Desktop Review to consolidate the knowledge and evidence for three priority issues in the cancer care system

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Acknowledgement of Country

Menzies School of Health Research and the Victorian Aboriginal Community Controlled Health Organisation (VACCHO) acknowledge the strength of Aboriginal and Torres Strait Islander peoples and the power and resilience that is shared as members of the world's oldest living culture. We acknowledge Aboriginal people as Australia's First Peoples who have never ceded their sovereignty.

We acknowledge this report was developed on the traditional lands of the Wurundjeri/Woiwurrung and the Turrbul and Jagera peoples, and acknowledge the richness and diversity of all Traditional Owners across these lands. We pay our deepest respect and gratitude to ancestors, Elders, and leaders—past, present, and emerging. They have paved the way, with strength and fortitude, for our future generations.

Special thanks to project partners and supporters

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The Working Group, a coalition of expert stakeholders and influencers, comprised representatives from the Australian Centre for the Prevention of Cervical Cancer (formerly VCS Foundation), BreastScreen Victoria, Cancer Council Victoria, Goulburn Valley Health, Hume Regional Integrated Cancer Service, Menzies School of Health Research, Peter MacCallum Cancer Centre, St Vincent's Health Australia, The University of Melbourne, VACCHO and the Victorian Government Department of Health (formerly Victorian Department of Health and Human Services).

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Note on terminology

The word ‘Aboriginal’ is used throughout this report to refer to both Aboriginal and Torres Strait Islander peoples. We respectfully recognise the diversity of cultures, identities, perspectives and experiences of the First Peoples of Australia.

Executive summary

A Desktop Review was commissioned to inform the *Improving Cancer Outcomes for Victorian Aboriginal Communities* Working Group about existing evidence and knowledge in the areas of: 1) participation in clinical trials and research; 2) culturally safe and effective cancer treatment; and 3) self-identification and data quality. Extensive searching of the peer-reviewed and grey literature was undertaken. This report provides information on the 11 specific questions posed on behalf of the Working Group and identifies gaps and potential next steps for the Working Group's consideration. These are summarised below.

1) Improving Aboriginal participation in clinical trials and research

a). What is the current level of participation by Aboriginal and Torres Strait Islander people in clinical research? What are the current issues in collecting this information?

Information about Aboriginal and Torres Strait Islander people's participation in clinical trials is only available for *Aboriginal-focused* clinical trials. Over the last decade there has been substantial and increasing participation of Aboriginal people in this type of research. No information is currently available about the level of participation of Aboriginal people in clinical trials that are *not specifically aimed at Aboriginal people*. In these trials, investigators are either not collecting or are not reporting data on the Aboriginal status of participants. Given the relatively small numbers of Aboriginal patients in the cancer treatment centres that conduct most clinical trials, there is an increased risk that Aboriginal trial participants will be identifiable; this risk must be managed to ensure confidentiality.

b). What is the evidence that inclusion and exclusion criteria are a barrier for Aboriginal people to participate in research?

No information is publically available on inclusion and exclusion criteria as a barrier to participation by Aboriginal people. Several international reviews have identified strict exclusion criteria as an important barrier to trial participation by under-represented population groups, such as ethnic minorities in the US, and it is likely that this is the case in Australia.

c). What are effective best practice models for improving Aboriginal people's participation in clinical research?

Most of the existing literature identifies and discusses barriers and enablers to participation by underrepresented groups, rather than effective strategies or best practice models for increasing participation. A large number of barriers have been identified in the areas of *awareness, opportunity* and *acceptance.* Barriers to opportunity appear to have the greatest impact, with gatekeeping and study design factors (including strict eligibility criteria) particularly important. Mistrust, ineffective communication, lack of knowledge and awareness of trials, logistics/costs, and inappropriate study materials are other barriers that are likely to be relevant locally. Key enablers include a commitment to inclusion, building long-term relationships with community, greater flexibility in study design and implementation, and employing appropriate staff. Three models identified as worthy of consideration in the Victorian context include: patient navigation, tele-trials and community-based participatory research (CBPR).

It should be noted that there are a number of published guidelines on best practice in research involving Aboriginal people in Australia; the principles and approaches are largely consistent across these documents and should be seen as essential for Aboriginal health research. However, their implementation in other research settings, in which the recruitment of Aboriginal patients is not the central focus, requires careful consideration.

What do we need to know/do?

- There is a tension between the current Australian focus on streamlining ethics/governance approvals for clinical trials and the imperative to ensure a fair opportunity for Aboriginal patients to participate in clinical research that is culturally safe. Aboriginal leadership and advocacy are required to manage this tension in collaboration with other stakeholders to ensure the best possible outcomes for Aboriginal people with cancer and their families and communities.
- Collecting and reporting on the Indigenous status of all trial participants is needed to enable monitoring of the participation of Aboriginal people in clinical trials. This must be done in a way that protects patient confidentiality.
- A better understanding of inclusion and exclusion criteria as they relate to Aboriginal people is required. A study currently under way will provide some insight based on document analysis, but further work will be needed to understand what is actually happening in practice. This will require gaining an understanding from the perspectives of multiple stakeholders including, but not limited to, researchers, clinical trials coordinators and Human Research Ethics Committees.
- Information is needed about the knowledge of and attitudes towards clinical trials among Aboriginal cancer patients, carers and community members.
- Work is needed to explore the feasibility, acceptability and potential effectiveness of a clinical trials patient navigation program. The program’s design should be determined through a collaborative partnership involving cancer care services, Aboriginal community-controlled health services, cancer survivors/carers, researchers and other relevant stakeholders. Clinical trials navigation could be incorporated into a broader care navigation role, or it could be a separate function. A key element of this work will be to identify ways to overcome likely workforce constraints.

- The newly developing tele-trials programs need to be designed to facilitate inclusion of Aboriginal patients, and evaluated to assess their performance in improving opportunities for participation.
- Stakeholders must work together to identify and create meaningful opportunities for Aboriginal community engagement in the design, development, implementation, analysis and dissemination of cancer clinical trials.

2) Improving culturally safe and effective cancer treatment for Aboriginal people with cancer

Relevant National and Victorian documents have been outlined to provide background and context. Several relevant frameworks have the potential to guide future activities, which must be guided by an approach to program design and research that is acceptable to Aboriginal people.

2.1. What are the barriers experienced by Aboriginal people in accessing cancer treatment?

2.2. What are the barriers experienced by Aboriginal people in completing cancer treatment?

Barriers to culturally safe cancer treatment and care for Aboriginal people are well documented and are present across all levels of the system including: a background of institutionalised racism and discrimination; health system factors; interactions within the health system; and barriers at the individual level. Enablers are also widely reported in the literature and there is strong evidence for many of them, particularly those placing culture at the centre of interventions. Incorporation of local context is a crucial consideration. Rigorously evaluated programs are a gap in the literature.

2.3. What are the service models that have successfully increased the number of Aboriginal people commencing and completing optimal cancer treatment pathways?

References to service models which document increased commencement and completion of optimal care pathways were not found, however there is a large amount of information about service models which have been found to be effective in improving care and engagement with treatment for Aboriginal people with cancer. The literature around service models generally contains reports or evaluations of a specific aspect of cancer care or the health system. This report includes some articles not specifically focussed on cancer, where the models have been reported as contributing to improved treatment and/or outcomes for Aboriginal people. Service models (or aspects of service models) reported as improving care and treatment for Aboriginal people include: those which are underpinned by respect for culture and build genuine relationships with Aboriginal communities; patient navigators / care coordination; telehealth; ACCHOs; person centred care; models employing use of data from patient reported outcome and experience measures; models which address practical aspects of treatment; collaborative approaches which have strong relationships with Aboriginal community as the centre of the strategy; and those which provide a central role of Aboriginal health workers. There is a need for more nuanced evidence of effective palliative and supportive care models.

2.4. What is the effectiveness and impact of cultural safety developments?

Definitions are provided for the various terms used in this area (see **Table 2.4.2**). A number of AIHW Closing the Gap resources (see **Table 2.4.1**) provided detailed and evidence-based advice on high level strategies to improve health outcomes for Aboriginal people. The main message to be taken from the studies included in this report is that more rigorous evaluation of the effectiveness of cultural safety and cultural competency efforts is necessary, particularly in relation to health outcomes. The studies focused on chronic disease management and primary health care for Aboriginal people provide considerable opportunity for lessons learned to be applied to the cancer area. The recent Victorian hospital cultural safety grants were not available to be included in this review, but may enlighten this topic.

2.5. What is the evidence of best practice models or key factors that have successfully improved five-year survival rates experienced by Aboriginal people?

While this review has not identified any direct links from best practice models to the improvement of survival rates, numerous factors have been put forward that may improve survival for Aboriginal people, including: early diagnosis and management of chronic disease; tailored models of screening using best practice models linked to diagnosis and treatment services; improving cancer treatment uptake including increasing rates of surgical treatment for particular cancers; personalised cancer care; the development and application of cancer care guidelines and multidisciplinary care that can meet the needs of complex patients; improving cancer detection and care in rural and remote areas; and incorporating factors which enhance survivorship into routine care.

What do we need to know/do?

- Scope the establishment of an Aboriginal Patient Navigator program in Victoria.
- Explore ways in which Aboriginal and biomedical approaches can be integrated in cancer treatment.
- Further explore the establishment and support of peer support programs.
- Using Optimal Care Pathways, document adherence to best practice pathways and detect reasons for deviations from recommended pathways.
- Investigate cancer-related decision making and how this can impact on the design of culturally appropriate programs for Aboriginal people with cancer.

- Investigate capacity of tele-oncology models to improve cancer-related outcomes compared with face-to-face models and consider new models of telemedicine.
- Evaluate Aboriginal-specific programs.
- Undertake qualitative exploration of palliative and supportive care pathways.
- Assess integration of patient reported measures specifically designed for Aboriginal people. Identify and address gaps in existing measurement.
- Examine successful models of increasing Aboriginal people in the health workforce, incorporating appropriate support and development (not only training).
- Establish processes for using the National Safety and Quality Health Service Standards user guide for Aboriginal and Torres Strait Islander health to structure systematic evaluation of cultural safety, cultural responsiveness and cultural competence efforts.
- Consider an organisational cultural competence stocktake in cancer care for Aboriginal people, against identified characteristics. In organisations that have integrated cultural competency standards, examine impact on health professional behaviour, health outcomes, and other outcomes.
- Consider how to decolonise health governance.
- Investigate potential drivers of treatment and survival differentials for specific cancers including the relationship between comorbidity and mortality.
- Improve data quality relating to cancer in Aboriginal people and identify opportunities for data linkage to fill gaps in the short to medium term.
- Undertake documentation and evaluation of relevant models and of the implementation of strategies and programs over time to enable assessment of their impact on cancer survival. (This is a longer-term goal.)

3) Improving Aboriginal people’s self-identification and the quality of cancer data

a). What is the impact of Aboriginal identification questions on: (i) Aboriginal engagement or disengagement in health services (primary and tertiary care), (ii) health-seeking behaviour (iii) early discharge, and (iv) discontinuation of treatment?

No studies were identified that directly examined the impact of Aboriginal identification questions on health service engagement, health seeking behaviour, early discharge or discontinuation. Barriers to self-identification and engagement with health services are often shared, with cultural safety of critical importance. Under-identification of Aboriginal patients can impede access to culturally appropriate services and result in an under-estimate of health service utilisation.

b). What are the systems in place in cancer services for self-identification and data management?

Service-level practices and processes relating to Aboriginal identification included: staff training (including cultural awareness/competency and how to ask the question); resources such as prompt cards; service-level goals and policies; engagement with Aboriginal staff to ensure complete data; cross-checking with other data sources; and providing information to patients.

Limited detail was provided on practices relating to data management.

c). What are the best practice models for cultural safety and engaging patients in self-identification?

Strategies/initiatives identified which reported effectiveness and/or improvements in identification were nearly always multi-component in nature, comprising a combination of: cultural awareness or cultural competency training to address staff knowledge/attitudes; training and support in the use of information systems to record Indigenous status; practical staff-directed resources containing key messages/prompts on asking the question; service-level changes in policy and/or procedure; changes to the physical environment (such as display of artwork, flags, Acknowledgement of Country) to create a more welcoming space; and employment of Aboriginal staff.

What do we need to know/do?

- Identification must be considered in the context of creating and maintaining culturally safe and effective health services, as discussed above. Many of the barriers are shared.
- Barriers to Aboriginal identification are widely reported; there is a lesser focus on enablers and what works to improve identification. Programs need to be implemented and evaluated for impact on identification in addition to other quality improvement outcomes
- Strategies need to address multiple components and must be developed and implemented in collaboration with Aboriginal people.

Conclusion

Targeted strategies addressing the level of Aboriginal people’s participation in clinical trials and research are required. While some progress has been made in terms of the number of Aboriginal-specific clinical trials being conducted, there remain many gaps.

Improving Aboriginal identification and ensuring culturally safe and effective cancer treatment for Aboriginal people with cancer both require multiple strategies across many levels to improve outcomes. Both service innovation and ongoing research and evaluation are needed.

Strategies and actions to accelerate progress across the three priority areas must be led by Aboriginal people, as Aboriginal leadership and engagement are essential and indispensable elements for success. It is therefore critical to ensure that appropriate structures and supports are in place to facilitate the genuine inclusion of Aboriginal people and organisations in determining future directions.

Background

Menzies School of Health Research (Menzies) was commissioned by the Victorian Aboriginal Community Controlled Health Organisation Inc. (VACCHO) to undertake a desktop review with the key objective of consolidating the knowledge and evidence for the following priority issues in the cancer care system:

(1) Improving Aboriginal participation in clinical trials and research;

(2) Improving culturally safe and effective cancer treatment for Aboriginal people with cancer; and

(3) Improving Aboriginal self-identification and the quality of cancer data.

The purpose of the Desktop Review was to inform the *Improving Cancer Outcomes for Victorian Aboriginal Communities* Working Group about the existing evidence and knowledge regarding the reasons for disparities in the cancer care system experienced by Aboriginal people in Victoria, and what has/is being done to address these issues, and to identify best practice. This report summarises and consolidates this information in relation to the following questions:

1. Improving Aboriginal participation in clinical trials and research
a). What is the current level of participation by Aboriginal and Torres Strait Islander people in clinical research? What are the current issues in collecting this information?
b). What is the evidence that inclusion and exclusion criteria are a barrier for Aboriginal people to participate in research?
c). What are effective best practice models for improving Aboriginal people's participation in clinical research?
2. Improving culturally safe and effective cancer treatment for Aboriginal people with cancer
a). What are the barriers experienced by Aboriginal people in accessing cancer treatment?
b). What are the barriers experienced by Aboriginal people in completing cancer treatment?
c). What are the service models that have successfully increased number of Aboriginal people commencing and completing optimal cancer treatment pathways?
d). What is the effectiveness and impact of cultural safety developments?

e). What is the evidence of best practice models or key factors that have successfully improved five-year survival rates experienced by Aboriginal people?
3. Improving Aboriginal people’s self-identification and the quality of cancer data
a). What is the impact of Aboriginal identification questions on: (i) Aboriginal engagement or disengagement in health services (primary and tertiary care), (ii) health-seeking behaviour (iii) early discharge, and (iv) discontinuation of treatment?
b). What are the systems in place in cancer services for self-identification and data management?
c). What are the best practice models for cultural safety and engaging patients in self-identification?

As required, the report includes a documentation of the methodology; summary key findings for each of the research questions; a section with the detailed analysis; and a complete bibliography. The structure of the report is intended to enhance readability by including more technical and/or detailed material in Appendices rather than in the main text. A summary of key findings is provided in the Executive Summary, with detailed analysis contained within the main body of the report. A complete reference list is included after the main text, followed by a full description of the methods in **Appendix A**, and all tables in **Appendix B**.

Findings

1. Improving Aboriginal participation in clinical trials and research

Three questions were posed in relation to improving Aboriginal participation in clinical trials and research. Methods used to identify evidence are detailed in **Appendix A1**. In brief, a series of searches of the peer-reviewed and grey literature (including searches of the websites of key organisations) were undertaken, focusing on: a) Aboriginal and Torres Strait Islander Australians; and supplemented by b) Indigenous groups in other countries; and c) other underrepresented groups. In addition, selected records from the Australian New Zealand Clinical Trials Registry (ANZCTR) were abstracted and analysed.

The clinical trials landscape

Before addressing the specific questions posed, it is useful to review the current context of clinical trials in general, both in Australia as a whole, and in Victoria in particular. This is summarised below; more details are presented in **Table 1.1.1**.

There has been considerable activity relating to clinical trials in recent years in Australia. Underlying much of this work is a recognition of the importance of trials in improving health care, alongside a desire to make Australia a ‘destination of choice’ for trials.

