continuing professional development, review of Pap test recall/reminder and health promotion activities/resources. A range of quantitative and qualitative data from questionnaires, reports, needs assessment, minutes of meeting, patient records and records of continuing professional development activities were used to identify outcomes. Findings from the evaluation indicated improvements in service collaboration, general practitioners' awareness and knowledge, community participation, and cervical screening and participation rates of Aboriginal and Torres Strait Islander women at the local BreastScreen service. While there were differences in outcomes between sites, which could be explained by local differences and differing contexts, the overall findings were encouraging.

3. What is the evidence of effectiveness of interventions and approaches for improving their knowledge and experience following a cancer diagnosis?

EVIDENCE SNAPSHOT

Primary evidence (Quantitative)

Four quantitative studies[18, 27,35,51] reported evidence of effectiveness of interventions and approaches aimed at improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer. These four studies described strategies such as an innovative cancer education course for Indigenous Health Professionals in Western Australia, use of a personal approach in improving attendance for Pap smears, a new model of care and its impact on compliance with radiotherapy in Darwin, and use of teleoncology for rural cancer care in North Queensland. Collectively, findings from these researches indicated mostly positive outcomes for knowledge, experience, satisfaction, participation, compliance and access for the Aboriginal and Torres Strait Islander people, and similar positive outcomes in awareness, confidence and knowledge for health providers. Outlined below is the NHMRC Body of Evidence matrix for primary quantitative research.

Component	Evidence Grading
Evidence base *The evidence base is assessed in terms of the quantity, level and quality (risk of bias) of the included studies.*	**D** **(Poor)**
Consistency *The consistency component of the 'body of evidence' assesses whether the findings are consistent across the included studies.*	**B** **(Good)**
Clinical impact *Clinical impact is a measure of the potential benefit from application of the findings to a population.*	**D** **(Poor)**
Generalisability *This component covers how well the subjects and settings of the included studies match those of the recommendations.*	**B** **(Good)**
Applicability *This component addresses whether the evidence base is relevant to the Australian healthcare setting generally.*	**B** **(Good)**

Primary evidence (Qualitative)

Two qualitative studies[39,41] explored the effectiveness of interventions and approaches aimed at improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer. These two studies, collectively, discussed the importance of *respect for, recognition of, and engagement with Aboriginal and Torres Strait Islander people and the roles of the state-based cancer councils.* This could be achieved through establishment of support groups, dedicated resources which are culturally appropriate, training opportunities for health providers (such as cultural awareness) provided by state based cancer councils.

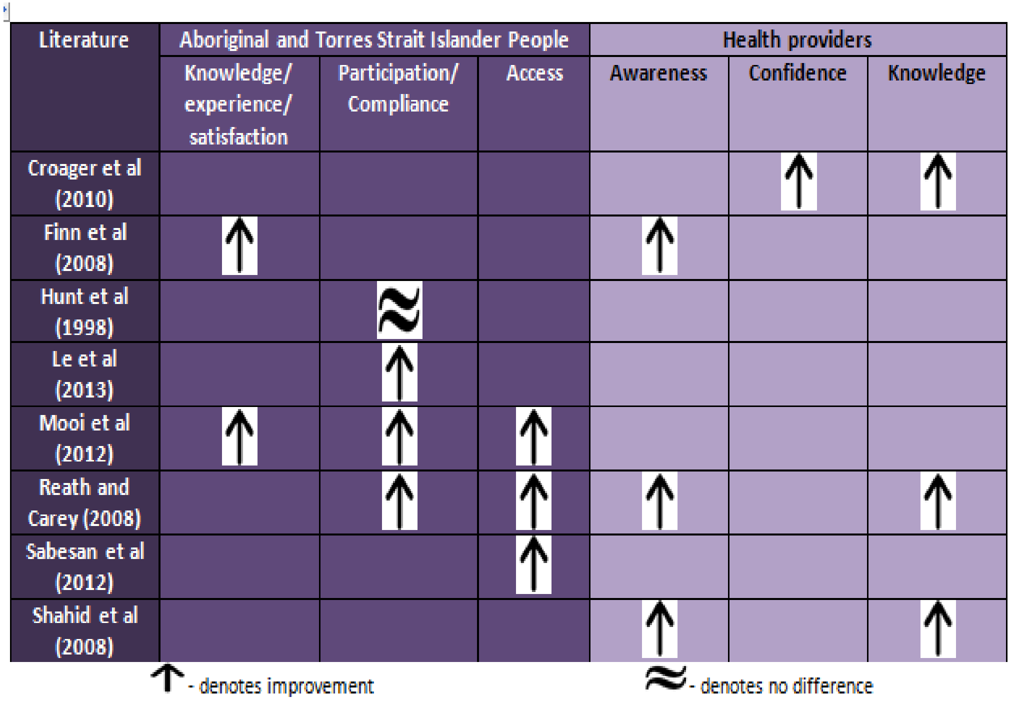
Primary evidence (Mixed methods)	Two mixed methods studies[24,43] reported evidence of effectiveness of interventions and approaches aimed at improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer. The teleoncology for Indigenous patients and a multifaceted initiative aimed at early detection and management of breast and cervical cancer in Aboriginal and Torres Strait Islander women reported positive outcomes in terms of awareness and knowledge, community participation, improved screening and participation rates, and overall satisfaction.