- The Council of Australian Governments (COAG) Health Council developed a ‘Revised Clinical Trials Agenda’ in 2016, setting out a number of principles agreed to by the States/Territories and the Commonwealth in relation to clinical trials; among these are the essential role of trials and research in the health system, and the need to improve access for patients.[1] Partnerships are recognised as a critical success factor, and both consumers and Aboriginal and Torres Strait Islander groups are explicitly named as relevant partners. The Clinical Trials Project Reference Group (CTPRG; formerly the Clinical Trials Jurisdictional Working Group) was charged with identifying options to ‘support regional redesign to streamline and expedite start-up, enhance recruitment and retention and embed quality clinical trials systems in health care’.[1, p.1] The aim of the CTPRG’s work is a ‘streamlined and consistent national approach to clinical trials within Australia with the intention of enhancing health outcomes and building Australia’s ability to attract national and international clinical trials’.[2]
- The Commonwealth Health Department has commissioned several pieces of work, including a report on issues and solutions in recruitment and retention,[3] an analysis of critical success factors in recent trials,[4] and a review of the ANZCTR (not yet released); two sets of National Aggregate Statistics have also been released, showing the time required for ethics and governance approvals for trials.[2]

- The National Health and Medical Research Council (NHMRC) has undertaken work to streamline the approvals process, including development of a national ethics application form which underpins the National Mutual Acceptance Scheme. Under this Scheme, which is currently in place in most Australian jurisdictions, a single ethics review process replaces the need for multiple approvals for multi-centre research.[5, 6]
- Consultation is currently under way by the Australian Commission on Safety and Quality in Health Care to develop the National Clinical Trials Governance Framework.[7] Improved governance is a key requirement for optimising the performance of the sector, and the standards in the framework will be included as part of the National Safety and Quality Health Service Standards. Importantly, the draft framework 'aims to embed processes to ensure that Aboriginal and Torres Strait Islander people and those from culturally and linguistically diverse (CALD) backgrounds are not disadvantaged in research, either by being excluded or through lack of cultural safety.'[8, p.3]
- The *Optimal Care Pathway for Aboriginal and Torres Strait Islander People with Cancer* was released in 2018 [9] to complement the growing number of tumour-specific optimal care pathways. Clinical trial participation is mentioned throughout the document, with the focus on Aboriginal patients being given the opportunity to participate at all stages of care. The document recognises the special ethical requirements of research involving Aboriginal people and recommends the use of culturally appropriate information resources.
- Improving access to clinical trials is a priority under the current *Victorian Cancer Plan, 2016-2020*.[10] Although improving 'equity of access to clinical research' is mentioned as a focus for the period 2016-2020, the section on improving outcomes for Aboriginal Victorians does not mention clinical trials. While the Monitoring and Evaluation Framework Report indicates that the number of new enrolments in cancer interventional trials is a performance measure to be reported on, it does not appear that this will be disaggregated by Aboriginal status.[11]
- Clinical trials are also prominent in *Healthier Lives, Stronger Economy: Victoria's Health and Medical Research Strategy, 2016-2020*,[12] with one of only 6 key strategic directions focusing on this area. The stated objective is to 'optimise the performance of the Victorian clinical trials sector and position the state as the premier destination for clinical trials in the Asia-Pacific region.'[12, p.12] The strategy includes funding for a 'Streamlining Clinical Trial Research Program' within DHHS.
- There have been a number of initiatives in the last few years to increase the reach of clinical trials in the state. In 2017, the Victorian Regional Cancer

Clinical Trials Network was established with 6 regional sites. The Network is supported by Cancer Council Victoria in partnership with Cancer Trials Australia.[13] The Victorian Comprehensive Cancer Centre (VCCC) has initiated a tele-trial program based on the Clinical Oncology Society of Australia (COSA) Australasian Tele-trial Model (described below).[14] The description of the tele-trial program indicates that there has been consultation with regional consumers, but it is not clear whether or to what extent this has included Aboriginal people. An initial trial involving a cluster with a metro site and two regional sites (Albury Wodonga and Bendigo) appears to be under way and is to be evaluated.[15] New funding was announced by the Commonwealth Health Minister in March 2019 to support an initiative linking the Alfred Hospital/Monash University with regional hospitals to increase access to clinical trials, with Rosebud, Casey and Bendigo hospitals named as the first to participate. The program will focus initially on rare cancers, melanoma and prostate cancer.[16]

- To provide consumers and health care providers with information about available trials, Cancer Council Victoria (CCV) hosts the Victorian Cancer Trials Link, a searchable database of cancer clinical trials in the state.[17] Information about Victorian trials is also available through national trials portals including the ANZCTR, Australian Cancer Trials and Australian Clinical Trials. CCV also has a Trial Connect program, a peer-support program for people interested in joining a trial.

Efforts to improve Aboriginal participation in clinical trials must take into account this context and identify and use appropriate levers to effect change. In particular, it should be noted that there is a tension between the current Australian focus on streamlining ethics/governance approvals for clinical trials and the imperative to ensure fair opportunity for Aboriginal patients to participate in clinical research that is culturally safe. Aboriginal leadership and advocacy are required to manage this tension in collaboration with other stakeholders, to ensure the best possible outcomes for Aboriginal people with cancer and their families and communities.

1.1. What is the current level of participation by Aboriginal and Torres Strait Islander people in clinical research? What are the current issues in collecting this information?

For the purposes of answering this question, a distinction needs to be made between: a) clinical research that is not specific to Aboriginal people but for which they may be eligible (e.g. international cancer treatment trials); and b) clinical research that is purposely designed to include Aboriginal people, either solely or substantially (i.e. to a great enough degree that results for Aboriginal people can be determined with sufficient precision).

Clinical trials not specific to Aboriginal people

For clinical trials in general (that is, not Aboriginal-specific), which are often multinational and for which individual Australian sites may recruit relatively few patients, no information is currently publically available about the level of participation of Aboriginal people.

No information about the ethnic background of trial participants is provided in the on-line records of the Australian New Zealand Clinical Trials Registry (ANZCTR), and it appears that the peer-reviewed publications resulting from these trials do not consistently report information about ethnicity, given they were not identified in the literature search. While Cancer Australia's National Cancer Control Indicators set includes an indicator on the adult clinical trial participation ratio, the online documentation indicates that:

> *'The number and proportion of adult cancer patients enrolled in clinical trials is currently not known in Australia. As a result, an understanding of the unwarranted variation in clinical trial participation between population groups is also not known.'* [18]

The Psycho-oncology Cooperative Research Group (POCoG), one of several National Cancer Collaborative Trials Groups (NCCTGs) funded by Cancer Australia, indicates on its 'Minimum Data Set' web page that NCCTGs are required to demonstrate the participation of Aboriginal people (among other groups) in clinical trials, and that NCCTGs have been requested to collect information on Indigenous status for all trial participants.[19] However, there is no indication whether, or to what extent, this is currently happening, and what, if anything, is to be done with the data.

There is limited information on clinical trials participation by geographic area for the general population, although the usefulness of this indirect evidence for Aboriginal people is debatable. In New South Wales in 2017-18, about 9% of new cancer patients were enrolled in clinical trials, but there was extremely wide variation by Local Health District, with the highest rates in Sydney and Newcastle and lower rates elsewhere. There was no indication of participation rates by Indigenous status.[20] In Victoria, an assessment of barriers and enablers for access to clinical trials in the Loddon Mallee Region indicated that participation rates for cancer patients in the Mildura and Swan Hill Local Government Areas (LGAs) were much lower than those for patients in the Macedon Ranges and Bendigo LGAs, but figures were not provided for Aboriginal patients specifically.[21]

There was no direct, and limited indirect, information about the interest and/or willingness of Aboriginal people to participate in clinical research. Sabesan and colleagues asked 178 cancer patients in Townsville and Mount Isa about their knowledge of, attitudes about and willingness to participate in clinical trials.[22] Although knowledge about trials was low, over half of respondents (56%) said they were willing to participate. Indigenous status was not reported, but it is likely, given the setting, that Aboriginal patients were included. Carey et al. conducted a cross-sectional survey of 383 medical oncology patients about whether they had been invited to participate in a clinical trial and, if so, whether they had agreed.[23] Of the 5 participants who identified as Aboriginal, 3 said they had been invited to participate; no information was provided about whether or not they had subsequently agreed.

With respect to current issues in collecting this information, there appear to be two main issues: 1) ensuring that appropriate questions and response categories are included in trial forms to enable recording of Indigenous status; and 2) addressing the increased risk of identifiability (and consequent loss of confidentiality) of individual Aboriginal participants, especially in cases where individual sites enrol only a handful of patients, or where the total number of Australian patients is small.

Aboriginal-specific trials

For research specifically focusing on Aboriginal people, there has been substantial and increasing participation, particularly over the last decade.

A systematic review by Morris in 1999 found only 13 RCTs addressing the health needs of Aboriginal Australians up to that time. Twelve of the 13 involved children; the single trial involving adults included only 11 participants.[24] A subsequent systematic review by Saini and Quinn, covering the period from 1999 to 2010, found an additional 6 trials of Australian Aboriginal people.[25] (More information about these reviews is provided in **Table 1.1.2**)

Since then, there has been a major increase in trials relating to Aboriginal health. An analysis of ANZCTR records indicates that over 50 trials have been completed, with another 81 trials in progress, all relating to Aboriginal health. **Table 1.1.3** provides details (including sample size) about these trials according to their recorded status. While not all of these trials are focused on treatment, and most are not cancer-related, it is clear from the table, and from publications arising from the completed studies, that Aboriginal participation in clinical research studies can be high in the right circumstances. The factors facilitating participation are addressed in response to **Question 1.3**, below.

1.2. What is the evidence that inclusion and exclusion criteria are a barrier for Aboriginal people to participate in research?

No publically available evidence was found in relation to inclusion/exclusion criteria as a barrier for Aboriginal people. Several reviews, mainly from the US, have identified strict exclusion criteria as an important barrier to trial participation by under-represented population groups including ethnic minorities (see, for example, references [26-32] and **Section 1.3** below). It is highly likely that a similar situation exists for Aboriginal Australians.

Work is currently underway by researchers from the Menzies School of Health Research using on-line information from the ANZCTR to examine cancer treatment trials that include Australian sites. This project is looking at a range of factors including trial site location, cancer type, comorbidities, and other eligibility criteria to ascertain whether there are systematic barriers to participation for Aboriginal cancer patients. Preliminary results for Phase III treatment trials indicate that: there are marked differences between where Aboriginal people live and where trials are conducted; there is a mismatch between the most common types of cancer experienced by Aboriginal people and those that are the subject of trials; exclusions relating to comorbidities and/or organ function are common; and many trials explicitly include investigator judgment/opinion about patient suitability as an inclusion/exclusion criterion (J. Cunningham 2019, Pers. Comm., 15 May). ***Note: these results are provided in confidence and are not for publication or circulation; publically available results are expected in late 2019.***

Exclusion based on English language proficiency could impact some Aboriginal people. A study by Stanaway and colleagues examined language-based exclusions in Australian trials registered in the World Health Organisation's Clinical Trials Registry Platform during a 3-month period in 2015.[33] Overall, 21% of trials explicitly excluded people with low English proficiency, but this was less common for cancer trials than for trials in areas such as mental health and pain. Smith and colleagues found that culturally and linguistically diverse (CALD) cancer patients with a preferred language other than English were less likely than other cancer patients in Southwest Sydney to enrol in a clinical trial; however, CALD patients with English as their preferred language had participation rates similar to non-CALD patients, suggesting that language rather than culture was the critical barrier.[34] It is not clear how much of the difference was due to English language proficiency being an explicit trial exclusion criterion, and how much was a result of the added difficulties/costs of including participants for whom English is not their preferred language.

1.3. What are effective best practice models for improving Aboriginal people's participation in clinical research?

Most of the existing literature identifies and discusses barriers and enablers to participation by under-represented groups, rather than effective strategies or best practice models for increasing participation, although there are notable exceptions, as discussed below. Given that an understanding of barriers and enablers/facilitators is an important first step in the development of appropriate, effective responses, key findings from the Australian and international literature are presented here (for more details, see **Table 1.3.1**), followed by discussion of potential strategies and models that may be appropriate.

With respect to participation in Aboriginal-specific research, some information is available about barriers and facilitators from a systematic review by Glover and colleagues.[35] The authors looked at barriers and enablers for participation in RCTs in health-related areas for Indigenous peoples in Australia, Canada, New Zealand and the USA. Key barriers identified included: lack of access; mistrust; inappropriate research materials; and loss to follow-up. Facilitators included: partnership and relationship building; culturally appropriate study design and study materials; employing Indigenous research staff; and targeted recruitment.[35] In interviews with 8 Aboriginal research participants in Victoria, Guillemin and colleagues observed that perceived benefit to their community was the main reason given for participating in research.[36] Aboriginal participants described a decision-making process that was characterised by the authors as thoughtful and considered, one in which perceptions about the researchers' integrity and motivations were critically important, and mistrust, or at least caution, was the default starting position.[36]

There are a number of published guidelines on best practice in research involving Aboriginal Australians. Selected guides are included in **Table 1.3.2**. For example, Jamieson et al. identified 10 principles relevant to working successfully in this area, and Couzos et al. described 22 principles of community-controlled health research based on the experience of the NACCHO Ear Trial.[37, 38] The NHMRC has recently updated three key resources relating to ethical conduct and research involving Aboriginal people.[39-41]

There is a large degree of consistency across these reports and guidelines about what constitutes 'best practice', and these principles and approaches should be seen as essential for Aboriginal health research. However, their implementation in other research settings in which the recruitment of Aboriginal patients is incidental rather than the central focus (such as large international treatment trials) requires careful consideration in order to manage the tension between the current Australian focus on streamlining ethics/governance approvals and the imperative to ensure a fair opportunity for Aboriginal patients to participate in clinical research that is culturally safe.

For clinical trials in which Aboriginal people are not the specific focus, no information is available about best practice models for improving Aboriginal participation per se, but there are several strands of indirect evidence which may be of use. Although Cochrane systematic reviews have been conducted on improving recruitment and retention in trials, on strategies to help clinicians recruit patients to trials, and on incentives and disincentives for clinician participation in trials (**Table 1.3.3**), the findings do not appear to be especially relevant for under-represented groups. Of greater use are the large number of reviews and research reports that have examined barriers to and facilitators of participation in clinical trials for ethnic minority populations, as well as the smaller number of reviews and papers on specific strategies to improve participation. The vast majority of these publications, which are detailed in **Table 1.3.1**, have focused on ethnic minority groups in the US. Given the very different health care system and demographic profile of that country, care must be taken in extrapolating the findings to Aboriginal people in Australia. However, with the exception of health insurance-related issues, many of the barriers and enablers are similar to those identified by Glover et al. [35] and are likely to be relevant in the Australian context.

Different frameworks have been developed to consider barriers and facilitators/ promoters relating to participation. For example, Ford and colleagues viewed participation in clinical trials as a function of barriers and promoters relating to: 1) *awareness*; 2) *opportunity*; and 3) *acceptance/refusal* (or decision-making).[27, 42]

A large number of barriers have been identified, but arguably the two most important ones are ‘gatekeeping’ [43-47] and study design [27, 31, 32, 42, 48], both of which are barriers to opportunity. Gatekeeping refers to whether or not a care provider actually discusses possible trial participation with a given patient. Study design barriers include stringent inclusion and exclusion criteria, as well as other aspects such as the timing, duration, location and focus of the study.

Other barriers that affect one or more of awareness, opportunity, and decision-making include: mistrust of health and research institutions [26, 29, 31, 35, 42, 43, 45-47]; lack of knowledge about trials in general, and about specific trials for which one might be eligible [26, 29, 42]; perceived harms/fear [30, 31, 42, 47, 49-51]; ineffective cross-cultural communication in the clinical and/or research settings [31, 46, 52]; patients’ lack of English proficiency [31, 45, 46, 53]; lack of staff diversity [45]; inappropriate materials with respect to language, literacy level, and cultural beliefs/practices [35, 45, 52]; logistical and cost factors, including time, money, access to transport, child-care, distance, appointment scheduling, etc. [26, 30, 32, 42, 45, 47, 50-52, 54]; lack of care provider knowledge about relevant open trials [29, 31, 47]; and a mismatch between where people receive their care and where studies are conducted [26, 44, 53]. More information about barriers is provided in **Table 1.3.1**. Although these various barriers are not insignificant, they do not appear to have as large an impact as gatekeeping and study design.[42]

Critical elements of improving participation of under-represented groups in clinical trials include: a commitment to inclusion, by both individuals and institutions [29, 30, 43, 53, 55, 56]; creating community partnerships and involving the community throughout the research process (and allowing the necessary time to do so) [26, 27, 29, 31, 35, 43, 45, 46, 51-59]; increasing cultural competency of clinicians and researchers [26, 29-32, 43, 45, 46, 51-57, 59]; active targeting and recruitment of under-represented groups [26, 35, 49, 55-57]; building inclusion into the study design, including increased flexibility in trial protocols [27, 30, 32, 42, 43, 51-53, 55-57, 60, 61]; assisting with logistical and cost barriers [26, 27, 30, 42, 43, 49-52, 57, 61]; conducting trials in community settings [57, 61]; appropriate staffing (bicultural/bilingual) and training and supporting researchers from diverse communities [26, 30-32, 34, 35, 43, 49, 51-57, 60]; and shifting the balance towards pragmatic clinical trials that focus on the needs of groups that are disproportionately affected by cancer(s) rather than on particular types of cancer [48, 53]. Other strategies are shown in **Table 1.3.1**.

It is clear from the literature that action at multiple levels is needed to overcome barriers to participation. A small number of models have been developed to address multiple barriers/levels. Three models worthy of consideration in the Victorian context include patient navigation, tele-trials and community-based participatory research.

Patient navigation

One model that has been designed to incorporate many of the key elements of improving participation is patient navigation (PN; **Table 1.3.4**), which has been mentioned in several papers as a potential enabler for participation [28, 49, 50, 53, 57, 59]. PNs are intended to bridge the gap between cancer care services and the community, and to help patients find their way through the complexities of the system. Most PN programs to date have addressed cancer care as opposed to trial participation (for example, see Whop et al. 2012 [62] for a systematic review of PN programs for Indigenous peoples). Barriers to cancer care and barriers to trial participation can overlap, and the PN role can include increasing awareness, knowledge and access to clinical trials. Key characteristics of PN include providing community engagement, cultural competence and integration with the cancer care team.[28] This approach has been tried in several sites in the US and early results have been promising.