Key findings

Only a few studies reported on the evidence of effectiveness of interventions and approaches for improving the knowledge and experience of Aboriginal and Torres Strait Islander people following a cancer diagnosis. This review did not identify any high level evidence (such as systematic reviews and randomised controlled trials) which demonstrated a causal link between interventions or approaches targeted at Aboriginal and Torres Strait Islander People and/or health providers and improvements in outcomes (such as knowledge, experience, participation, access etc.). Much of the literature underpinning this topic is observational, descriptive and qualitative with small samples; therefore caution is required when considering the results. Literature related to pre-diagnosis screening and specialised staff training for Indigenous cancer care has been included for this question because of the potential benefit that these programs may provide for cancer patients (for example the potential treatment benefits as a result of early and timely diagnosis and good quality of care and service provision).

Table1 provides an overview of the evidence of effectiveness of interventions and approaches for Aboriginal and Torres Strait Islander people and health providers.

Table 1 Effectiveness of interventions and approaches



Literature	Aboriginal and Torres Strait Islander People			Health providers		
	Knowledge/ experience/ satisfaction	Participation/ Compliance	Access	Awareness	Confidence	Knowledge
Croager et al (2010)					↑	↑
Finn et al (2008)	↑			↑		
Hunt et al (1998)		≈				
Le et al (2013)		↑				
Mooi et al (2012)	↑	↑	↑			
Reath and Carey (2008)		↑	↑	↑		↑
Sabesan et al (2012)			↑			
Shahid et al (2008)				↑		↑

↑ - denotes improvement ≈ - denotes no difference

Finn et al [41] and Mooi et al[26] demonstrated that using initiatives such as Indigenous Women's Cancer Support Group and teleoncology services resulted in improved knowledge, experience and satisfaction of the Aboriginal and Torres Strait Islander People with their cancer care. Le et al[18], Mooi et al[26] and Reath and Carey [43] also reported that targeted strategies such as implementation of a holistic patient treatment model which addressed social, cultural and treatment needs of Indigenous

	patients, use of Indigenous Liaison Officers and innovative strategies such as complimentary telephone use and the provision of laptop computers, videoconferencing and multifaceted strategies can improve participation and compliance. Hunt et al[51] were not able to demonstrate any difference between personal approach, letter and control groups in improving Pap smear recruitment. Mooi et al [26] and Sabesan et al[27] reported the teleoncology service in Queensland, which demonstrated improved access to care. Reath and Carey [43] who undertook a multifaceted initiative aimed at improving general practitioners' (GP) early detection of breast and cervical cancer in Aboriginal and Torres Strait Islander women reported positive findings. This was developed and implemented by a female Indigenous worker and female GP across three sites, resulting in improved cervical screening and participation rates of Aboriginal and Torres Strait Islander women at the local BreastScreen service. Improvements in awareness, confidence and knowledge of health providers were also reported in some studies. Finn et al[41] and Shahid et al[39] reported positive improvements in awareness and knowledge about Aboriginal people's perspectives in cancer care as a result of initiatives such as Indigenous Women's Cancer Support Group and the state-based cancer councils. Croager et al[35] described an innovative cancer education course aimed to provide culturally relevant training in cancer control for Indigenous Health Professionals in Western Australia. This resulted to improvements in confidence and knowledge in some areas of cancer care. However, while these improvements were statistically significant at course completion, they were not necessarily sustained at follow up (approximately eight months). Another study reported a multifaceted initiative aimed at improving GPs' early detection of breast and cervical cancer in Aboriginal and Torres Strait Islander women. [43] This study reported improvements in GPs' awareness and knowledge of Indigenous women's health issues and cultural issues.

4. What are the key features or characteristics (such as parameters) of effective interventions and approaches (i.e. key success factors)?

EVIDENCE SNAPSHOT

Primary evidence (Quantitative)	Three quantitative studies[18,35,51] reported key features of effective interventions and approaches aimed at improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer. However, no single study focused exclusively on this question. Collectively, findings from these researches indicated that there are a range of key success factors that need to be considered including ensuring ready access to care, use of an Indigenous liaison officer and/or support group, and respect for culturally relevant care. From a health provider perspective, training in cultural awareness and engagement with, and first hand experience of, Aboriginal and Torres Strait Islander people's view of cancer care were important considerations.

Component	Evidence Grading
Evidence base *The evidence base is assessed in terms of the quantity, level and quality (risk of bias) of the included studies.*	**D** **(Poor)**
Consistency *The consistency component of the 'body of evidence' assesses whether the findings are consistent across the included studies.*	**B** **(Good)**
Clinical impact *Clinical impact is a measure of the potential benefit from application of the findings to a population.*	**D** **(Poor)**
Generalisability *This component covers how well the subjects and settings of the included studies match those of the recommendations.*	**B** **(Good)**
Applicability *This component addresses whether the evidence base is relevant to the Australian healthcare setting generally.*	**B** **(Good)**

Primary evidence (Qualitative)	Four qualitative studies[14,36,39,41] reported key features of effective interventions and approaches aimed at improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer. These four studies collectively described the importance of recognising a range of critical factors when engaging with Aboriginal and Torres Strait Islander people and health providers in cancer care. For Aboriginal and Torres Strait Islander people example of these factors include access to care, cultural awareness and the role of traditional health practices. For health providers example of these include training opportunities and engaging with and experiencing Aboriginal and Torres Strait Islander people's perspectives through communication and cooperation.
Primary evidence (Mixed methods)	The findings highlighted above were also supported by two mixed methods studies[24,43] which reported how the use of these key features resulted in positive outcomes within

	their individual research initiatives.

Key findings	Only a few studies reported key success factors of interventions and approaches for improving the knowledge and experience of Aboriginal and Torres Strait Islander people following a cancer diagnosis. These were often reported as an "add-on" to the original research and no single study focused exclusively on this question. Table 2 provides an overview of key success factors of interventions and approaches targeted to Aboriginal and Torres Strait Islander people and health providers.

Table 2 Key success factors

Literature	Aboriginal and Torres Strait Islander People				Health providers		
	Ready access to care	Aboriginal liaison officer/ support groups	Respect for and culturally relevant care	Bush medicine and traditional healing	Training in cultural awareness	Communication and cooperation	Engagement and experience
Croager et al (2010)					✓		✓
Finn et al (2008)			✓	✓		✓	✓
Hunt et al (1998)		✓					
Le et al (2013)	✓	✓	✓				
Mooi et al (2012)	✓		✓				
Reath and Carey (2008)		✓	✓		✓	✓	✓
Shahid et al (2008)					✓	✓	✓
Shahid et al (2010)				✓			
Thompson et al (2014)					✓	✓	✓

Overall, the literature highlighted that there is no "one size fits all" approach, and that a range of key success factors need to be considered if interventions are to be successful. This finding highlights the complexities of entwined factors which currently exist, and hence the need for a system-wide focus when addressing this issue, rather than singular, stand-alone strategies.

From the Aboriginal and Torres Strait Islander people's perspectives, factors such as ready access to care (with reduced waiting times, costs, burden of travel as demonstrated by Le et al [18] and Mooi et al[26]), use of Indigenous liaison officers, Aboriginal health workers and support groups (as demonstrated by Hunt et al[51], Le et al [18] and Reath and Carey [43]), respect for Indigenous culture/belief systems/perspectives, tailoring care to meet Indigenous people's needs,[18,26,41,43] and acknowledging the role of bush medicine or traditional healing[36,41] need to be considered. From a health provider perspective, ensuring training in cultural awareness, which can then feed into health care decision making and supporting Aboriginal and Torres Strait Islander people with cancer [14,35,39,43] was considered to be important. Similarly, ensuring communication and cooperation with Aboriginal and Torres Strait Islander people, their local representatives and councils[14,39,41,43] were reported to be

	an important factor. Ensuring timely engagement with and experience of Aboriginal and Torres Strait Islander people and their culture so that health providers can view the world through the perspectives of Aboriginal and Torres Strait Islander people[14,35,39,41,43] was a commonly reported finding.

5. What are the barriers (e.g. health literacy) to the effectiveness and uptake of interventions aimed at improving the experience and knowledge of Aboriginal and Torres Strait Islander people with cancer?

EVIDENCE SNAPSHOT

Primary evidence (Quantitative)	One quantitative study[51] reported barriers to the effectiveness and uptake of interventions aimed at improving the experience and knowledge of Aboriginal and Torres Strait Islander people with cancer. As such, the NHMRC Body of Evidence matrix cannot be completed. This study however sheds light on a range of barriers (personal, organisational, cultural etc.) to the effectiveness of such interventions.
Primary evidence (Qualitative)	There were no qualitative studies which reported barriers to the effectiveness and uptake of interventions aimed at improving the experience and knowledge of ATSI people with cancer.
Primary evidence (Mixed methods)	Two mixed methods studies[24, 43] described barriers to the effectiveness of initiatives aimed at improving the experience and knowledge of Aboriginal and Torres Strait Islander people with cancer. Collectively, these two studies, using qualitative and quantitative data, identified historical issues (resistance to change), medico-legal constraints, meagre resources and limited timeframes as barriers to the effectiveness and uptake of interventions aimed at improving the experience and knowledge of Aboriginal and Torres Strait Islander people with cancer.