In a systematic review of PN for under-served groups, Ghebre and colleagues found that PN was increasingly being used to assist in reducing barriers to participation in clinical trials for minority groups.[28] Six studies reported on the impact of PN on trial enrolment, while another 5 described training programs for PN. In some cases, PNs were integrated into the cancer care team; in other cases, they were separate to it. Based on available evidence, it appears that most people who are offered PN accept it. While there was promising evidence of a positive impact of PN, the authors concluded that more, larger studies were needed. Even with PN in place, however, the lack of suitable trials remained a major obstacle.[28]

One of the programs included in the review (accounting for 3 of the 6 papers looking at PN impact) is the *Walking Forward* Program.[63-66] This program may be of particular relevance for Aboriginal Australians. The program is based at the Rapid City Regional Hospital (RCRH), which includes a large Native American population within its service area of approximately 100,000 km^2. The program started in 2002-2003 as part of the US National Cancer Institute's Cancer Disparities Research Partnership (CDRP) program, which includes PN as a key element in all partnership sites. The RCRH site was the sole CDRP program focusing on Native Americans; other CDRP programs focused on African American and/or Latino communities. The RCRH PN program was designed to: 1) provide culturally appropriate community education; 2) facilitate trial participation; and 3) guide patients in using the health system. By 2011, over 400 Native American patients had received PN, and approximately 2,500 people had participated in research studies, including community-based surveys to assess potential barriers and solutions relating to screening, diagnosis, and treatment, as well as individual and cultural beliefs and perceptions. Some 10% of patients were enrolled in a clinical trial; while still low in absolute terms, this was a substantial increase (and higher than enrolment rates for the US cancer patient population in general). The main reason for not enrolling was the lack of a suitable trial and/or ineligibility (73%) rather than refusal (5%). Because the median distance patients had to travel for treatment was 110 miles, the program also developed Phase II trials to assess shorter treatment protocols (e.g. 1-4 weeks of radiation treatment rather than 6-8 weeks), with protocol adjustments to reduce the risk of radiation toxicities. Program sustainability was mentioned as a key challenge. The program received an additional 5 years of funding in 2009, but its webpage has not been updated since 2016.

Fouad and colleagues have reported on two programs relating to PN. In one study, trained volunteer community health advisors were used to support retention and adherence among minority and low income women already participating in a trial; women who were assigned to the PN arm had higher rates of attendance at scheduled trial visits.[67] In a later study, Fouad and colleagues trained and employed lay people as clinical trials navigators to provide education about trials to potentially eligible patients and to provide individual support to patients enrolled in a trial to overcome barriers to their participation.[68] The PNs, who were included as part of the cancer care team, identified barriers based on needs assessment and discussion with the patient. A range of supports could be provided, such as assistance with transportation/accommodation, referrals to the social worker and/or links to various community/social services and resources. From 2007-14, 272 African-American patients were provided PN. Trial participation for African Americans increased over that time from 9% to 16%. Almost 80% of patients referred to PN were in a trial, and navigated patients were nearly 5 times more likely to complete the trial than other patients.[68] Given these initial indicators of success, the authors recommended that the cost-effectiveness of the model be investigated.

McDonald reported on her Churchill Fellowship to investigate the role of PN in cancer care and to assess the feasibility of implementing PN in Australia.[69] She identified a number of navigations needs, and several types of navigators, with different skill sets, and different areas of focus. Although she identified a need for Aboriginal cancer navigation to ensure cultural safety and support navigation and coordination of care, she highlighted workforce shortages as a key barrier, noting that the required investment was beyond what appears to be available at present. Key requirements in developing a navigation program include the need for clarity about the issues to be addressed and the role and scope of practice of the PNs, the need to include PNs as part of a multidisciplinary team, the importance of co-design, and the need for evaluation, including assessment of return on investment.

Work is needed to explore the feasibility, acceptability and potential effectiveness of PN for Aboriginal people in Victoria, both for cancer care in general (see **Q2**, below) and for clinical trials specifically (whether alone or as a component of cancer care PN). The program's design should be determined through a collaborative partnership involving cancer care services, Aboriginal community-controlled health services, cancer survivors/carers, researchers and other relevant stakeholders. A key element of this work will be to identify ways to overcome likely workforce constraints.

Tele-trials

Tele-trials are now being established in Australia and provide a potential model for increasing access to clinical trials for Aboriginal patients (**Table 1.3.5**).

The Australasian Tele-trial Model was developed under the auspices of the Clinical Oncology Society of Australia to increase accessibility to trials for patients in rural and remote areas as well as in metropolitan areas. Tele-oncology has been used successfully in Australia to deliver cancer care closer to home for people in rural and remote areas, and this model can be extended to facilitate clinical trials.[14] Under this model, satellite sites can identify, recruit, enrol and treat patients under the direction of the primary site, which takes overall responsibility for the trial.[70] The special ethics requirements for research involving Aboriginal people were noted as an important consideration in tele-trial implementation.[14]

The VCCC now has a Tele-trial program based on the COSA model, with an initial trial involving Bendigo and Albury Wodonga. Tele-trials are described as a 'key tool for reducing barriers, such as time, cost and social disruption, for regional patients' access to cancer clinical trials'.[15] It is critical that these and other newly developing tele-trials programs be purposefully designed to facilitate inclusion of Aboriginal patients, and evaluated to assess their performance in improving opportunities for participation.

Community-based participatory research (CBPR)

The use of CBPR principles and approaches has been proposed as a way of improving participation by under-represented groups in cancer clinical trials [27, 51, 58, 59, 71]. The basis of this approach is meaningful and active community involvement across the entire research process, from conception and development to design and implementation to analysis and dissemination. A strategic plan for applying CBPR to cancer treatment trials, developed by a US consortium through extensive consultation,[58, 71] provides a useful model that can be translated to the Australian setting. The plan provides extensive guidance on why and how to include communities and includes 58 recommendations in 7 areas across the research process, along with an action guide. Two key challenges identified in implementing the plan include: 1) mistrust and 'a lack of an organised constituency to advocate for change' [58, p. 42]; and 2) 'a well-established cancer research system reluctant or unable to change'.[58, p. 44]

2. Improving culturally safe and effective cancer treatment for Aboriginal people with cancer

Five questions were posed in relation to improving culturally safe and effective cancer treatment for Aboriginal people with cancer. Methods used to identify evidence are detailed in the **Appendix A2**. Due to the wide scope in Question 2, limits were required in order to focus the search. Following discussion with the project team, the search was limited to activity within Australia, with a focus on Victoria. A small number of articles outside these limits have been included, due to their direct relevance to the questions. These include articles from the international arena or other Australian states, which provide evidence specifically related to the care of Indigenous people. There is considerable overlap in the literature related to the five questions: **Tables 2.0.1 – 2.5.1** contain further detail about articles referenced in the text. **Table 2.6.1** outlines current or recent activities in the area which may be worthwhile following up.

The Australian context

Briefly outlining the context in which cancer care is delivered to Aboriginal and Torres Strait Islander people in Australia and recent national reviews will be constructive, before answering each of the questions. Developments since 2010 are included here, as activities prior to this are summarised in Cancer Australia's Aboriginal and Torres Strait Islander Cancer Control Research Project.[72] A summary of this report is in **Table 2.0.1**. For further detail on the documents below, see **Table 2.0.2**.

- National Aboriginal and Torres Strait Islander Health Plan 2013–2023 and the Implementation Plan for the National Aboriginal and Torres Strait Islander Health Plan.[73, 74] These documents place culture at the centre of the strategy and are underpinned by principles of a human rights approach to equality, Aboriginal community control and engagement, partnership and accountability. Cultural competency is described though the concept of respect and the argument for developing culturally competent services and workforces is positioned within a human rights framework.
- National Safety and Quality Health Service (NSQHS) Standards and user guide,[75], which now require health services to address better health care for Aboriginal and Torres Strait Islander people. Importantly, these requirements include improving cultural competency, creating a welcoming environment and identifying people of Aboriginal origin.
- Australian Institute of Primary Care, in the Improving the Culture of Hospitals Project, developed a range of resources, tools and guidelines to assist hospitals improve their services to Aboriginal and Torres Strait Islander people.[76]

- NACCHO Healthy Futures 10-point plan (2013-2030). Outlines targets and long-term actions critical to health, communities and services. Outlines steps needed to achieve targets, the first of these being investing in the ACCHO sector.[77]
- Closing the Gap Analysis of progress and key drivers of change. This report is broad and guided by themes entirely relevant to the cancer space.[78]
- Cancer Council Australia has recommended that all Australian governments develop an Indigenous cancer strategy to address risk factors and cancer in Indigenous populations, based on tobacco control initiatives, vaccination, improved screening, improved access to health services and data collection, establishment of measurable targets and targeted funding.[79]
- The recent development of Optimal Care Pathways for Aboriginal and Torres Strait Islander people and associated documents is discussed in **Section 2.3**.[9, 80]
- Development of a National Palliative Care Strategy which contains recommendations specific to Aboriginal and Torres Strait Islander people (An implementation Plan and Monitoring and Evaluation Plan will also be developed).[81]
- Evidence of poor cancer related outcomes for Aboriginal and Torres Strait Islander people is summarised in the following selected references. Data limitations continue to exist and it is likely that statistics underrepresent the true situation.
    - Cancer in Aboriginal and Torres Strait Islander Australians: An overview - a summary of cancer related statistics.[82]
    - Commonwealth Department of Health Aboriginal and Torres Strait Islander Health Performance Framework Report.[83]

National framework documents

- Cancer Australia and Menzies School of Health Research developed a National Framework through a widely consultative process. The Framework sets strategic direction to address disparities and improve cancer outcomes for Aboriginal and Torres Strait Islander people with cancer and outlined seven priorities, all of which are relevant to this question.
- Development of national best practice frameworks for gynaecological cancer and lung cancer.[84, 85]
- Cultural Respect Framework 2016–2026 for Aboriginal and Torres Strait Islander Health, which aims to ensure health services are accessible, responsive and safe for Aboriginal and Torres Strait Islander people through

embedding cultural respect principles in health systems. Commits Commonwealth and State governments.[86]

- Development of a National Framework for Continuous Quality Improvement (CQI) in Primary Health Care (PHC) for Aboriginal and Torres Strait Islander People.[87]
- Indigenous Allied Health Australia has developed a Cultural Responsiveness Framework, which places culture at the centre of the model, describes cultural responsiveness as an extension of patient centred care and sets out a framework with six key capabilities and outcomes, guided by 'being, knowing and doing'. This also addresses culturally responsive governance.[88]

National reviews relevant to the questions

- Review of the key attributes of high-performing person-centred healthcare organisations.[89] This review is not focussed specifically on Aboriginal and Torres Strait Islander people, but contains case studies of various services and efforts to improve care for Aboriginal people through the delivery of person centred care. Along with a desktop review, site visits to eight high-performing health care organisations (four in Australia) were conducted, aimed at complementing the NSQHS Standards and providing practical information to health services to assist in the delivery of person-centred care and help meet NSQHS Standards.
- The Australian Commission on Safety and Quality in Health Care, published a rapid review of patients' experiences in Australian hospitals, which advised larger multisite studies with qualitative components, focusing on Aboriginal patients (and other groups), to address the failure of structured survey methods to capture nuanced experiences.[90]

Relevant Victorian documents include:

- The Victorian Government's Cancer Plan 2016-2020 and accompanying Monitoring and Evaluation Framework, outline long term goals, priorities and underlying principles and mechanisms by which to assess progress against the plan. These documents have direct relevance to these questions and have been identified within the responses.[10, 91]
- Evaluation of Koolin Balit, which focused on: case management and care coordination models (discussed later in the report); the Gathering Place model; improving cultural responsiveness in Victorian hospitals; and traineeships and workforce development.[92] Social Compass were commissioned by DHHS to examine Victorian hospitals' efforts to improve cultural responsiveness and cultural safety.[93] The evaluation report found three domains of change influenced a hospital's ability to provide culturally

responsive care and cultural safety: 1. Hospital leadership and organisational culture. 2. Aboriginal and Torres Strait Islander workforce. 3. Aboriginal community relationships – including local ACCHOs, Traditional Owners and Aboriginal patients. Numerous relevant findings are contained in this report (see **Table 2.0.2)** and challenges in assessing progress are outlined (e.g., non-mandatory reporting, lack of systematic approach to measurement).[93]

- Korin Korin Balit-Djak: Aboriginal Health, Wellbeing and Safety Strategic Plan 2017-2027, which lists improving cancer outcomes for Aboriginal Victorians as a strategic direction.[94]
- Rethinking cancer, Raising Hope identified priority areas for action following a Roundtable in 2014 which aimed to improve collaboration in clinical care and research into cancer in Victorian Aboriginal and Torres Strait Islander communities.[95]
- Victoria's end of life and palliative care framework for Aboriginal and Torres Strait Islander people.[96]

2.1. What are the barriers experienced by Aboriginal people in accessing cancer treatment?

2.2. What are the barriers experienced by Aboriginal people in completing cancer treatment?

The first two questions were combined due to the large amount of overlap and as they are commonly discussed in the same literature. Following discussion with the project team, this report has included and focussed on enablers or facilitators which address these barriers, which will assist in informing future directions.

Barriers

Evidence of a range of barriers experienced by Aboriginal people in accessing and completing cancer treatment is extensive. Relevant references are summarised in **Table 2.1.1**, with columns indicating whether the article contains evidence related to Barriers Accessing (BA) and/or Barriers Completing (BC) treatment. A review of cancer in Aboriginal and Torres Strait Islander people [97] presented a summary of barriers experienced by Aboriginal people in accessing and continuing treatment across the continuum of cancer care and which are present at all levels:

- the context in which Aboriginal people undergo cancer diagnosis and treatment, with a background of colonisation, institutionalised racism, discrimination and socioeconomic deprivation, and the majority of the system being set up from a non-Aboriginal approach, ACCHOs being a notable exception;

- health system factors, including lack of Aboriginal involvement in design, multiple workforce issues including insufficient employment of Aboriginal people in the system and high staff turnover, workplace culture issues, systems containing gaps in care, lack of flexibility, difficulty maintaining or simple lack of local partnerships, environments that are not culturally safe, focus on a ‘throughput’ approach rather than a person-centred approach, access issues.
- interactions within the health system, including lack of dedicated coordinators, communication challenges, assessment of outstanding needs, safety in the system, lack of cultural understanding.
- individual factors including belief systems and challenges of incorporating belief systems in biomedical treatment plans, health literacy, lack of acknowledgement of the importance of connection to Country and family.[97]

Enablers

Although the evidence is markedly weaker than that for barriers to cancer care, there is some evidence about the characteristics needed by health services to enable Aboriginal people to access and complete cancer treatment (indicated in **Table 2.1.1**, Column En - Enablers) (also see **Section 2.3, Service Models**). It is widely acknowledged that more research is needed in this area: research frequently reports strategies that may be effective, rather than strategies that have been shown to work. Caution is required in the replication of successful approaches due to variations in geographical and health system settings and local circumstances. Enablers have been reported at all levels: high level organisational policies and throughout the system; health system factors and interactions within the system; or at the individual level. Cultural safety and cultural competence are highly relevant to this question: see **Section 2.4** for more detail.

It is acknowledged that many of the high-level documents referred to earlier have incorporated the issues outlined below, however whether this has translated to changes at the service level has not been established.

Enablers relevant to the whole system and high-level organisational policies:

- respect for culture [98, 99] and the importance of maintaining Aboriginal identity.[99, 100] Within cancer treatment plans, recognise that connection to family, community and land is integral to the Indigenous expression and experience of life.[101] This international systematic review into cancer related decision making by Indigenous people found that many Indigenous people will prioritise these connections over any benefits to be gained from successful cancer treatment and that acknowledgement and respect for these views must be present in order to improve cancer outcomes for Indigenous patients.

- the centrality of including the voice of Aboriginal people, communities and organisations through consultation, ownership or partnership [98, 102-107] and the need for Aboriginal people to be empowered and engaged in these relationships.[101]
- Aboriginal people being involved in the planning, design and delivery of care, ensuring compatibility with existing systems and processes.[95, 104, 108, 109]
- Increasing the cultural safety of mainstream services,[98, 110-114] through multiple strategies including: employing more Aboriginal people in the health workforce,[103, 106, 115] encouraging referral from Aboriginal Liaison Officers to non-Aboriginal specific services, and building relationships between Aboriginal organisations and mainstream support services.[113, 116] See **Section 2.4** for more detail.
- Attention to the policy and funding environment and leadership.[93, 104]

Enablers relevant to health system factors

(refer to **Section 2.3, Service Models** for more information, including palliative care)

- Workforce related aspects. An international systematic review examining implementation of successful chronic disease interventions for Indigenous people found that workforce issues were one of the key factors and required consideration of recruitment and retention, training and development of local people, dedicated positions with clear roles, inclusion of Indigenous Health Workers in decision making and supporting staff wellbeing,[104] and embedding culturally safe work practices.[104, 117] Training of Aboriginal health professionals in cancer related issues, including programs which facilitate sustained knowledge following training by (for example) being integrated into ongoing professional development has also been highlighted.[116, 118, 119] Cultural competence in the workforce is included in **Section 2.4**.
- As support services are a mechanism for addressing barriers, attention is needed to ensure they are located where Aboriginal people live.[113] The use of patient reported measures such as supportive care needs assessment, outcome measures and patient experience measures to assess delivery of support services has a strong evidence base due to recent work in the field (see **Section 2.3, Service Models**).
- Improved linkages between mainstream cancer services and ACCHOs are recommended,[62, 93] particularly around admission and discharge.[120] Shared care arrangements have been reported as both a barrier (to continuity of care) and an enabler (developing relationships across a range of specialists).[106] In a qualitative study involving Aboriginal cancer

patients, their families and health care providers, improved linkages between PHC physicians, specialists, and cancer services were reported to be a way of reducing delayed diagnosis of cancer in Aboriginal people,[121] along with addressing accessibility issues and cultural safety.