Key findings	Only a few studies specifically addressed the issue of barriers to the effectiveness and uptake of interventions aimed to improving the experience and knowledge of Aboriginal and Torres Strait Islander people with cancer. Therefore due to this limited body of evidence, these findings must be considered with caution. Hunt and colleagues (1998) reported the results of a practice audit and an evaluation of recruitment strategies arising from a Pap smear recruitment intervention trial. In this study, 372 women were randomly allocated to personal approach, letter and control groups. For the personal approach, Aboriginal Health Workers were asked to follow up women either in the community or in the clinic. Women in the letter group received a letter designed by Aboriginal Health Workers, indicating that they were due for a Pap smear. The control group did not receive any intervention other than pre-existing file tags. At the end of a three-month follow-up period, files were examined to determine attendance at the clinic and whether Pap smears had been done. The findings from this study indicated that the Aboriginal Health Workers contacted only 22 of the 119 women in the personal approach group. In the letter group, 37 of the 125 women's letters were undeliverable or returned to the sender. Overall, there were no marked differences in attendance between the three groups (7% of women in the personal approach group, 2% of women in the letter group and no women in the control group had Pap smears during the three-month follow up period). When "unpicking" the invention in this study (personal approach), and why only 22 of the 119 women were contacted, the Aboriginal Health Workers reported that they did not feel comfortable approaching women that they did not know outside a clinic setting to discuss pap smears. Furthermore they also highlighted that it was usually inappropriate to visit women at their homes for the sole purpose of telling them a routine Pap smear was due and many Indigenous women (in the Darwin area where the study was conducted) were not contactable by phone. In addition, Aboriginal Health Workers reported other work commitments and difficulties locating Aboriginal women as significant barriers to the implementation and uptake of the intervention. Mooi and colleagues[26] reported the evaluation of teleoncology for Indigenous Australian patients, an overview of which was provided by Sabesan and colleagues. [27] This evaluation focused on the satisfaction levels of Indigenous Australian patients, their family members and Indigenous health workers about various aspects of teleoncology service. Overall, all stakeholder groups indicated preference for teleoncology through videoconferencing over face-to-face consultation, due to a number of reasons including reduced waiting time, cost, burden of travel and removal from local supports. The health workers also highlighted benefits in terms of added educational value and fostering closer working relationships with the specialist team. The authors, however, highlighted some potential barriers

to this innovative model of care in the form of resistance to new technology (especially those health providers who may not have experienced videoconferencing) and medico- legal concerns.

Reath and Carey[43] reported a short term evaluation of a project which focused on early detection and management of breast and cervical cancer in Aboriginal and Torres Strait Islander women. For this project, a partnership between local division of general practice and Aboriginal Community Controlled Health Service was required. Pilot sites from three states including one regional centre with a substantial Torres Strait Islander community (A), one capital city (B), and one rural centre (C) participated in this project. Each site received funding for a part time Indigenous worker and a female general practitioner. These personnel, in consultation and collaboration with local organisation and stakeholders, developed and implemented a multifaceted initiative which recognised barriers and implemented enabling strategies to improve general practitioners' early detection of breast and cervical cancer in Aboriginal and Torres Strait Islander women. Findings from the evaluation indicated improvements in service collaboration, general practitioners' awareness and knowledge, community participation, and cervical screening and participation rates of Aboriginal and Torres Strait Islander women at the local BreastScreen service. Reath and Carey[43] acknowledged that despite the positive findings in the short term, limited resources and short follow-up timeframes acted as barriers to ongoing implementation and long term follow up. Without sufficient long-term data from rigorous research studies, the evidence of effectiveness of interventions aimed at improving the experience and knowledge of Aboriginal and Torres Strait Islander people with cancer remains equivocal.

6. What innovative and/or technological approaches have been used to effectively engage Indigenous Australians?

EVIDENCE SNAPSHOT

<table>
<tr><td>Primary evidence (Quantitative)</td><td>Two quantitative studies[18, 27] reported two innovative approaches to effectively engage Indigenous Australians. Collectively, the findings from these studies indicated that if appropriate and targeted strategies are in place, it is possible to effectively engage Indigenous Australians in their cancer care. Outlined below is the NHMRC Body of Evidence matrix for primary quantitative research.
<table>
<tr><th>Component</th><th>Evidence Grading</th></tr>
<tr><td>Evidence base
<i>The evidence base is assessed in terms of the quantity, level and quality (risk of bias) of the included studies.</i></td><td>D
(Poor)</td></tr>
<tr><td>Consistency
<i>The consistency component of the ‘body of evidence’ assesses whether the findings are consistent across the included studies.</i></td><td>B
(Good)</td></tr>
<tr><td>Clinical impact
<i>Clinical impact is a measure of the potential benefit from application of the findings to a population.</i></td><td>D
(Poor)</td></tr>
<tr><td>Generalisability
<i>This component covers how well the subjects and settings of the included studies match those of the recommendations.</i></td><td>B
(Good)</td></tr>
<tr><td>Applicability
<i>This component addresses whether the evidence base is relevant to the Australian healthcare setting generally.</i></td><td>B
(Good)</td></tr>
</table></td></tr>
<tr><td>Primary evidence (Qualitative)</td><td>There were no qualitative studies which reported innovative approaches to effectively engage Indigenous Australians.</td></tr>
<tr><td>Primary evidence (Mixed methods)</td><td>One mixed methods study (Mooi et al[26] which provided evaluation data from the teleoncology model of care described in Sabesan et al[27]) highlighted positive findings from the use of Teleoncology service in rural Queensland, both from the perspectives of Aboriginal and Torres Strait Islander people and health providers.</td></tr>
</table>