- Delivering more services locally, such as telehealth [115, 120, 121] and improving services in regional areas: Murphy and colleagues present a summary of projects focused on improving cancer care for Aboriginal people in regional areas of NSW and border areas of Victoria, including Sharman and Murray's 'Let's Yarn with the Aboriginal community of Albury about cancer…' project.[116, 122] Also see **Section 2.3, Service Models**.
- Flexibility around appointment times and lengths: limited appointment times lead to not developing rapport and insufficient time to ask questions and access to ongoing care is impacted if appointment times do not take the need for travel into account.[106, 121, 123]
- Provision of practical assistance: Many studies have found that addressing access issues improves Aboriginal people's engagement with treatment.[110, 120, 123-127]
- Indigenous Patient Navigation (IPN) or care coordination (also see **Section 1.3**)

Many authors have proposed IPN programs as a culturally acceptable way of improving cancer care for Aboriginal people across the continuum.[9, 62, 106, 107, 120, 121, 128-131] Some authors have used other terms or incorporated navigation into a coordinator role, however the principle of including dedicated coordination into routine care to assist Aboriginal people in attaining good quality person-centred care during their cancer treatment is consistent. In the Victorian setting, recent reviews have highlighted the potential of this approach. Although not focussed on cancer care, the evaluation of Aboriginal Health Case Management and Care Coordination Models reviewed projects where patients had complex needs requiring healthcare across a range of different services.[123] This evaluation outlined multiple positive outcomes of this approach. A care coordination model was reported to provide a structure based on relationships, which was found to impact on patients' engagement with health services and is consistently found to be a critical factor in effective service provision for Aboriginal people. This approach, which incorporated navigation of the system, was critical to engaging with the patient and was valued by Aboriginal patients. The report highlighted the range of skills required in such a role and the crucial aspect of support for the coordinator, particularly due to the pronounced effect of caring for community members who have undergone trauma, when you are from that community. Benefits extended to improving relationships across local service networks, improving trust in the service, and ensuring patients with complex needs were not lost to the system.[123] Interviews with Aboriginal Health Workers (AHW) through the 'Let's Yarn About Cancer' project found that although AHW's currently perform some navigation roles, there is a need for specific cancer patient navigation and the author proposed consideration of such a program in that region, linked with recent work at Peter MacCallum Cancer Centre.[120] Following US and UK visits as part of a Churchill Fellowship, McDonald outlined the case for and challenges facing the investigation of a patient navigator program at Peter MacCallum Cancer Centre, with Aboriginal people being one of the five possible areas of focus.[69] Challenges include workforce issues, the need for clarity around roles (also highlighted by other authors [132-134]), integration within multidisciplinary hospital teams, and the need for co-design. There is agreement that rigorous impact evaluation is necessary.[62, 69, 132]

The Managing Two Worlds Together project identified the need for an Aboriginal Patient Pathway Officer (APPO) to support country patients attending city hospitals, and stressed that such roles must be clearly defined, understood and supported for both city and country staff and organisations.[131]

The IPN approach has been tested in South Australia [126] and in a small trial in Queensland.[132] Reilly et al. examined the care coordination role as part of the CanDAD project, however it was acknowledged that this was not a formal evaluation, which would be an important future step.[126] This group reported that "navigating the health system" was one of the roles of a care coordinator, along with "information and communication," "things to manage at home" and "cultural safety". This navigation was found to promote adherence and sustainable engagement, particularly for those with complex cancer or circumstances, addressed gaps in care or otherwise influenced Aboriginal people's experiences of cancer care. The Queensland trial of an IPN program with 18 Indigenous patients in Queensland found that the following issues should be considered: consideration of patient acceptance (valuing personal interaction versus privacy) and cultural boundaries; the time taken to develop the role within a service; tensions between research and usual care expectations with the potential for misalignment of roles; the need for flexible recruitment strategies; and the time taken to integrate an intervention into routine care.[132]

Other reported potential benefits of IPN programs are reducing delayed diagnosis,[121] improving survivorship,[129] and reducing barriers to care by (for example) improving adherence and engagement, travel and accommodation and access to supplies and resources.[126] The evidence warrants investigation of establishing an IPN in Victoria, in an effort to facilitate access to and completion of cancer treatment for Aboriginal people.

- Communication: although focussed on the clinical setting generally rather than cancer care specifically, several authors demonstrated evidence for the importance of talk or yarning as a critical aspect of improving access to health care.[135-137] Lin et al. presented a framework for using clinical yarning and examples from practice.[129] Although a small qualitative study, Tam and colleagues found that communication and the development of a positive relationship with health care providers facilitated a positive care experience, and enhanced decision making and understanding of disease and treatment, from the perspective of Aboriginal patients.[130] In the cancer setting, building of trust and rapport is clearly a contributing factor to successful provision of care [98, 107, 121, 138] and was reported as an enabler from the health professional perspective.[106] Other strategies to improve communication from the health professional perspective include more Aboriginal staff in the system, continuity of care, plain language, cultural training for staff, cancer education for Aboriginal people, meeting support needs [139] and addressing institutional racism.[140] Transparent and respectful communication was reported as an important part of building trust between Aboriginal and non-Aboriginal people in an effort to improve services and reduce delayed diagnosis [121] and time is needed to build this trust.[123]

Enablers at the individual level

- Use of traditional medicine. It is recognised that many Aboriginal Australians use traditional medicine or complementary medicine for their cancer care [111, 121, 141, 142] and that it can boost the confidence of Aboriginal people to engage in mainstream services,[111] particularly if health care providers had respect for and knowledge of traditional medicine.[142] There is a need for respectful enquiry about traditional medicine use due to the lack of knowledge about many plants and possible interaction with treatment [121] and possible nondisclosure if disrespect is suspected.[142] Offering traditional healing practices with biomedicine was found to support wellbeing in an international systematic review, though this was not focussed on cancer.[99] This article reviewed 21 studies (5 Australian) presenting strategies that have or could support the wellbeing of older Indigenous people and was included here due to the inextricable link between wellbeing and health and that cancer predominately affects older people.[99]
- Facilitation of family efforts to support the patient and strong social support were reported as enablers to cancer care for Aboriginal people from the perspective of health professionals,[106] and patients.[120, 124] Those receiving significant psychosocial support were seen as more likely to complete treatment.[106]
- There is evidence for appropriately developed peer support networks being a culturally safe part of cancer treatment and care.[106, 120, 143-145] Cuesta-Briand and colleagues outline challenges and strategies in their establishment.[144, 145]

- Some authors advocate that improving health literacy has potential to improve outcomes [112, 121, 146] advocate that a better understanding of Aboriginal cancer patients' health literacy is required before designing related interventions.[146]

What we need to know/do (barriers / enablers)

- Investigate and implement an Indigenous Patient Navigator program in Victoria, particularly with services that have identified this as desirable, incorporating co-design processes and impact evaluation.
- Examination of the use of traditional medicine in Aboriginal people with cancer, potentially focusing on specific cancer(s). Explore ways in which Aboriginal and biomedical approaches can be integrated in cancer treatment.
- Further explore the establishment and support of peer support programs.

2.3. What are the service models that have successfully increased the number of Aboriginal people commencing and completing optimal cancer treatment pathways?

There are few references to Aboriginal people with cancer and optimal care pathways, as expected given their relatively recent emergence, and no evidence has been found of increased numbers of Aboriginal people commencing or completing optimal cancer treatment pathways. A small collection of resources specific to Aboriginal people and Optimal Care Pathways is listed in **Table 2.3.2**. Although a direct link with optimal care pathways is not evident, it is worthwhile reviewing service models or aspects of service models reported to be effective and which may be appropriate to develop. Along with research about cancer specific models, some review articles about PHC and chronic illness have been included, as the models have been assessed as contributing to improved treatment and/or outcomes for Indigenous people, and as cancer is considered alongside chronic disease. Key common aspects of effective service models are (more detail in **Table 2.3.1**):

- Aboriginal community engagement with strong relationships as the centre [98]; shared responsibilities or patient/provider partnerships; incorporation of local knowledge [104, 105, 147, 148], high levels of integration in existing services [148, 149] and including data systems [105, 147, 150], a central role for Aboriginal Health Workers, [104, 147, 148] nurse-led care, intensive follow-up, provision of culturally-appropriate education, governance structures supporting community ownership, and robust clinical systems supporting communication.[147]
- models which enable critical reflection on barriers and facilitators to providing respectful and culturally safe quality care at all levels, determined

through a review to inform a collaborative model to improve hospital based care for Aboriginal people [103]; In the PHC setting, addressing key enablers has been shown to improve health outcomes such as occasions of service, health assessment uptake, and some quality of care indicators.[151] Though this study was undertaken in a different setting incorporating remote areas (NW WA), it describes a partnership between an ACCHO, a hospital and a community health service and may have application in Victoria.

- Those which maintain Aboriginal identity [99] underpinned by culture and containing characteristics including accessible services, flexible approach to care, community participation, self-determination and empowerment, CQI, holistic health care and a culturally appropriate and skilled workforce, as determined through a systematic scoping review aimed at developing a new PHC service delivery model.[152]
- Those employing flexible strategies to support attendance and continued engagement, which recognise the necessity of maintaining connection to family and Country, such as in the radiotherapy study by Le et al.[125]

The user guide for implementing the National Safety and Quality Health Service Standards outlines in some detail how many of these characteristics can be developed and progress measured.[75]

These findings are consistent with key reports from the Victorian setting [120, 123] and with the Cancer Plan.[10] The Evaluation of Aboriginal Health Case Management and Care Coordination Models in Victoria found that culturally informed, relationship based models of care were delivering significant benefits for individuals, families and organisations.[123] Although this report advised exercising caution regarding replication of these models as they were developed in response to the local context, the general approach has great potential for replication. Cancer service improvements for Aboriginal people in Victoria were proposed in the ‘Let’s Yarn About Cancer’ project report and are included in specific aspects of service models outlined below.[120]

Regarding the ACCHOs model of care, Gomersall and colleagues conducted a systematic review of qualitative evidence to determine how ACCHO clients perceive the characteristics and value of care provided by ACCHOs compared to care provided in mainstream PHC.[153] Although a small number of articles were eligible for inclusion (10 articles on 9 studies), this review found that the ACCHO system was a highly valued, accessible and culturally safe system of care. These findings [153] backed up those of Davy and colleagues [154] who found that Aboriginal health care services appear to be best placed to overcome both the social and cultural determinants of health that affect access to health care and presented a framework for Indigenous people accessing PHC. In WA, population health gains were demonstrated through an impact evaluation of a PHC model which included an

ACCHO, hospital and community health service,[151] though it is acknowledged this was in a specific setting.

Patient reported measures

Services which assess patient reported measures routinely and incorporate the ability to identify and address gaps have been recommended in relation to Aboriginal inpatient experience (not cancer specific),[114, 155, 156] screening experience,[11] Aboriginal cancer patient experience,[10, 11, 124, 126, 137] supportive care needs throughout the patient pathway [157-159]; health related quality of life of Aboriginal people with experience of cancer [160, 161] and in reference to best practice for cancer treatment.[84, 85] Specific questions and tools developed in true partnership with Aboriginal people are required to do this effectively.[124, 156] These findings align with the Koolin Balit evaluation [92] and Victoria's Cancer Plan 2016-2020,[10] which aims to improve patient experience and achieve equitable outcomes as long term aims and improve patient experience as a priority. Patient reported measures are also an important way of determining whether person centred care has been delivered, which is a principle underlying the Cancer Plan and reported as a way of reducing delayed diagnosis [121] and improving survivorship.[143]

Palliative care

There is a need for more nuanced evidence of effective service models in this area. An Australian palliative care review focussed on Aboriginal people found that it was preferable for palliative care to be delivered through ACCHOs in partnership with mainstream services and that models need to reflect local needs and acknowledge cultural beliefs.[162] These findings supported those of McGrath, who outlined an evidence based model, termed 'The Living Model', for delivering palliative care to rural and remote Aboriginal people and also highlighted the importance of beliefs.[163] The Living Model of service delivery to Aboriginal Australians emphasizes cultural safety and incorporates effective communication, attention to psychological issues and practical barriers to care, education, involvement and support of family members. Woods and colleagues examined timeliness of palliative care episodes from a national dataset and compared Indigenous and non-Indigenous patients against a benchmark.[164] This study found that Indigenous patients may experience a delay of initiation of services, especially if younger and at the first encounter and the authors recommended the use of qualitative methods to more fully understand determinants of delay in accessing this care for Indigenous patients. In a comprehensive international review of the provision of culturally safe palliative care service delivery to Indigenous people in Australia, NZ, Canada and the USA,[165] successful models of care were those that incorporated community engagement and ownership, flexibility in approach, continuing education and training, a whole-of-service approach, and local partnerships among multiple agencies into the model. This study found that Indigenous people had a preference to die at or close to home.[165]

Telehealth / telemedicine / teleoncology

While acknowledging that more research is needed in this area, and the reporting of studies with small sizes and descriptive findings, telemedicine has been reported to be a successful model of care for Aboriginal patients. A recent systematic review examining outcomes of services delivered by telehealth to Aboriginal Australians found that all authors reported beneficial health, process and economic outcomes, although only one of the 11 reported services was conducting teleoncology services (across two articles) and one palliative care.[102] A review of telehealth models for cancer care found that they were applicable to all fields of oncology, but that new models of telehealth are needed (e.g. nursing, pharmacy) to decrease disparity of access and survival outcomes between urban and rural patients.[166] Tan et al. and Shahid et al. suggested that telemedicine could reduce the delay experienced by some Aboriginal patients from diagnosis to first treatment.[121, 167] Other benefits of teleoncology reported in the literature include high levels of patient satisfaction, attendance of family at appointments,[168] enhanced partnership between local health workers and specialist teams and delivery of quality care 'at their doorstep'.[169] Mooi et al. also advised that formal skills training and effective communication were essential to maintain safety of practices,[169] which is also reported by Sabesan and colleagues [166] along with the importance of integration of the model into the core business of hospitals. Reported benefits of telehealth in general include improved social and emotional wellbeing, screening rates and access to services, positive perceptions from Aboriginal participants, reduced travel and improved affordability and convenience, reduced stress and that it is supportive of a holistic view of health.[115]

Telehealth progress in Victoria in recent years: An Aboriginal Telehealth project was piloted by VACCHO from 2013-2015, focusing on Gippsland with other regions to follow.[170] Following a needs analysis to identify specific services for each region, this project aimed to enable ACCHOs to offer patients access to specialists via videoconferencing.[170] Leverage from existing services is likely to be possible and has been suggested as worthwhile,[120] however would require more detailed investigation as to reported outcomes of previous work than is possible via this review.

What we need to know/do (Service models)

- The emergence of Optimal Care Pathways provides an opportunity to document adherence to best practice guidelines across multiple services and potentially detect reasons for deviations from recommended pathways.
- Investigate cancer related decision making and how this can impact on the design of culturally appropriate programs for Aboriginal people with cancer.

- Assess the extent to which telehealth / teleoncology models improve cancer related outcomes compared with face to face models and investigate possibility of new models of telemedicine (e.g., nursing, pharmacy)
- Evaluate Aboriginal-specific programs, including aspects of the cancer experience that are important to Aboriginal people in addition to outcomes.
- Undertake qualitative exploration of palliative and supportive care pathways including examination of timely referral for specialist palliative care
- Assess the degree to which patient reported measures that are specifically designed for Aboriginal people, are incorporated into routine care. Identify and address gaps in existing measurement approaches.

2.4. What is the effectiveness and impact of cultural safety developments?

Multiple related terms are used interchangeably and / or erroneously in this area, including cultural safety, cultural competence, cultural appropriateness, cultural respect, and cultural responsiveness. Definitions we have used are in **Table 2.4.2**. Efforts to rigorously evaluate the impact of cultural safety programs on health outcomes are limited, however the literature widely reports that cultural safety and cultural competency efforts are crucial to improving treatment outcomes for Aboriginal people and there is significant agreement regarding which characteristics of the system or health programs contribute to improving cultural safety. The need for rigorous evaluation is widely accepted. More detailed information on references included here is in **Table 2.4.1**.

National background

There are a number of Closing the Gap (CTG) resources relevant to this area.[171-173] It must be noted that the CTG approach is controversial due to its deficit approach and that it was not perceived to entail true partnership with Aboriginal bodies. The recent Coalition of Peaks group may address this, as it has emerged from the ACCHO system.[174]

Effectiveness of cultural safety efforts in cancer specific interventions:

- Effective cancer screening activities which entailed cultural safety efforts include: Translational Research with CQI in pap screening [175]; education by respected Aboriginal women, care and support by Aboriginal women in community, culturally appropriate health promotion in mammography screening.[176]
- A strategy reported to enable building of workforce capacity to address complex health problems was developing deeper cross-cultural collaboration in a Participatory Action Research project in a rural NSW cancer setting.[177] Other studies have found that education strategies

aimed at improving culturally safe care can be effective, however they need to be embedded into long term implementation strategies.[119, 178]

- Care coordination or patient navigation: The care coordination relationship promoted cultural safety [123] and improved cultural safety by educating staff about Aboriginal identification and other aspects of cultural safety, racism, mistrust, facilitating support.[126] See also **Section 2.1, Enablers**.
- Talk, yarning, communication: See **Section 2.1, Enablers**, for how 'talk' has been shown to improve cultural safety.
- Tools developed with Aboriginal people for eliciting patient reported measures enable this to be done in a culturally safe way. See **Section 2.3, Service Models**.
- Delivery of cancer care: Taylor et al., in an online survey of Australian public cancer centres found that the most common initiatives to contribute to cultural safety for Aboriginal people were links or proactive partnerships with Aboriginal community health organisations and making a dedicated effort to address the needs of Aboriginal patients.[179] Further exploration through interviewing staff at a subset of services revealed critical aspects of delivery of culturally appropriate treatment and care were: having a trained workforce with effective cross-cultural communication skills; providing best practice care; and improving the knowledge, attitudes, and understanding of cancer by Aboriginal people.[117]

Cultural safety and cultural competence effectiveness outside cancer

Frameworks which assist health services' examination of cultural safety and cultural competence are detailed in **Table 2.4.1**.