Key findings	There is a dearth of literature on innovative and/or technological approaches that have been used to effectively engage Indigenous Australians. Absence of evidence does not necessarily equate to evidence of absence and it is possible that small scale pilots have been undertaken but are yet to be reported in published documents (such as peer-reviewed literature and/or grey literature). It is also possible that while innovative and/or technological approaches for effective engagement with Indigenous Australians in cancer care are underway, it might be poorly documented with dissemination of such initiatives and successes absent or ad hoc. This sentiment has been reflected by Thomson and colleagues[14]. Two studies specifically reported about innovative models of care in engaging with Indigenous Australians in cancer care. Sabesan and colleagues[27] and Mooi and colleagues[26] reported on the processes and outcomes of an innovative model of care involving telemedicine for rural cancer care in North Queensland. The teleoncology model of care demonstrated that the process of delivering care through videoconferencing had addressed an important barrier to cancer care, access for rural communities. Access to cancer care resulted in Indigenous cancer patients to receive specialist consultations and chemotherapy treatments closer to home. Le and colleagues[18], on the other hand, reported a pilot study conducted at the Alan Walker Cancer Care Centre in Darwin, which aimed to determine whether there was a difference in compliance with radiotherapy between Indigenous and non-Indigenous Australian patients. The findings from this pilot study did not support the perception that Indigenous patients have overall poorer compliance with recommended radiation treatment courses. Interestingly, the Alan Walker Cancer Care Centre had implemented a holistic patient treatment model which addressed social, cultural and treatment needs of Indigenous patients. This model included funded transportation, accommodation, meals and transfers from health services to their lodgings. The model also utilised Indigenous Liaison Officers who aided in the practical aspects of cancer treatment and hence were essential part of patient care. The model also used additional innovative strategies such as complimentary telephone use and the provision of laptop computers to the patient and their families living afar for the duration of treatment, allowing communication via Internet applications. This innovative model of care which used multifaceted strategies to ameliorate barriers to compliance resulted in positive outcomes for Indigenous patients. These two studies, albeit limited by the quantity and quality of the evidence base, provide some emerging evidence for innovative models of care in engaging with Indigenous Australians in cancer care. It is likely with emerging technologies, such as use of smart phones and tablets, applications (apps) and electronic health records, the evidence base will continue to evolve and further research may provide unique solutions to effectively engaging with Indigenous Australians in cancer care in the future.

7. What are the literature and knowledge gaps in improving the experiences of Aboriginal and Torres Strait people with cancer and their families?

EVIDENCE SNAPSHOT

<table>
<tr><td>Secondary evidence</td><td>Four systematic reviews[16,25,31,34] identified gaps in improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer and their families. A number of gaps including those which relate to service provision, funding, data availability, and knowledge/information were identified. Some strategies to address these gaps have also been described.</td></tr>
<tr><td>Primary evidence (Quantitative)</td><td>Five quantitative studies[23,28,45,48,53] identified gaps in improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer and their families.
<table>
<tr><th>Component</th><th>Evidence Grading</th></tr>
<tr><td>Evidence base
<i>The evidence base is assessed in terms of the quantity, level and quality (risk of bias) of the included studies.</i></td><td>D
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(Good)</td></tr>
<tr><td>Applicability
<i>This component addresses whether the evidence base is relevant to the Australian healthcare setting generally.</i></td><td>B
(Good)</td></tr>
</table>
All five studies described gaps in service provision (e.g. lack of Indigenous-specific resources, limited access to services, inadequate promotion of screening interventions), with three of these studies focusing on screening interventions for Aboriginal and Torres Strait Islander people with cancer.[23,48,53]</td></tr>
<tr><td>Primary evidence (Qualitative)</td><td>Seventeen quantitative studies[14,19,20,22,29,30,36,37,38,40,41,44,49,46,47,50,54] identified gaps in improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer and their families. These gaps extended across key areas of service provision (e.g. limited cultural awareness and competency, issues with access to services), workforce (e.g. limited</td></tr>
</table>

	Indigenous staff in with work force) and research (e.g. innovations in service delivery to overcome barriers to Indigenous people's participation in cancer care). These gaps highlighted the need for ongoing financial and intellectual investment in order to sufficiently address these gaps in the future.

Secondary evidence	Four systematic reviews[16,25,31,34] identified gaps in improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer and their families. Some strategies to address these gaps have also been described. A number of gaps including those which relate to service provision, funding, data availability, and knowledge/information were identified. *Service provision* The availability of culturally appropriate, Indigenous-specific educational resources to increase health literacy in Aboriginal and Torres Strait Islander patients, particularly around screening interventions, is limited.[34] Ways to increase the general knowledge and awareness about screening interventions in this population should be explored.[34] Further research into Indigenous Australians' understandings and perceptions of screening, including knowledge, beliefs and attitudes is necessary to inform appropriate approaches for intervention and resources. To improve health promotion and address the poor knowledge about screening intervention and limited availability of culturally relevant resources, the following strategies have been proposed. Greater coverage of bowel cancer screening in health promotion campaigns and the media is needed to increase general knowledge and awareness in the Indigenous Australian population.[34] Promotional activities should also occur prior to individuals receiving the screening kit so there is some awareness and expectation of the test.[34] Information and brochures should be made available in Indigenous Australian language, and greater emphasis on pictorial methods of education including videos and diagrams should be included with the screening kit.[34] Research into Indigenous Australian understandings and perceptions of bowel cancer should include a greater emphasis on participatory methods of health promotion.[34] There are insufficient numbers of Indigenous health workers/navigators/care coordinators in cancer services at hospital and community levels of care, and more needs to be known about the models for attracting, training, and retaining Indigenous people as cancer workers. [25] For example, only a limited number of Indigenous workers are working at BreastScreen services. [25] Increased numbers of Indigenous workers are required in BreastScreen services and methods of increasing participation should be investigated and assessed for effectiveness. Further research could determine methods of engaging Aboriginal and Torres Strait Islander people in cancer care and methods of maintaining and up-skilling the existing group of Indigenous Health Workers.[25] There is inadequate participation in and ownership of cancer health

services by Aboriginal and Torres Strait Islander people outside the realm of community-controlled health service. There is also uncertainty about the best models to pursue to involve Indigenous Australians in service governance arrangements.[25]

Mainstream services vary in their level of responsiveness to Aboriginal and Torres Strait Islander people, but the reason for this variance is not fully understood. Novel approaches to health promotion that are culturally sensitive and respect the health and life priorities of Indigenous Australian communities are required. Piloting and evaluation of culturally sensitive activities designed to address lifestyle choices also requires attention.[25]

Funding provision

One review reported that funding is complex and fragmented, which allows only for short term goals or projects; more streamlined approach to funding must occur with funding being made available for sustainable and long-term programs.[16]

Available data

Cancer registration data on Indigenous status are incomplete.[25]. There is also little information about variations within the Indigenous Australian population in cancer incidence and outcomes or on changes in these across time.[25] For many aspects of cancer control, the data are of variable quality thereby compromising comparisons between Indigenous Australians and non-Indigenous Australian populations and also potentially between Indigenous communities (e.g., rural and urban).[25] Research should be carried out on the variance in Indigenous cancer-related incidence and survival between urban and remote areas, as well as possible changes in this variance over time.[25] Opportunities to close data gaps through data linkage should be explored, including the linking of registry and administrative databases to assess effects of early diagnosis initiatives.[25] It is important also to collect data on staging and treatment.[25]

Another study described gaps in available data specifically for Aboriginal and Torres Strait Islander patients with lung cancer.[16] There are minimal data available reporting lung cancer survival rates for Indigenous Australians.[16] Poor quality data is a consistent barrier in identifying and analysing cancer incidence and outcomes within the Indigenous Australian population.[16] Stage of diagnosis information is also not often available, and improvement of the identification of Indigenous Australian populations within datasets also needs to occur.[16]

Knowledge/information available

Literature detailing the methods for combining biomedical and bush medicine treatment or what constitutes an appropriate blend between

	these two approaches is nearly non-existent. [25,31] Few data have been collected about beliefs in efficacy of bush medicine when used specifically for cancer.[31] Data about the broad range of thinking in relation to healing, and specific beliefs about bush medicine – how it works, and what inhibits and what facilitates its use – could promote among healthcare providers greater willingness to use a more holistic healing model when treating Indigenous patients.[16, 31] Research into traditional approaches is valuable so it can be represented in policies and translated into practice.[16] Little is known about methods of improving Indigenous awareness, perception and understanding of palliative care; involving Aboriginal and Torres Strait Islander people and their families in palliative care decisions; providing effective palliative care in the context of Indigenous Australian communities; ways in which end of life decisions are made by Indigenous people, how effectively pain is managed, and methods of incorporating family involvement into mainstream palliative care services for Aboriginal and Torres Strait Islander people. [25] The applicability of mainstream health promotion campaigns and approaches to Aboriginal and Torres Strait Islander people, and their success in moderating lifestyle risk factors in these communities have not yet been determined. [25] For example, reliance on mainstream social marketing programs to reduce smoking among Indigenous Australians is yet to be established as an effective approach despite high levels of efficacy in the non-Indigenous community. [25] There is also lack of published information about factors behind cancer control program success or failure in Indigenous Australian patients. [25] There is lack of research to explain and analyse reasons for delayed diagnosis and treatment choice.[16] This could ensure that barriers to early diagnosis and treatment are minimised; such research must be conducted in sincere collaboration with Aboriginal and Torres Strait Islander people.[16] Research is also needed regarding Indigenous expectations about side-effects and treatment toxicity and the difficulties associated with patient-physician communication.[31]
Primary evidence (Quantitative)	Five quantitative studies[23,28,45,48,53] identified gaps in improving the knowledge and experience of ATSI people with cancer and their families. All five studies described gaps in service provision, with three of these studies focusing on screening interventions for Aboriginal and Torres Strait Islander people with cancer.[23,48,53] There is a lack of cervical cancer screening resources designed specifically for Indigenous Australian women.[48] What are readily available are resources designed for the 'general' population. Therefore, Indigenous women have to rely on resources that do not target them specifically. The resources available