An international review of evidence on cultural competence in health care settings (not cancer specific), focussed on identifying effective strategies.[173] A positive relationship between cultural competency and healthcare outcomes was demonstrated in 15 studies. There was a consistent message that knowledge alone was insufficient in fostering improvements.

There is evidence for cultural safety measures and cultural competence to be integrated and led at the highest levels.[93, 133, 180] In an international systematic review examining efforts to improve cultural competency in health care for Indigenous people, Clifford et al. (2015) found that improving adherence and health outcomes required changes at the organisational level to reinforce and sustain health professional behaviour changes.[180] Strategies to achieve this include embedding cultural competency in policy protocols and key performance indicators. This was also found in Dwyer et al., after using a cultural competence based framework to examine responses of 26 South Australian public hospital staff, who were asked to identify barriers and enablers in implementation of official policy regarding care of rural Aboriginal patients.[133] Problems were identified in operationalising policy and the authors concluded that a large part of the problem lies in misinterpretation of the principle of equal treatment. Two themes were identified by Dwyer et al.: individual cultural (in)competence and the impact of 'business as usual' requirements.[133] Effective strategies and interventions found in these studies were: workforce education and training, culturally specific health programs and Indigenous workforce recruitment;[180] ALOs and clinical coordinators and the availability of support services.[133] Dwyer et al. found that such strategies usually fell into the category of 'bolt ons' rather than enabling flexibility within the routine system of care.[133] Both studies emphasised the need for more rigorous evaluation studies.[133, 180]

An important finding to inform future research activities is from a Queensland study which found disparities between Aboriginal community members and staff, regarding whether PHC services provide culturally appropriate care.[181] Although this was a small descriptive study, it highlights the importance of obtaining multiple perspectives, particularly from those receiving the service, also highlighted in Davy et al.[182] Also see **Section 2.3, Service Models** regarding acceptance of ACCHOs as a culturally safe space [153] and telehealth evidence.

Victoria specific programs

DHHS has provided Cultural Safety Project grants to various hospitals in Victoria in recent years, however these reports were not available to the Menzies team prior to submission of this desktop review. The Evaluation of Aboriginal Health Case Management and Care Coordination Models in Victoria [123] and 'Let's Yarn About Cancer [120] entail assessment of cultural safety and are discussed in **Section 2.3, Service Models**. Social Compass's evaluation of the ICHP reported highly consistent themes of strategies to improve cultural safety and cultural competence, which are echoed in the literature as described above.[93]

The experience of Tynan et al. in a partnership to develop a health service cultural competence assessment tool and the implementation process in regional Victoria may be informative here. The authors refer to organisations' Aboriginal Cultural Competence Action Plans and the need for systematic analysis of their quality. [183] In the PHC setting, Liaw et al. described challenges to measuring impact of a cultural safety intervention in a randomised controlled trial in general practice, which did not demonstrate improvements in outcome measures. The authors recommended local and regional coordination, and participatory mixed methods research in efforts to conduct robust evaluations.[184]

The aim of the Possum Skin Cloak project at Peter MacCallum Cancer Centre is to increase survivorship rates among Aboriginal and Torres Strait Islander women with breast cancer and other cancers.[185] It is not known to what extent this program has been evaluated.

What do we need to know/do (Cultural safety impact)

- Examine successful models of increasing Aboriginal people in the health workforce, incorporating appropriate support and development (not only training).
- The National Safety and Quality Health Service Standards User Guide for Aboriginal and Torres Strait Islander Health [75] could assist in structuring systematic evaluation of cultural safety, cultural responsiveness and cultural competence efforts and there are multiple frameworks which may also be relevant.
- Consider a stocktake of organisational cultural competence in cancer care for Aboriginal and Torres Strait Islander people, against identified characteristics of effective culturally competent care. This would need to determine the extent to which true partnerships were evident, rather than 'tacked on' cultural safety programs. Such an approach was undertaken in national maternity programs.[186] Other potentially useful references may be a metasynthesis,[187] and assessment of cultural competence.[188]
- In organisations that have integrated cultural competency standards into policies and practices:
    - do health professionals develop more culturally competent behaviours
    - what impact has this had on health outcomes of Aboriginal people
    - conduct evaluation studies that employ rigorous study designs, recruit representative samples, utilize validated measurement instruments and conduct high-quality economic evaluations
- Consideration of Hunter New England Health's decolonising approach, which has undertaken to embed cultural inclusion and leadership into every public health program delivered through their system at research, service delivery, local and operational levels. HNE Health has established a Joint Governance Group which formally assesses all public health work for cultural appropriateness, and a cultural governance network and committee where public health staff can seek cultural advice.[189]

2.5. What is the evidence of best practice models or key factors that have successfully improved five-year survival rates experienced by Aboriginal people?

This review has not identified evidence of best practice models which have been shown to improve survival rates, however numerous factors have been put forward that may improve survival of Aboriginal people with cancer and the need for ongoing monitoring and the development of efforts to improve survival is clear. Best practice in cancer care and treatment for lung cancer and gynaecological cancer have recently been developed [84, 85]: these and other national initiatives to improve cancer care are summarised in Haigh et al.[97] The recently developed optimal care pathways could also be considered best practice guidelines (see **Section 2.3**). An overarching issue is the collection and management of data and use of this data for improving cancer outcomes.

Reports documenting significant disparities in cancer survival rates for Aboriginal Australians compared with non-Aboriginal Australians have been published [82, 97, 190-195]. Contributing factors include screening factors, comorbidities, stage at diagnosis, treatment uptake, and location of residence and are discussed below. More advanced cancer stage at diagnosis amongst Aboriginal people, which contributes to poorer outcomes,[97, 192, 194, 196] has been found in breast cancer,[197] cancer overall,[191] and head and neck cancer amongst others.[198]

Screening: Lower cancer screening rates for Aboriginal people and programs designed to address these are summarised in Haigh et al.[97] Participation in cancer screening may be affected by comorbidity, which has been suggested as a barrier to screening, leading to more advanced disease at diagnosis.[193, 199] Diaz et al. found that improving early diagnosis of cervical cancer may increase cancer-specific survival in the year after diagnosis.[199]

Diagnosis and management of chronic disease: The suggestion that comorbidities are a contributing factor to poorer cancer survival outcomes for Aboriginal people is well documented for cancer overall,[191, 192] and for some cancers: head and neck,[200] breast cancer,[190, 192, 197, 201] although evidence regarding colorectal [202] and cervical cancer [193] is less clear. (See **Table 2.5.1.**)

Treatment uptake: Evidence of lower treatment uptake for the Aboriginal population is demonstrated in the following cancers: prostate cancer,[195] cervical cancer,[203] lung cancer,[203, 204] head and neck cancer,[200] lower surgical treatment in breast cancer,[197] and less treatment overall compared with non-Indigenous patients.[191]

Remoteness of residence is associated with higher diagnostic interval,[205] lower survival, [190, 192, 194, 204] and larger gaps in patient experience.[155] Indigenous cancer patients in rural/remote Queensland were less likely to be diagnosed with localised disease and less likely to receive treatment than urban living people,[206] suggesting that programs which improve services and treatment uptake in non-urban areas may improve survival.

Factors which may improve survival rates for Aboriginal people with cancer include:

- Evidence based, tailored screening programs based on best practice, which include follow-up after abnormal screening, link to diagnostic and treatment services, and incorporate chronic disease and wellness checks.[175, 192, 203, 204, 207] Using translational research and CQI was shown to improve pap screening rates in an urban ACCHO.[175]

- Early diagnosis and management of chronic diseases as a cancer risk reduction strategy.[192, 197, 200]
- Improved treatment uptake, including surgical treatment.[195, 197, 200]
- Personalised cancer care.[191]
- Development of cancer care guidelines and multidisciplinary care that meet the needs of complex patients, though there is some evidence that those without comorbidity and experience of the health system may also need particular attention.[193]
- Strategies to improve regional cancer services such as improved telehealth.[121, 167]
- Consideration of service models as outlined in **Q2.3** and factors reported to enhance survivorship for Aboriginal people, which may encourage treatment completion, such as: advocacy and peer support, cancer specific Indigenous PHC workers and Indigenous patient navigators, tailored prompt lists and cancer survivorship care plans.[129]

What do we need to know / do (Best practice and survival)

- Where best practice guidelines exist, establish pathways by which to monitor the progress of Aboriginal people diagnosed with these cancers, determine the degree to which guidelines are followed and reasons for divergence/s. Understand reasons for disparities in cancer treatment uptake in Aboriginal Australians with cancer and devise strategies to address them.
- Investigation of potential drivers of treatment and survival differentials for specific cancers including the relationship between comorbidity and mortality.
- Improve data quality relating to cancer in Aboriginal people and identify opportunities for data linkage to fill gaps in the short to medium term.
- Undertake documentation and evaluation of relevant models and of the implementation of strategies and programs over time to enable assessment of their impact on cancer survival. (This is a longer-term goal.)

3. Improving Aboriginal people's self-identification and the quality of cancer data

Three questions were posed in relation to improving Aboriginal peoples' self-identification and the quality of cancer data. Methods detailing the obtaining of evidence are provided in **Appendix A3**. Due to the anticipated lack of evidence specifically relating to cancer, evidence across the health sector was considered, in that findings could potentially be applied to the cancer context. In brief, searches of the peer-reviewed and grey literature (including searches of key organisations' websites) were conducted.

3.1. What is the impact of Aboriginal identification questions on:
(i) Aboriginal engagement or disengagement in health services (primary and tertiary care);
(ii) health-seeking behaviour;
(iii) early discharge; and
(iv) discontinuation of treatment?

Twenty-nine papers relating to this question were retrieved. Only four of these related to cancer. The majority applied to non-cancer-related primary- or secondary-care (n=15), or the tertiary setting (n=8). Other focuses included cardiovascular health, mental health and maternal health. Studies addressing this question primarily reported on findings of qualitative research. (More details are provided in **Table 3.1.1**.)

None of the included studies provided in-depth discussion explicitly on the impact of the Aboriginal identification question in relation to health service engagement, health-seeking behaviour, early discharge or discontinuation of treatment. Only one quote was identified which explicitly highlighted sentiments around the question in relation to service utilisation:

> *"We should only need to answer the question (Are you Aboriginal or Torres Strait Islander?) once. The data systems should talk to one another. I won't go back there if I keep getting asked if I'm Aboriginal. I already told you. Doesn't Government believe me?"* [208, p. 24]

It cannot be concluded whether this sentiment is representative of the broader community, and it was not highlighted as one of the key findings of that study.

The COAG's Cultural Respect Framework 2016-2026 considers Indigenous identification as key to health service access and the uptake of health interventions.[86] Some studies in the present review considered that information on health service utilisation relies on accurate data, and therefore not collecting (by asking the question) and/or recording Indigenous status may result in apparent underutilisation of services by Aboriginal people.[179, 209] Other studies reported on providers' and other practice staff perceptions that no or few Aboriginal clients attend the service, and therefore not appreciating the importance of knowing patients' Indigenous status or considering a need to offer culturally appropriate services.[106, 210-213]

In other studies, asking the question, and subsequently identifying Aboriginal patients, was seen by both providers and clients as important in offering/providing additional relevant services such as referral to an Aboriginal Health Worker or actioning Indigenous-specific healthcare initiatives (e.g. 715 Health Check, Indigenous-specific vaccination schedule).[114, 214-216]

Much of the literature sourced in the current review has reported on factors (most often barriers as opposed to enablers) affecting Indigenous identification, not dissimilar to that which has been previously published on this topic.[217-219] Many of these factors are in common with those reported to impact upon health service engagement, health-seeking behaviour, early discharge or discontinuation of treatment by Aboriginal people. Discharge against medical advice (DAMA) has been cited as an indirect measure of the responsiveness of hospital services to Aboriginal peoples' needs;[86] reasons for and prevention of DAMA among Aboriginal patients has been explored in greater detail by Shaw and the Aboriginal Policy Directorate,[220, 221] and in **Sections 2.1 and 2.2** relating to access and completion of cancer treatment.

Factors reported to influence health service utilisation and/or Indigenous identification include, but are not limited to:

- Previous negative experiences within health services, including racial bias and other negative attitudes from practitioners and staff.[126, 208, 215, 216, 222-233]
- Historical factors and distrust in the system.[126, 220, 222, 224, 225, 228, 230, 231]
- An unwelcoming or culturally unsafe environment.[220, 226, 234]
- Absence/presence of Aboriginal personnel within services.[220, 221, 231, 233, 235-237]
- Communication and language barriers - for Indigenous identification, this can include the way the question is asked (wording, tone, orally, on a form) and whether an explanation is provided as to why collecting the information is important and how it will be used.[208, 230, 231, 238, 239]

It is noted that these factors are largely interrelated,[221] and therefore 'asking the question' itself may not be a deciding factor but rather relate to the setting in which it occurs.

For instance, culturally safe and appropriate environments have been reported by Aboriginal interview participants to improve health service engagement and utilisation,[188, 240, 241] and similarly, factors including cultural safety, competence, awareness and appropriateness of health services and staff were often raised in qualitative research exploring the issue of Indigenous identification.[126, 216, 232] Some documents explicitly made this link, for example:

> *"The extent to which Aboriginal patients identify themselves as Aboriginal to ED staff and levels of incomplete ED attendance among Aboriginal patients are considered indirect measures of the cultural appropriateness of ED service provision."* [242, p. 5]
>
> *"identifying Aboriginal patients is the first step toward culturally appropriate care."* [126, p. 933]
>
> *"…well-evidenced ways to measure quality of care and cultural safety [include:] Information technology systems that support the recording of Aboriginal status and communication between staff and departments"* [76, p. 74]

Indigenous identification is also considered in several documents alongside or in addition to cultural safety and cultural appropriateness. See **Section 3.3** and **Table 3.3.2** for further detail.

In summary, there is no clear indication that the Indigenous status question itself has an impact on health service engagement, health-seeking, early discharge or discontinuation of treatment. However, failure to ask the question can result in apparent underutlisation of health services, and prevent the offer and provision of culturally appropriate services which in turn may impact upon these decisions.

The context and setting in which the Indigenous status question is asked plays an important role in a person's decision to identify as Aboriginal and their health seeking/service utilisation. Improvements in cultural competence and safety are required within health services to facilitate identification and improvements in service delivery.

3.2. What are the systems in place in cancer services for self-identification and data management?

Nineteen studies addressed the question regarding systems in place for data management and Indigenous identification; five of these related specifically to cancer. (See **Table 3.2.1** for more information.)

Across the identified studies, there was limited detail provided on actual systems relating to data management. Four studies cited variations in or a lack of effective or standardised information management systems as a challenge in identifying Indigenous patients, specifically within the general practice or cardiac rehabilitation settings.[211, 233, 243, 244] Extensive work has been conducted within the general practice setting regarding improvements to clinical software systems to support Indigenous identification,[212, 218, 245] however to date, no sector-wide changes were identified in the literature.

The present review identified several studies reporting on service-level practices and process relating to Indigenous identification, which were either in place or had been previously undertaken. These were largely reported in limited detail, as often they were only some of many other points raised during interviews in relation to service delivery. Those relevant to Indigenous identification included:

- Staff education and training including cultural awareness/competency training, asking the question and using software to record and retrieve data on Indigenous status.[117, 126, 246-249]
- Hard-copy and electronic resources for staff including resource folders and prompt cards related to asking the question.[210, 246]
- Introduction of service-level goals and policies to encourage and ensure collection of Indigenous status by staff.[117, 209, 233, 241, 244, 250]
- Changes to the way in which Indigenous status is collected, either through a change in staff approach, or modifying paper-based data collection forms.[233, 251]
- Engagement with Aboriginal staff members to complement or correct known missing or inaccurate data.[235, 236]
- Data validation exercises, including cross-checking against other reliable sources of data, e.g. Indigenous Mental Health Worker Register.[236, 252]
- Provision of information to patients and the wider Aboriginal community about why the question is being asked and how the information is used.[210, 250]

Participant and/or author suggestions for improvement reflected the above.[210, 216, 232, 253, 254]

Studies that involved implementation and evaluation of such strategies are discussed in **Section 3.3**.

There were also a number of resources identified within the grey literature regarding asking the question, however evidence of their use and implementation in practice is limited (aside from where reported in intervention studies, see **Section 3.3**). Examples of such resources include:

- AIHW *National best practice guidelines for collecting Indigenous status in health data sets*.[255]
- State health department online training modules e.g. [256, 257]
- Training resources from other organisations e.g. RACGP [258]

These and others are summarised in further detail in **Table 3.2.2**.

3.3. What are the best practice models for cultural safety and engaging patients in self-identification?

It is noted that there are several existing documents, plans and guidelines which make consideration of cultural safety and/or Indigenous identification. Although the link is not always explicit, neither occurs in isolation. Relevant documents are summarised in **Table 3.3.2**.

Whilst many of these are based on best practice principles or identify priorities or strategic directions, we obtained limited, if any, evidence of their implementation in practice.[76, 123, 259] Thus, in addressing this question, we considered "best practice models" to be those initiatives or strategies which had been implemented and evaluated with demonstrated positive impact.

Nineteen studies were identified, only one of which was indirectly related to cancer (Quitline service delivered by Cancer Council Tasmania). The majority were conducted in the primary care setting. While none reported directly on cultural safety as an outcome, several reported on components of this, which included improvements in Indigenous identification by the service and self-identification by Aboriginal people. See **Table 3.3.1** for further detail.