	are also not of suitable readability level for Indigenous women. [48] In another study, the authors argued that the level of screening is unlikely to be sustained without structural support from local health service providers, such as the state health departments and Indigenous medical services. [53] Other gaps such as inadequate promotion of the screening intervention (i.e. bowel cancer screening test) and poor education about how to carry out the test were identified in another study.[23] Access to medical practitioners, health services and allied health professionals are limited for Aboriginal and Torres Strait Islander persons who live in rural and remote areas.[28] If outcome of cancer treatment is to be improved for Indigenous Australian population, the issues of social and cultural proximity should also be addressed, not just geographical proximity. [45]
Primary evidence (Qualitative)	Seventeen qualitative studies[14,19,20,22,29,30,36,37,38,40,41,44,46,47,49,50,54] identified gaps in improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer and their families. *Gaps in service provision* Limited cultural awareness and lack of acknowledgement of the legitimate needs and expectations of Indigenous Australian people has been highlighted in the literature. [19,46,47] If change is to be achieved within the healthcare system, it will require a shift in the culture of health care services to acknowledge that Indigenous Australians have a specific set of cultural needs and expectations which need to be recognised and accommodated.[19,38,40] The need for cross cultural awareness, education and training for all health services is highlighted in the literature. [41,46] Cross cultural work stems from the notion of power sharing where respect is given to those with cultural expertise and the ethical authority to direct understanding as to how to engage in culturally appropriate care. [47] In cross cultural training, participants emphasise the importance of a two-way educational strategy whereby Indigenous Australian people could share their views of cancer and its treatment with healthcare providers and vice versa. [47] Therefore, while education of clinicians could be delivered in formal strategies (e.g. seminars, workshops), Indigenous education should also happen in an informal way during the care of patient and family. [47] A culture-centred approach not only facilitates a deeper engagement of Indigenous Australian people in their own health care but also facilitates input from the family in shared-care.[37,40] Fostering a shared-care approach in cancer care requires a relationship of trust and respect that enables Indigenous Australian families to feel at liberty to negotiate their cultural needs.[37] Ensuring cultural competency should occur at all levels, including clinical, organisational and system level. Strategies such as recruiting, involving and providing training to Indigenous staff, providing cultural safety

	training to all staff, and improving patient record system so that Indigenous identification can be improved have been suggested. [38,40,54] Service environment should be made welcoming to Indigenous Australian people[29,30,40,54] by displaying images that recognise and are inclusive of Indigenous people, having Indigenous staff visibility (in reception areas or welcome desk in the entrance), using images and art to help explain what cancer is and cancer treatments including Indigenous-specific resources in the display rack,[30,54] and ensuring ready access to information that helps cross cultural understanding.[30] Indigenous support and liaison to provide assistance to patient and their family by negotiating system barriers has also been recommended in the literature.[30] Where it is possible, care and follow-up should be provided closer to home as this is preferable by Indigenous Australian patients and their families.[38] Health service providers should be aware of the effect that distance and travel is likely to have on Indigenous clients.[29] Alternatively, minor follow up can be undertaken via video conferencing or telehealth or at a local health service. [29] Distance issues may also be addressed by establishing cancer services in outer urban and large regional centres (if feasible), or increasing outreach delivery of specialist care in community-based services.[29] If travel is necessary, patients should be provided with support, including culturally safe accommodation facilities that are easily accessible to treatment services and offer adequate safety, and other support services. [29] The literature suggests that there is no service that assists with finding accommodation for visiting Indigenous families, and should therefore be addressed.[30] Continuity of care and coordination of services is poor, and communication issues are also common. [20,38] Addressing these issues (e.g. by providing Indigenous Australian interpreters) and improving the coordination and integration of care between cancer treatment services, primary and community-based care are critical to the care of Aboriginal and Torres Strait Islander people with cancer. [20,29,38] On screening: Women's awareness of breast cancer and the benefits associated with preventive health behaviour is limited. [49] There is limited counselling service for Indigenous Australian women and their families and only a limited number of Indigenous Liaison Officer supports, which means that only a few women have access to this support. [49] There is a call for increasing community participation in health care services, which is believed to be crucial in the wellbeing and health of Indigenous communities. [49] Improved screening, detection and treatment for breast cancer and the care of women with the disease requires health practitioners to better serve the needs of Indigenous Australian people and Indigenous people to take an active and participatory role in their own health and health care. [49]

Evaluation of screening programs is advocated to ensure information is fed back to the program operators to ensure outcomes are achieved. [50]

On palliative care:
One study specifically identified gaps in understanding and accommodation of cultural concerns of Aboriginal and Torres Strait Islander patients related to palliative care services. [54] There is lack of culturally appropriate information and resources to address misconceptions about palliative care, and coordination of services is also poor. [54] Linking palliative care with advanced care planning to facilitate earlier referral is recommended so that there is more time to establish rapport and support. [54] Health departments and palliative care services may need to partner with Indigenous radio stations, National Indigenous Television and like media to communicate with and inform Indigenous Australian communities about palliative care. [54]

There are limited local palliative care and respite services for Aboriginal and Torres Strait Islander people in rural and remote areas. [44] Aboriginal and Torres Strait Islander people are relocated for end-of-life specialists' care away from the comfort of their homes and communities which causes a lot of fear and distress.