The majority of strategies or initiatives incorporated some form of cultural awareness training for staff. Other projects explicitly incorporated training on Indigenous identification. Whilst the importance of cultural respect training was recognised, it was considered insufficient on its own to improve Indigenous identification.[229, 231] Similarly, the display of Aboriginal images alone was not considered sufficient on its own to encourage Aboriginal patients to identify as such.[233]

Although not always discussing cultural safety and Indigenous identification together, the strategies/initiatives identified which reported effectiveness and/or improvements were nearly always multi-component in nature, comprising a combination of the following:

- Addressing the knowledge and attitudes of staff via cultural awareness and competency training.[75, 123, 212, 238, 239, 242, 260, 261]
- Provision of training and support in the use of information systems to record Indigenous status.[212]
- Practical resources containing key messages/prompts related to asking the question, for use by practitioners and other staff in the workplace (e.g. mouse-mat, signs/stickers for workstations).[123, 233, 260]
- Changes to policy and/or procedures (e.g. updating new patient registration forms, approach to asking the question, participation in training, setting of targets).[75, 188, 212, 214, 238, 242, 262-264]
- Creating safe and inviting spaces by prominently displaying, for example, artwork, an Acknowledgement of Country statement, Aboriginal and Torres

Strait Islander flags, and culturally appropriate resources.[212, 226, 238, 262, 265]

- Employment of and working together with Aboriginal staff within the health service.[75, 123, 188, 233, 261-269]
- Engagement with Aboriginal people and communities to promote services, raise awareness and develop processes for change.[75, 123, 188, 233, 238, 242, 262]
- A commitment from staff and management.[188, 212, 238, 265]

Reported outcomes included:

- improvements in service utilisation by Aboriginal people.[75, 123, 188, 226, 261, 262, 264, 268]
- identification of Aboriginal patients by staff, completeness of records, and self-identification by Aboriginal people.[212, 233, 238, 242, 263, 266]
- cultural appropriateness of the service.[75, 242, 265]
- patient experience,[123, 188, 268, 269] including feeling safe and comfortable to identify.[212, 242]
- processes and procedures within services to facilitate collection and recording of indigenous status.[184, 188, 233, 242, 262, 263]
- confidence and attitudes around asking the question among providers.[212, 214, 233, 238, 260, 268, 269]

Conclusion

This Desktop Review has identified and critically analysed the existing evidence and knowledge in three priority areas relevant to improving cancer outcomes for Victorian Aboriginal Communities: 1) participation in clinical trials and research; 2) culturally safe and effective cancer treatment; and 3) self-identification and data quality. Gaps in the literature have also been identified, and potential next steps highlighted.

Targeted strategies addressing the level of Aboriginal people's participation in clinical trials and research are required. While some progress has been made in terms of the number of Aboriginal-specific clinical trials being conducted, there remain many gaps.

Improving Aboriginal identification and ensuring culturally safe and effective cancer treatment for Aboriginal people with cancer both require multiple strategies across many levels to improve outcomes. Both service innovation and ongoing research and evaluation are needed.

Strategies and actions to accelerate progress across the three priority areas must be led by Aboriginal people, as Aboriginal leadership and engagement are essential and indispensable elements for success. It is therefore critical to ensure that appropriate structures and supports are in place to facilitate the genuine inclusion of Aboriginal people and organisations in determining future directions.

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List of Appendices

Appendix A. Methods

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Appendix A - Methods

A1. Improving Aboriginal participation in clinical trials and research

1. Australian New Zealand Clinical Trials Registry (ANZCTR)

As part of describing the current level of participation by Aboriginal and Torres Strait Islander people in clinical research, a search of the Australian New Zealand Clinical Trials Registry (ANZCTR: www.anzctr.org.au) was undertaken to identify clinical trials involving Aboriginal and Torres Strait Islander people and/or organisations (such as Aboriginal Community Controlled Health Organisations and Aboriginal Community Stores).

The ANZCTR is a *primary registry* for the registration of clinical trials in Australia and New Zealand and elsewhere. It contributes data to the Australian Government's Australian Clinical Trials on-line database (www.australianclinicaltrials.gov.au) and the Australian Cancer Trials database (http://www.australiancancertrials.gov.au), as well as to the World Health Organisation's International Clinical Trials Registry Platform (ICTRP: https://www.who.int/ictrp/en/). The ANZCTR also links to information from the US National Library of Medicine's clinical trials registry (https://clinicaltrials.gov) for trials with sites in Australia and/or New Zealand.

Trials were identified using the following approach:

Search terms	**Aborigin* OR Torres Strai* OR Indigenous**
Registry	ANZCTR OR ClinicalTrials.gov
Study type	Interventional (as opposed to Observational)
Countries of recruitment	Australia (+/- other countries)

A total of 213 trials were identified, including 195 from ANZCTR and 18 from ClinicalTrials.gov. Duplicates (n=6) and trials not involving Aboriginal and/or Torres Strait Islander people and/or organisations either exclusively or substantially were excluded (n=68). 'Substantially' was defined to mean that the trial description gave at least some indication that the level of involvement of Aboriginal and/or Torres Strait Islander people and/or organisations in the trial was likely to allow for Indigenous-specific results. When the level of involvement was not clear from the title of the trial, a search of the full on-line record was undertaken.

There remained 139 trials for inclusion. Information about these trials is presented according to current status in **Table 1.1.3**.

2. Peer reviewed literature

Three groups of searches of the peer-reviewed literature were undertaken. The *Primary Search* related to Aboriginal and Torres Strait Islander Australians. *Supplementary Search A* focused on Indigenous groups in other countries, and *Supplementary Search B* focused on other underrepresented groups (e.g. ethnic minority groups) in English-speaking countries. Search strategies and results are detailed below. (Note: Searches of the Cochrane Library, iPortal and Google Scholar are described in separate sections below.)

a. Australian Aboriginal and Torres Strait Islander people

This search was intentionally broad, in order to maximise sensitivity at the expense of specificity. Only terms relating to *Main population* and *Main focus* were used. Databases searched included: PubMed; EBSCOhost (PsycINFO, CINAHL, SocIndex); and Informit (Health Collection). Search terms were as follows:

	(a) Keywords	(b) MESH Terms
1) Main population	Indigen* OR Aborigin* OR Torres Strai* OR First Nation* OR First People*	“Oceanic Ancestry Group”[mh]
2) Main focus	trial* OR randomi* control* trial* OR randomi* clinica* trial* OR clinical stud*	“Clinical Trials as Topic”[mh]

In general terms, the search included *Main population* (1a OR 1b) AND *Main focus* (2a OR 2b), although slight changes were required for specific databases. To reduce the large number of irrelevant records, proximity operators were used in Informit, (using !) and EBSCOhost (using N1) to ensure that keywords were next to one another (e.g. ‘Torres’ and ‘Strai*’ or ‘First’ and ‘Nation*’). For Informit and EBSCOhost, a wildcard term was used to allow either s or z in ‘randomised’, and the word ‘control*’ was not used. A proximity operator between words (%5 or N5, or !) was used to ensure that the words ‘randomised’ and ‘trial’ or ‘clinical’ and ‘study’ appeared near one another.

After eliminating duplicates, a total of 920 articles were available for screening of titles and abstracts. This was performed using Rayyan, a free web-based application developed by the Qatar Computing Research Institute (available at: http://rayyan.qcri.org). An additional 10 duplicates were identified in Rayyan and were excluded. Another 899 articles were excluded for one or more of the following reasons: wrong population (not Australian Aboriginal and/or Torres Strait Islander people, and not relevant to Supplementary Search A or B, as records identified in the Primary Search were considered duplicates in these later searches); wrong study design (not interventional research); wrong outcome (not related to participation); wrong publication type (conference report or thesis); or Aboriginal-specific research. In consultation with the project steering group, individual Aboriginal-specific research projects were deemed to be outside the scope of the review. Eleven articles underwent full-text review and 4 were subsequently excluded. There remained 7 articles for inclusion, 4 of which were relevant to the *Primary Search* (Couzos et al. 2005; Glover et al. 2014; Morris 1999; Sabesan & Zalcberg 2018), 1 of which was relevant to *Supplementary Search A* (Selak et al. 2013) and 2 of which were relevant to *Supplementary Search B* (Ford et al. 2005; Ghebre et al 2014).

b. Indigenous groups in other countries

Databases searched included PubMed and Informit (Health Collection). Search terms were as follows:

	(a) Keywords	(b) MESH Terms
1) Main population	Aborigin* OR Indigen* OR Maori OR Metis OR Eskimo OR Yupik OR Inuit* OR Inupiat* OR Tribe* OR Tribal OR First Nation* OR American Indian* OR Native America* OR Native People* OR Native Population*	"Oceanic Ancestry Group"[mh] OR "Indians, North American"[mh] OR "Alaska Natives"[mh] OR "Inuits"[mh]
2) Main focus **(same as Primary Search)**	trial* OR randomi* control* trial* OR randomi* clinica* trial* OR clinical stud*	"Clinical Trials as Topic"[mh]
3) Secondary focus	participat* OR criteri* OR exclud* OR exclusion OR includ* OR inclusion OR barrier* OR improv* OR access* OR increas* OR enabl* OR recruit*	Patient Selection"[mh] OR "Patient participation"[mh]
Limits	Date=2010-2019 Language=English	

In general terms, the search included *Main population* (1a OR 1b) AND *Main focus* (2a OR 2b) AND *Secondary focus* (3a OR 3b), although slight changes were required for specific databases. Date (2010-2019) and language (English) limits were applied.

To reduce the large number of irrelevant records, proximity operators were used in Informit (using !) to ensure that keywords were next to one another (e.g. 'Native' and 'America*' or 'First' and 'Nation*'). Also, for Informit, a wildcard term was used to allow either s or z in 'randomised', and the terms 'trial' and 'control*' were not used. A proximity operator between words (%5 or !) was used to ensure that the words 'randomised' and 'trial' or 'clinical' and 'study' appeared near one another.

After eliminating duplicates, a total of 140 articles were available for screening of titles and abstracts in Rayyan. Of these, 136 were excluded for one or more of the following reasons: wrong population; wrong study design; wrong outcome. Of the remaining 4 articles identified for full-text review, 1 was potentially relevant for Supplementary Search A, 1 was potentially relevant for Supplementary Search B, and 2 were potentially relevant for both A and B. Following full-text review, two of the articles were excluded, and two were included (Sprague et al. 2013; Trinh-Shevrin et al. 2018).

c. Other underrepresented groups

Databases searched: PubMed only. Search terms were as follows:

	(a) Keywords	(b) MESH Terms
1) Main population	Underrepresented OR minorit* OR underserve* OR ethnic* OR CALD	“Ethnic Groups”[mh] OR “Vulnerable Populations”[mh] OR “Cultural Diversity”[mh] OR “Minority Groups”[mh]
2) Main focus **(same as primary search)**	trial* OR randomi* control* trial* OR randomi* clinica* trial* OR clinical stud*	“Clinical Trials as Topic”[mh]
3) Secondary focus **(same as Supp. Search A)**	participat* OR criteri* OR exclud* OR exclusion OR includ* OR inclusion OR barrier* OR improv* OR access* OR increas* OR enabl* OR recruit*	Patient Selection”[mh] OR “Patient participation”[mh]
4) Condition	cancer OR neoplas* OR malignan*	“Neoplasms”[mh]
Limits	Date=2010-2019 Language=English Publication type=Review	

The search included *Main population* (1a OR 1b) AND *Main focus* (2a OR 2b) AND *Secondary focus* (3a OR 3b) AND *Condition* (4a OR 4b). Date (2010-2019) and language (English) limits were applied. A geography limit was applied in the initial stages of the search, using the following MESH Terms: “Australia”[mh] OR “New Zealand”[mh] OR “United States”[mh] OR “Canada”[mh] OR “United Kingdom”[mh] OR “Ireland”[mh]. However, this was found to eliminate too many relevant articles (in large part because many US-based articles are not categorised as such using a MESH Term) and was subsequently removed.

Initial screening of the articles indicated that there had already been several relevant reviews of work in this area. Reviewing all of the original research reports would require a large input of time and effort, with only minor marginal benefits at best, in an area that was outside the main focus of the Desktop Review. Therefore, following discussion with the project steering group, it was agreed to limit the scope of this search to reviews.

After eliminating duplicates, a total of 239 articles were available for screening of titles and abstracts in Rayyan. Of these, 222 were excluded for one or more of the following reasons: wrong population; wrong outcome. The remaining 17 articles were identified for full-text review, 8 of which were subsequently excluded. There remained 9 review articles eligible for inclusion in addition to those already identified through the *Primary Search* and *Supplementary Search A* (Ahaghotu et al. 2016; Chen et al. 2014; Duma et al. 2018; Heller et al. 2014; Napoles et al. 2017; Rivers et al. 2013; Salman et al. 2016; Schmotzer et al. 2012; Symonds et al. 2012).

3. Cochrane Library Systematic Reviews

A search of the Cochrane Library's Systematic Reviews was conducted to identify relevant reviews. Several combinations of keywords were used to search titles, abstracts and keywords, including the following:

- Indigenous OR Aborigin* OR Torres (n=15 reviews; 0 relevant)
- Recruitment AND trial AND minority (n=35 reviews; 0 relevant)
- Participation AND trial AND minority (n= 320 reviews; 0 relevant)
- Recruitment AND trial AND ethnic (n= 0 reviews)
- Participation AND trial AND ethnic (n= 0 reviews)
- Recruitment AND trial AND Aboriginal (n=0 reviews)
- Participation AND trial AND Aboriginal (n=35 reviews; 0 relevant)
- Recruitment AND trial AND Indigenous (n=0 reviews)
- Participation AND trial AND indigenous (n=7 reviews; 0 relevant)
- Recruit AND trial AND improve (n=331 reviews; 3 relevant: Treweek et al. 2018; Preston et al. 2016, Brueton et al. 2013)
- Recruit AND trial AND increase (n=323 reviews; 0 additional relevant)

The 'Search related content' option for the above relevant reviews yielded one additional reference (Rendell et al. 2007).

4. Cochrane Library Trials

A search of the Cochrane Library's Trials collection was undertaken using the search terms: Aboriginal OR Aborigine OR (Torres AND Strait) NOT Canada.

A total of 294 records were identified. Of these, 101 were duplicates of articles previously identified in the search of peer-reviewed literature described in section 2a above, and 36 were trial protocols already identified through the search of ANZCTR (as described in section 1, above). Another 54 were not about Australia, and 36 were conference abstracts or letters. The remaining 67 were screened and all were excluded, because they did not report on interventional research and/or they reported on Aboriginal-specific research.

5. iPortal

A search of the University of Saskatchewan's Indigenous Studies Portal Research Tool (iPortal: https://iportal.usask.ca/) was undertaken to identify additional references relating to Indigenous groups, whether in Australia or in other countries, from both the peer-reviewed and grey literature.

The following keyword combinations were searched:

- cancer AND trial (n=4 articles; 2 potentially relevant: Boesch 2002; Rogers & Petereit 2005)
- clinical AND trial AND participation (n=0 articles)
- clinical AND trial (n=6 articles; no additional relevant articles beyond those identified above)
- trial AND participation (n=2 articles; 0 relevant)
- research AND participation (n=184 articles; 0 relevant)
- cancer AND study (n=49 articles; 0 relevant)
- study AND recruitment (n=22 articles; 1 potentially relevant: Stoddart et al. 2000)
- cancer research (n=38 articles; no additional relevant articles beyond those identified above)
- research study participation (n=40 articles; 0 relevant)
- Aboriginal research participation (n=70 articles; 0 relevant)
- clinical AND research (n=49 articles; no additional relevant articles beyond those identified above)
- random* AND trial (n=15 articles; 1 potentially relevant: Saini & Quinn 2013)

Only one article (Saini & Quinn 2013) included information about Aboriginal and Torres Strait Islander people in Australia. It was included in the review. The other three articles were outside the relevant time limits for research relating to Indigenous groups outside of Australia (2010-2019) and therefore not eligible. However, one of these related to a Patient Navigation program involving Native Americans and was included (Rogers & Petereit 2005).

6. Google Scholar

Several supplementary searches were undertaken using Google Scholar. For each search, the first 10 pages of results were screened using the title and, where necessary, the abstract. If new eligible articles were identified on pages 9 or 10, then screening was to continue until there were two consecutive pages with no new eligible articles identified. In practice, it was not necessary to go beyond the first 10 pages for any search. Exclusion criteria were more relaxed than for the searches reported above. For example, reviews that were about clinical trials in general (rather than cancer specific) could be included if they were focused on a relevant population group and explored enablers as well as barriers. Articles that reported on programs and initiatives related to increasing trial participation or otherwise shed light on a specific aspect of relevance to the questions were also considered for inclusion. The search terms used are shown below.

Primary:

- (Aboriginal OR Torres Strait OR Indigenous) AND (trial OR clinical study) AND (participation OR participate OR exclude OR exclusion OR include OR inclusion OR barrier OR criteria OR improve OR access OR increase OR enable OR recruit) (1 potentially relevant and not previously identified)
- Participation in clinical trials Indigenous (3 potentially relevant)
- Participation in clinical trials Aboriginal (2 potentially relevant)
- Participation in clinical trials Torres Strait Islander (1 potentially relevant)

A total of 7 new articles were identified for full-text screen; 5 were included (Whop et al.; Seifer et al.; McMahon et al.; Guillemin et al.; Jamieson et al.)

Supplementary Search A:

- (Maori OR First Nation OR Metis OR Native American OR American Indian) AND (trial) AND (participation OR participate OR exclude OR exclusion OR include OR inclusion OR barrier OR criteria OR improve OR access OR increase OR enable OR recruit). Publication date 2010 to present. (1 potentially relevant)
- Participation in clinical trials Maori (1 potentially relevant)
- Participation in clinical trials Native American (0 potentially relevant)
- Participation in clinical trials “First Nation” (0 potentially relevant)

2 new articles were identified for full-text screen; neither was included.

Supplementary Search B:

- (minority OR minorities OR ethnic OR CALD) AND (trial OR clinical study) AND (participation OR participate OR exclude OR exclusion OR include OR inclusion OR barrier OR criteria OR improve OR access OR increase OR enable OR recruit) AND (cancer) Publication date 2010 to present. (3 potentially relevant)

- Participation in clinical trials minorities (2 potentially relevant)
- Participation in clinical trials ethnic (1 potentially relevant)
- Participation in clinical trials CALD (5 potentially relevant)

11 new articles were identified for full-text screen; 5 were included (Lwin et al., Hughson et al.; Smith et al; Bonevski et al.; Stanaway et al.).

7. Grey Literature

Potentially relevant websites were identified based on the project team's knowledge of the field. This was supplemented by conducting a Google search using the terms 'clinical trials Australia' and 'clinical trials Aboriginal site:.au'.

Websites that were cancer-related were searched using search terms that included 'Aboriginal', 'Torres Strait Islander' and 'Indigenous'. If necessary, the term 'trials' was added to narrow the search.

For other websites, 'trials' was the primary search term. If appropriate, search terms including 'cancer', 'Aboriginal', 'Torres Strait Islander' and 'Indigenous' were added.

The following websites were searched:

- Commonwealth Health Department
- Cancer Australia
- Australian Government Department of Industry, Innovation and Science
- Australian Commission on Safety and Quality in Health Care
- Australian Institute of Health and Welfare
- Australian Bureau of Statistics
- Council of Australian Governments
- National Health and Medical Research Council
- Therapeutic Goods Administration
- Health Departments of Victoria, NSW, Qld, SA, WA, Tasmania, ACT, NT
- Victorian Cancer Agency
- Victorian Comprehensive Cancer Centre
- Cancer Institute NSW
- NACCHO and affiliates: VACCHO; AHMRC; QAIHC; AHCSA; AHCWA; TAC; Winnunga Nimmityjah Aboriginal Health Service; AMSANT.
- Australian Medical Association
- Clinical Oncology Society of Australia
- RACGP
- AIDA
- Medicines Australia
- Australian Healthcare and Hospitals Association
- Australian Indigenous HealthInfoNet
- Lowitja Institute
- AIATSIS

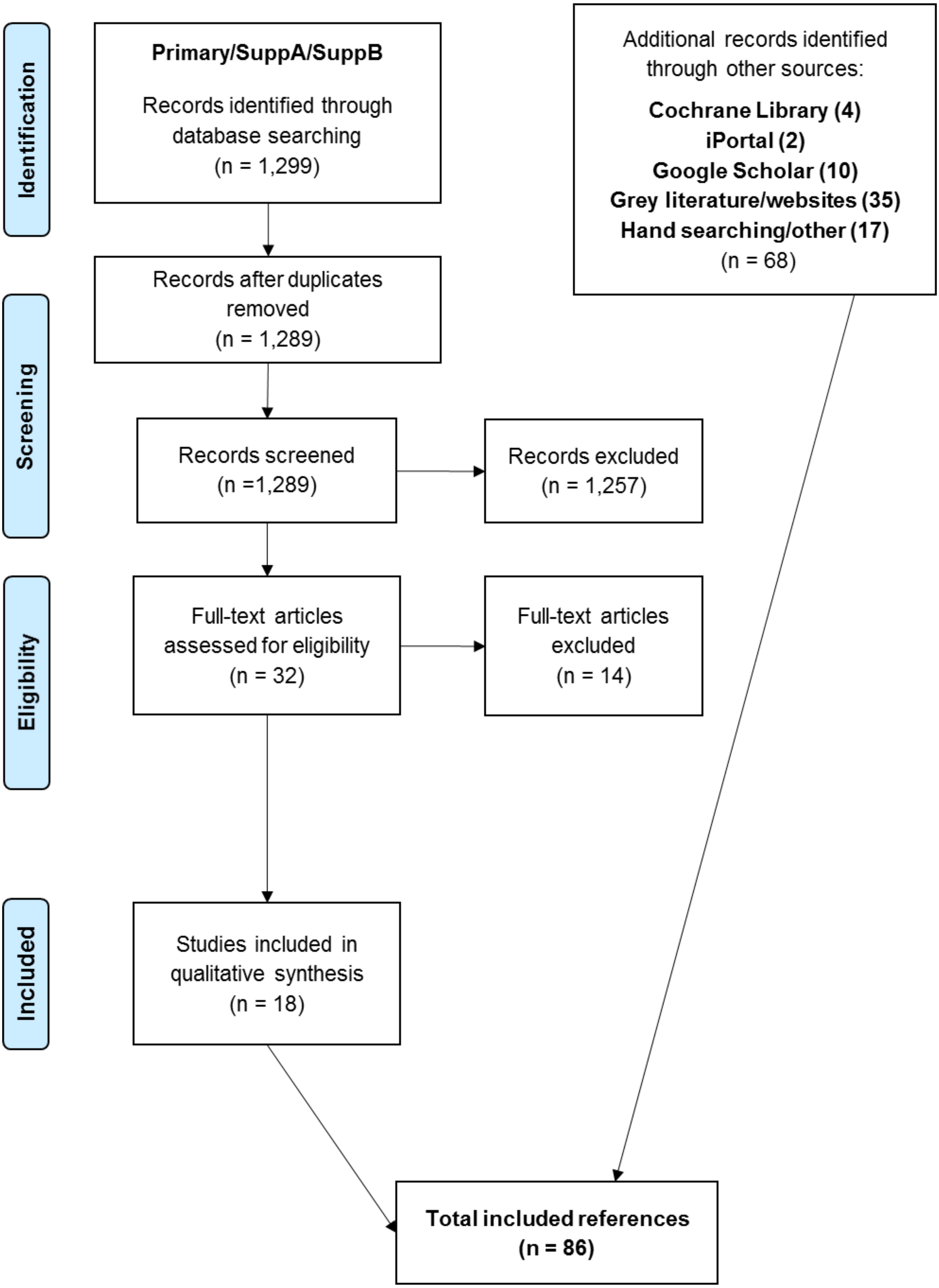
- Research Australia
- Cancer Council Australia; Cancer Council Victoria; Cancer Council NSW; Cancer Council Qld; Cancer Council SA; Cancer Council WA; Cancer Council Tasmania; Cancer Council ACT; Cancer Council NT
- NICAN - National Indigenous Cancer Network
- Cancer Voices Australia
- Australian and New Zealand Clinical Trials Registry (ANZCTR)
- Australian Cancer Trials portal
- Australian Clinical Trials portal
- Australian Clinical Trials Alliance
- Cancer Trials Australia
- ClinTrial Refer
- Health Direct
- Australian Clinical Research Network
- NHMRC Clinical Trials Centre
- Australian and New Zealand Children's Haematology/Oncology Group
- Australia New Zealand Gynaecological Oncology Group
- Australasian Leukaemia & Lymphoma Group
- Australasian Lung Cancer Trials Group
- Australasian Sarcoma Study Group
- The Australia and New Zealand Melanoma Trials Group
- Australian and New Zealand Urogenital and Prostate Cancer Trials Group
- Breast Cancer Trials
- CareSearch Palliative Care Knowledge Network
- Cooperative Trials Group for Neuro-Oncology
- Primary Care Collaborative Cancer Clinical Trials Group
- Psycho-oncology Co-operative Research Group
- Trans Tasman Radiation Oncology Group
- Ovarian Cancer Australia
- Lymphoma Australia
- Rare Cancers Australia
- Lung Foundation Australia
- Melanoma Institute Australia
- Leukaemia Foundation
- Bowel Cancer Australia
- Breast Cancer Network Australia
- Prostate Cancer Foundation of Australia
- Menzies School of Health Research
- SAHMRI
- QIMR Berghofer
- Bureau of Health Information, NSW
- Croakey
- Churchill Trust
- National Cancer Institute (USA)
- NCI Community Oncology Research Program
- American Cancer Society
- National Academies of Sciences, Engineering and Medicine (USA)
- Native American Cancer Research Corporation
- US National Library of Medicine

Following review of items identified through the website search, 15 web pages and 20 documents and reports were included in the review. Most of these related to the clinical trials landscape in Australia and Victoria, or to guidelines on Aboriginal and Torres Strait Islander health research.

8. Hand search of reference lists of included publications

Reference lists of included publications were searched for potentially relevant citations. As with the Google Scholar search described above, exclusion criteria were more relaxed than for the main search. As a result, 15 additional publications were included (Brooks et al. 2015; ENACCT and CCPH, 2008; Fouad et al. 2014; Fouad et al. 2016; Ford et al. 2008; Ford et al. 2013; Guadagnolo et al. 2009; Hamel et al. 2016; Hodge et al. 2000; Ibrahim & Sidani 2014; LaVallie et al. 2008; Petereit et al. 2004; Petereit et al. 2011; Sabesan et al. 2011; Society for Women's Health Research & United States Food and Drug Administration Office of Women's Health, 2011). A new review published after the search was conducted was also identified and included (Nipp et al. 2019), and an Australian paper on access to clinical trials was identified and included (Carey et al. 2017), making a total of 17 publications.

9. Summary of inclusions



A2. Improving culturally safe and effective cancer treatment for Aboriginal people with cancer

<u>1. Peer reviewed literature</u>

Two groups of searches of the peer-reviewed literature were undertaken. The Primary Search related to Aboriginal and Torres Strait Islander Australians and cancer. Cancer prevention was not a focus of this search, as the questions centred around care and treatment. A secondary search related to cultural safety in the Australian healthcare context, focused on Victoria, to address **Q2.4**. Search strategies and results are detailed below. (Note: Searches of the Cochrane Library and Google Scholar are described in separate sections below.)

<u>a. Australian Aboriginal and Torres Strait Islander people and cancer</u>

Only terms relating to Main population, Main focus and Secondary focus were used. Databases searched included: PubMed; EBSCOhost (PsycINFO, CINAHL, SocIndex); and Informit (Health Collection). For each database, the following limits were applied: the location of Australia; English language; and a publication date after 01/01/2010. Search terms were as follows:

	(a) Keywords	(b) MESH Terms
1) Main population	Indigen* OR Aborigin* OR Torres Strai* OR First Nation* OR First People*	"Oceanic Ancestry Group"[mh]
2) Main focus	cancer OR neoplas* OR malignan* OR palliat* OR radiotherapy OR chemotherapy	"neoplasms"[mh]
3) Secondary focus	treatment OR surviv* OR barrier* OR complet* OR access* OR improv* OR increas* OR enabl* OR optimal OR experien* OR satisfact* OR pattern*	"Health Services, Indigenous" [mh] OR "Outcome and Process Assessment (Health Care)" [mh] OR "Delivery of Health Care" [mh] OR "trust"[mh] OR "Patient-Centered Care" [mh] OR "Treatment outcome"[mh]

In general terms, the search included Main population (1a OR 1b) AND Main focus (2a OR 2b) AND Secondary focus (3a OR 3b), although slight changes were required for specific databases. To reduce the large number of irrelevant records, proximity operators were used in Informit, (using !) and EBSCOhost (using N1) to ensure that keywords were next to one another (e.g. 'Torres' and 'Strai*' or 'First' and 'Nation*').

After eliminating duplicates in Endnote, a total of 274 articles were available for screening of titles and abstracts. This was performed using Rayyan, a free web-based application developed by the Qatar Computing Research Institute (available at: http://rayyan.qcri.org). An additional 12 duplicates were identified in Rayyan and were excluded. Of the remaining 262 articles, 178 articles were excluded for one or more of the following reasons: wrong population (did not report on Australian Aboriginal and/or Torres Strait Islander people); wrong study design; wrong outcome (not related to cancer, primary care, or chronic disease); or peripheral to the questions. Of the remaining 84 articles which underwent full-text review, 26 were subsequently excluded. There remained 58 articles for inclusion.

b. Australian Aboriginal and Torres Strait Islander people and cultural safety

Only terms relating to Main population and Main focus were used. Databases searched included: PubMed; EBSCOhost (PsycINFO, CINAHL, SocIndex); and Informit (Health Collection). For each database, the following limits were applied: the location of Australia; English language; and a publication date after 01/01/2010. Search terms were as follows (both cultural safety and cultural competence were included in this search, due to the common use of both terms):

.	(a) Keywords	(b) MESH Terms
1) Main population	Indigen* OR Aborigin* OR Torres Strai* OR First Nation* OR First People*	"Oceanic Ancestry Group"[mh]
2) Main focus	cultural* safe* OR cultural* competen*	"cultural competency" [mh] "culturally competent care" [mh] "Health Services, Indigenous" [mh] "Medicine, Traditional" [mh] "trust" [mh]

After eliminating duplicates in Endnote, a total of 279 articles were available for screening in Rayyan. Five further duplicates were removed, leaving 274 articles for title and abstract review. Of these, 251 were excluded for one or more of the following reasons: wrong population; wrong study design; wrong outcome, lack of specificity. Of the remaining 23 articles, nine had already been reviewed in part a, leaving 14 new articles. Following full-text review, 14 articles were included.

2. Cochrane Library

A search of the Cochrane Library was conducted to identify relevant research. Keywords as tabled above were used to search titles, abstracts and keywords. MeSH descriptors [Oceanic Ancestry Group], [Neoplasms] and [Australia] were used, with the ‘explode all trees’ function. One article not previously identified was included (Banham et al. 2018).

For Question 2.4, a keyword search of titles, abstracts and keywords using the Main Population terms as tabled above, date and location limits, together with MeSH descriptor [Cultural competency], and the term ‘cultural* safe*’ did not yield any additional relevant items.

3. Google Scholar

Several supplementary searches were undertaken using Google Scholar. For each search, the first 10 pages of results were screened using the title and, where necessary, the abstract. If new eligible articles were identified on pages 9 or 10, then screening was to continue until there were two consecutive pages with no new eligible articles identified. The first search went to 16 pages before there were two consecutive pages with no new eligible articles identified. The second search lacked specificity and did not yield any new results. The search terms used were:

(Aboriginal OR Torres Strait OR Indigenous) and cancer

(Aboriginal OR Torres Strait OR Indigenous) and cultural safety or cultural competence.

One new article was identified for full-text screen (Murphy et al. 2015) and included.

4. Grey Literature

Potentially relevant websites were identified based on the project team’s knowledge of the field. This search yielded many reports or documents which could be considered framework or context related, with potential for significant overlap. After discussion with the Project Steering Group, inclusion of such documents were limited to Victorian and national documents. These are reported separately in **Table 2.0.2**.

Cancer-related websites were searched using terms including ‘Aboriginal’, ‘Torres Strait Islander’ and ‘Indigenous’. Due to the variety of formats and search results, judgements were frequently made regarding how best to search a particular website. This resulted in the use of tabs such as ‘Reports’ or ‘Publications’ to search for additional data if using the standard ‘search’ function yielded no results or results lacking specificity. The following websites were searched:

- Commonwealth Health Department
- Health Departments of Victoria, NSW, Qld, SA, WA, Tasmania, ACT, NT

- Council of Australian Governments
- Cancer Australia
- Australian Commission on Safety and Quality in Health Care
- Australian Institute of Health and Welfare
- Victorian Cancer Agency
- Victorian Comprehensive Cancer Centre / Peter MacCallum Cancer Centre
- Victorian Cancer Survivorship Program
- Victorian Regional Integrated Cancer Services (RICS)
- Cancer Institute NSW
- NACCHO and affiliates: VACCHO; AHMRC; QAIHC; AHCSA; AHCWA; TAC; Winnunga Nimmityjah Aboriginal Health Service; AMSANT.
- Australian Medical Association
- Clinical Oncology Society of Australia
- National Health and Medical Research Council
- ABS
- RACGP
- AIDA
- Indigenous Allied Health Association
- Australian Healthcare and Hospitals Association
- Australian Indigenous HealthInfoNet
- Lowitja Institute
- AIATSIS
- Cancer Council Australia; Cancer Council Victoria; Cancer Council NSW; Cancer Council Qld; Cancer Council SA; Cancer Council WA; Cancer Council Tasmania; Cancer Council ACT; Cancer Council NT
- NICAN - National Indigenous Cancer Network
- Psycho-oncology Co-operative Research Group
- Menzies School of Health Research
- SAHMRI
- QIMR Berghofer Medical Research Institute
- Bureau of Health Information, NSW
- Conference proceedings: World Indigenous Cancer Conference 2016
- Conference proceedings: Lowitja Institute International Indigenous Health and Wellbeing 2019; Patient Experience Symposium NSW 2018 and 2019; Health Services Research Assoc PROMs PREMs Forum 2018.