Gaps in the workforce
The importance of Indigenous Australian recruitment to the health workforce has been recognised in many policy documents but its implementation in practice remains an area of challenge.[14] The absence, for example, of an Indigenous employee at Cancer Council Australia appeared as a noticeable gap in efforts to provide Indigenous leadership and advocacy on Indigenous Cancer Control at a national level. To improve the engagement of Indigenous Australian people with Cancer Councils and cancer control, strategies on staffing, community engagement, advocacy and resources development have been raised in the literature.[14] On staffing, the following strategies were proposed: recruitment of Indigenous staff and supporting them through peer mentorship programs; information collection on the Indigenous identification of all staff and volunteers; establishment of a senior Indigenous person to work within the national office who works with the National Committee and all state cancer councils.[14] On community engagement, recommendations were: promotion of cancer council services, particularly the Cancer Council Helpline, within Indigenous Communities; a trial of an Indigenous staff member on the Quitline is recommended; development of a national reconciliation policy and strategy; development of strategies to engage and support Indigenous Board members and representation on committees; continuous implementation of symbolic gestures of Indigenous Australian people; and organising a national cancer conference at which recent research

and initiatives are discussed and disseminated.[14] Undertaking marketing strategies in web page portals to promote access for Indigenous Australian people and promoting Indigenous health facts in publications were also reported .[14]

Gaps in research
Further research is needed to explore other aspects of Aboriginal and Torres Strait Islander people's experience of cancer and to understand their responses to treatment; future research should aim to address the following questions: what are the perceptions and cancer experiences of Indigenous Australian men; are Indigenous Australian women's concerns about treatment the same for cancer of non-sexual organs or body structures; are current assessment procedure and symptom management techniques congruent with Indigenous Australian cultural values; how do Indigenous women manage pain and other physical symptoms associated with cancer; to what extend do Indigenous people rely on traditional healing and medicine; what is the epistemology and methodology of Indigenous healing.[37] Research is also lacking in the area of engagement of Indigenous people in screening programs and cancer care. Research activities should involve innovations in service delivery to overcome the already identified barriers that impede Indigenous people's participation in cancer screening and treatment.[14]

Research should explore the therapeutic value of traditional medicine to Aboriginal and Torres Strait Islander people with cancer, and the value of integrating bush or traditional medicine with Western Medicine be investigated. [36]

One study reported the lack of research on ways in which effective collaborative partnerships may be developed between Indigenous Australian people and non-Indigenous health service providers. [41]

Other gaps
Health literacy in relation to cancer among Aboriginal and Torres Strait Islander people remains a problem, and will require investment to reach the levels of understanding and skill achieved for other diseases prominent in Indigenous Australian communities.[22]

A repository of culturally-appropriate cancer resources should be established and made accessible to all Indigenous Australian people and communities.[14] These resources should also be available to a range of health professionals and community groups, clinical services, individuals and other organisations to promote access and reduce duplication of efforts.[14] It is recommended that this is undertaken in conjunction with Indigenous Australian HealthInfoNet.[14]

LIMITATIONS

Limitations of the review	As with any research, there are a number of limitations that should be considered when interpreting the results of this review: • Evaluation of research on barriers and enablers to improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer and their families pose numerous difficulties. Several publications within Aboriginal and Torres Strait Islander people with cancer span a wide spectrum of levels of evidence. This raises issues with the methodological quality of the literature and the interpretation of the findings within it. • Much of the literature on improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer and their families use research methodologies which could be considered as low level of evidence such as descriptive, observational and case studies. This may be appropriate in some instances as the focus on the research may be about describing or showcasing a resource, model of care or partnership approaches. However, what is lacking is high level evidence which have demonstrated a causal link between interventions and approaches targeted at Aboriginal and Torres Strait Islander People and/or health providers and improvements in outcomes. This evidence gap persists in the literature and requires ongoing further research to address it. • There is a dearth of literature on long term outcomes of interventions and approaches in improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer and their families. Much of the literature has a short term focus, mostly due to lack of resources and lack of ongoing opportunities for engagement, resulting in unknown effectiveness over the long term. Underpinning this is the need for research on cost-effectiveness of interventions and approaches in improving the knowledge and experience of Aboriginal and Torres Strait Islander people with cancer and their families. • This review also identified multiple publications from individual research concentrations within Australia. This is quite common as researchers produce multiple publications from individual research initiatives and subject groups, however it does mean that even though some topics have multiple publications available for consideration, the evidence base is actually derived from a very limited pool of subjects. • Finally, as with any systematic review of the literature, there exists the possibility that some publications could have been missed merely due to search parameters, time and resource

	constraints. All attempts were made to ensure rigour in the searching process however a systematic review is only the best effort at a point in time and it is possible more evidence may be identified in the future. Independent validation was sought and obtained during the search process, literature retrieval and literature selection. Publication bias was avoided by the interrogation of grey literature as part of this review. Due to the transparent and rigorous nature of the review process, and the inclusion of numerous iterative steps in validating key processes involved in this review, it is anticipated that the impact of any missing publications has been minimised.

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