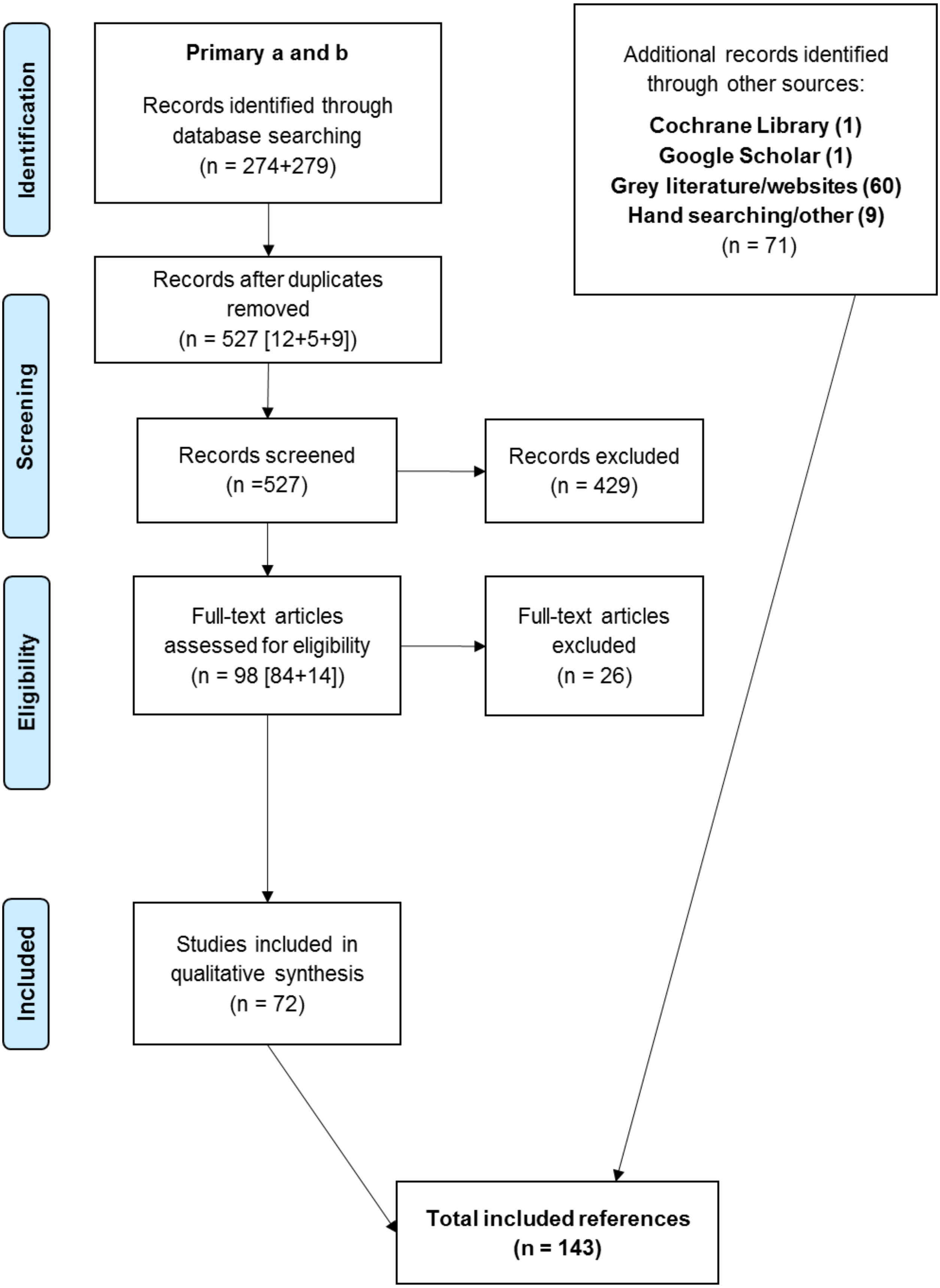
Following review of items identified through the website search, 45 reports or websites and 15 articles were included in the review.

5. Other mechanisms

a) A hand search of reference lists of included publications during full text review resulted in the inclusion of 6 additional articles (Cross et al. 1989; Williams et al. 1999; Clifford et al. 2015; Durey, Thompson et al. 2012; Durey, Wynaden et al. 2012; Gibson et al. 2015). Two additional articles were included, one published after the initial search (Liaw et al. 2019) and an Australian review about traditional medicine use in Indigenous cancer patients was identified (Gall et al. 2018).

b) Conference proceedings: One relevant presentation from a recent conference was included.

6. Summary of inclusions



A3. Improving Aboriginal people's self-identification and the quality of cancer data

1. Peer reviewed literature

A search of the peer-reviewed literature was undertaken in April 2019 to answer the following research questions:

a) What is the impact of Aboriginal identification questions on: (i) Aboriginal engagement or disengagement in health services (primary and tertiary care), (ii) health-seeking behaviour (iii) early discharge, and (iv) discontinuation of treatment?

b) What are the systems in place in cancer services for self-identification and data management?

c) What are the best practice models for cultural safety and engaging patients in self-identification?

Databases searched included: PubMed; EBSCOHost (PsycINFO, CINAHL and SocIndex); Informit (Health Collection) and the Cochrane Library. The search included Population (1a OR 1b) AND Identification as the main focus (2a OR 2b) AND Data acquisition and interaction with health service as the secondary focus (3a). The search was limited to Australia (4b), and to publication dates from 01/01/2010.

As described in the methods for **Q1**, proximity operators were applied in Informit and EBSCOhost where applicable.

	(a) Keywords (title/abstract)	(b) MESH Terms
1) Population	Indigen* OR Aborigin* OR Torres Strai* OR First Nation* OR First People*	"Oceanic Ancestry Group"[mh]
2) Main focus	status OR identif* OR origin OR descent OR question	"Patient Identification Systems"[mh]
3) Secondary focus	access* OR engage* OR report* OR collect* OR complet* OR record* OR request* OR ask* OR provide* OR inform* OR quality OR data OR coverage OR participa* OR accuracy OR accurate*	
4) Location		"Australia"[mh]

After eliminating duplicates, a total of 2,689 articles were available for screening of titles and abstracts. As for the other research questions, screening was performed using Rayyan, a free web-based application developed by the Qatar Computing Research Institute (available at: http://rayyan.qcri.org). Following screening on title/abstract, 298 articles were retrieved for full-text review. 219 were excluded for one or more of the following reasons: wrong population (not Australian Aboriginal and/or Torres Strait Islander people); wrong outcome (not related to Indigenous identification, health service utilisation, cultural safety and/or data management); wrong focus (administrative data, non-healthcare setting). There remained 30 articles for inclusion. A further 49 studies were indirectly related to the research questions; these were summarised separately and not included in the main qualitative synthesis.

2. Google Scholar

A supplementary search was conducted in Google Scholar using the terms (Aboriginal OR Torres Strait Islander OR Indigenous) AND identification. The first 10 pages of search results were screened using the title and, where necessary, the abstract or full text. If new eligible articles were identified on pages 9 or 10, then screening was to continue until there were two consecutive pages with no new eligible articles identified. In practice, the first 14 pages were searched. A total of 16 new articles were identified for full-text screen; 4 were included.

3. Hand search of included publications

Other potentially relevant publications were identified via citations during full-text review of included publications. These publications were sourced and abstracts or full texts reviewed. Three of these were included (Josif, Liaw, Schutze 2014).

4. Grey Literature

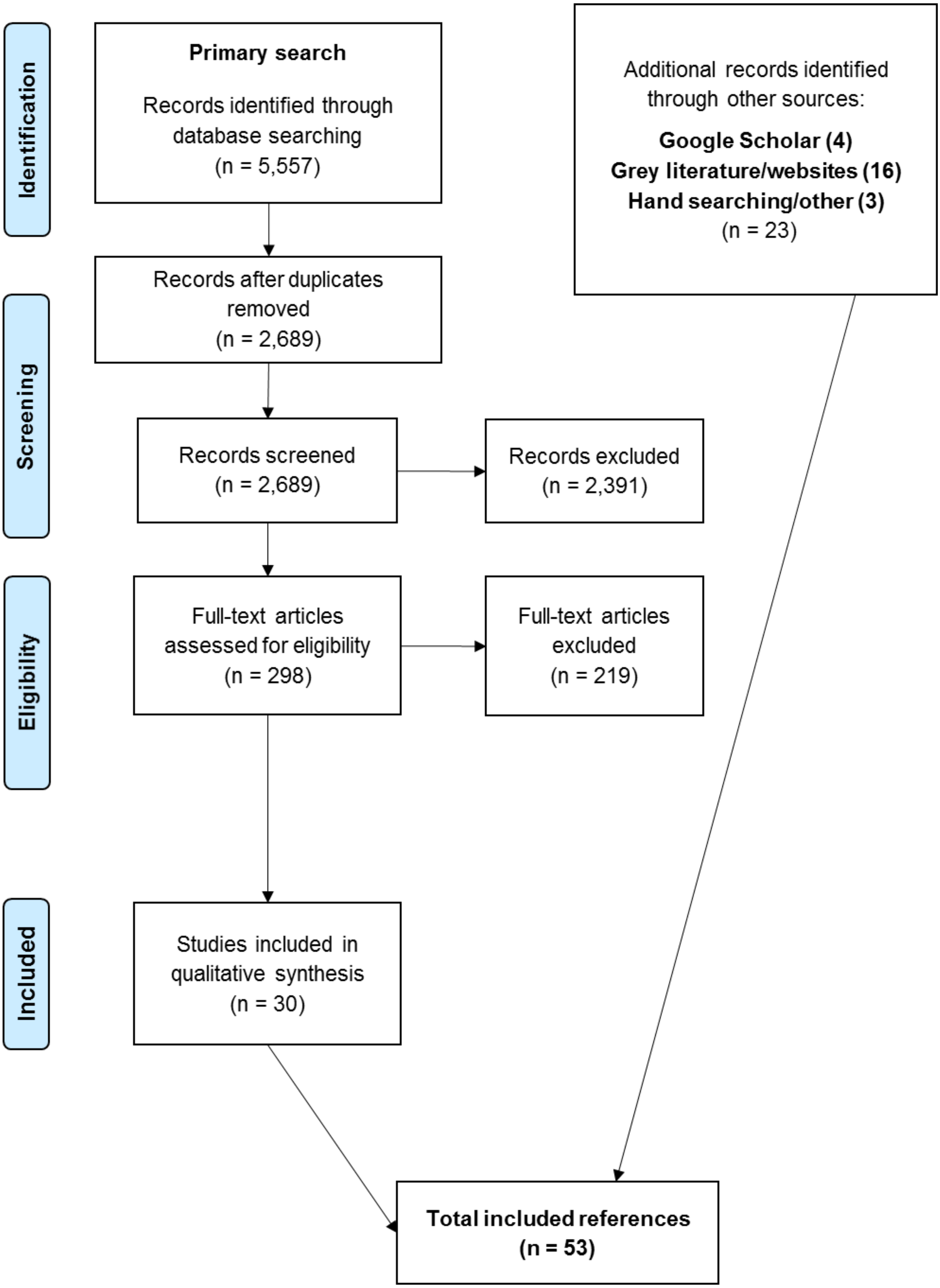
Potentially relevant websites were identified based on the project team's knowledge of the field.

Website search functions (where present) were used in the first instance; keywords included 'Aboriginal', 'Torres Strait Islander', 'Indigenous', 'identification' or 'status'. In addition, where websites had dedicated sections for Aboriginal and/or Torres Strait Islander health, or Publications and Resources, these were manually scanned for relevant documents. An initial keyword search as per above was conducted for each potentially relevant document, followed by full text scan where required to confirm relevance. The following websites were searched:

- Commonwealth Health Department
- Health Departments of Victoria, NSW, Qld, SA, WA, Tasmania, ACT, NT
- Council of Australian Governments
- Cancer Australia
- Australian Commission on Safety and Quality in Health Care
- Australian Institute of Health and Welfare
- Victorian Regional Integrated Cancer Services (RICS)
- Cancer Institute NSW
- NACCHO and affiliates: VACCHO; AHMRC; QAIHC; AHCSA; AHCWA; TAC; Winnunga Nimmityjah Aboriginal Health Service; AMSANT.
- Australian Bureau of Statistics
- Royal Australian College of General Practitioners
- Australian Indigenous Doctors Association
- Australian Healthcare and Hospitals Association
- The Heart Foundation
- Australian Indigenous HealthInfoNet
- Lowitja Institute
- Australian Institute of Aboriginal and Torres Strait Islander Studies
- Cancer Council Australia; Cancer Council Victoria; Cancer Council NSW; Cancer Council Qld; Cancer Council SA; Cancer Council WA; Cancer Council Tasmania; Cancer Council ACT; Cancer Council NT
- Menzies School of Health Research
- McCabe Centre for Law and Cancer
- Bureau of Health Information, NSW

Following review of items identified through the website search, 16 references were included.

5. Summary of inclusions



Appendix B - Tables

List of Tables

Table 1.1.1 The clinical trials landscape in Australia and Victoria.

Author	Description	Key findings
NATIONAL		
Department of Health, n.d. [2]	Clinical Trials – current and recent activity	Current/recent initiatives relating to clinical trials. 1) Clinical Trials Project Reference Group (CTPRG) - formerly the Clinical Trials Jurisdictional Working Group (CTJWG) - strategic leadership. Involves senior members from Commonwealth, State/Territory, NHMRC. Works with industry, consumers, registries, other stakeholders. Aim is 'streamlined and consistent national approach to clinical trials within Australia with the intention of enhancing health outcomes and building Australia's ability to attract national and international clinical trials.' Current implementation plan has 5 objectives: ' streamline coordination units and innovation; harness national networks and partnerships; improve clinical trials data and knowledge systems; embed research as essential health system business; enhance capacity and consistency of ethics approvals.' 2) COAG Health Council Revitalised Clinical Trials Agenda. April 2016 statement (see below). 3) National Clinical Trials Governance Framework (see below) - national consultation under way. 4) ANZCTR review by Aspex Consulting in 2018. Report being considered by Government. 5) National Aggregate Statistics - reporting on time required to gain ethics and governance approvals for trials in 5 jurisdictions. Second report in 2017 for 2015-16. Recruitment metrics NOT reported. 6) Clinical Trials Collaborative Forum - meets twice a year. 7) Report on 'Scoping and analysis of recruitment and retention in Australian Clinical Trials' by Ernst and Young (EY) in 2016 (see below). 8) Critical success factors - Health Outcomes International (HOI) consultancy in 2015 to assess key issues relating to success/failure of CTs in Australia (see below). 9) Independent Hospital Pricing Authority has developed standard costings for clinical trials. 10) Industry liaison - meetings held with key stakeholders in Sydney and Melbourne in 2015.
COAG Health Council, 2016 [1]	Revitalised Clinical Trials Agenda	Agreed principles: 'The patient is at the centre of clinical trials; Research and clinical trials are essential health system activities; clinical trials foster a culture of quality, safety and innovation; access for patients must be made easier - participation, navigation and delivery; partnerships and collaboration are at the core of any success; workforce support is central - capacity, capability and predictability, career pathways; knowledge and transparency - KPIs, data, accountability, value offer.' Under Networks and Partnership, is mention of 'working with Aboriginal and Torres Strait Islander groups'. Also mentions that 'effective consumer engagement will be a key element of such partnerships...' Under Research as essential health system business, mentions possibly using KPIs in performance agreements and corporate governance mechanisms.

Health Outcomes International, 2015 [4]	Analysis of case studies of recently conducted trials (2010-2015) - critical success factors	Under-recruitment and timeliness of approvals are major challenges. Report notes that 'trials specifically affecting the health and wellbeing of Aboriginal people and communities' are NOT eligible for the National Mutual Acceptance (NMA) scheme for ethics approval. Delays in ethics and governance approvals are problematic, even WITH the NMA scheme.
EY, 2016 [3]	Issues and solutions in recruitment and retention in Australian clinical trials - scoping and analysis for Clinical Trials Jurisdictional Working Group. National and international scan, literature review, stakeholder (n>150) workshops, patient (n=16) and public (n=17) interviews, 2015-2016	Scan and lit review identified: individual issues (e.g. perceived inconvenience, lack of awareness); barriers relating to design and conduct (e.g. lack of trial-dedicated staff, difficulty identifying suitable participants); and potential strategies (e.g. staffing, training, networking, awareness raising, better communication, early engagement with consumers, better design, using registries, social media, etc.). Very limited data on participation and retention rates for Australian trials (although oncology better than other areas), but there is evidence of widespread difficulties in meeting recruitment targets in Australia and internationally. Decrease in number of Phase III trials between 2009 and 2013. 14 recommendations provided regarding leadership & coordination, support for clinical trials, leading practice and performance ('how to'), awareness of clinical trials, and regulation and safety. Note Recommendation 9: 'The CTJWG, the NHMRC and research entities to focus on clinical trial recruitment and retention strategies in special groups such as culturally and linguistically diverse (CALD) communities, youth, Indigenous Australians, rural and remote communities, and people with a mental illness...' (p.5) Recognition that these populations are 'generally excluded from meaningful participation in clinical trials in Australia.' (p.32), and that strategies relating to trial design/conduct, eligibility criteria and methods of recruiting are needed. '...no single strategy that will improve recruitment and retention in Australian clinical trials. Rather, recruitment and retention must be considered together with the systemic, structural and cultural factors shaping the Australian clinical trials environment ant the national, jurisdictional and institutional level.' (p.6) Tele-trials, need for interpreters mentioned. Strong agreement that patient safety is of primary importance. For Indigenous people, barriers include: health literacy levels, mistrust, lack of engagement in protocol design, inflexibility and complexity of trial protocols. Need to partner with ACCHOs; use informal networks to build trust; use alternative communication approaches (e.g. pictures) and local languages. 'Stakeholders identified a high need for the establishment of an Indigenous clinical trial network to support trial design, recruitment and conduct.' (p. 24)
Askie et al., 2017 [270]	Description of the clinical trials landscape in Australia, 2006-15.	Describes registered trials recruiting in Australia, using data from ANZCTR and ClinicalTrials.gov. 18% were cancer trials; 47% were drug trials; 75% were treatment trials; 33% were multinational; median sample size=96.
National Health and Medical Research	Clinical trial reform	Among several areas being addressed by the NHMRC are improving research governance timeliness and efficiency, and increasing the efficiency of ethics approval processes (in part through the development of the Human Research Ethics Application, a national application form – see below).

Council, n.d. [271]		
National Health and Medical Research Council, n.d. [5]	The Human Research Ethics Applications	The Human Research Ethics Application form is an important component of the National Mutual Acceptance (NMA) Scheme, which is now operating in several jurisdictions. Under the NMA Scheme, a single ethics review replaces the previous requirement for multiple reviews for multiple sites. This applies to 'most human research'.
Australian Clinical Trials, n.d. [6]	National Approach to Single Ethical Review of Multicentre Research	The need for review by multiple ethics committees for research conducted in multiple sites can extend the start-up time for trials. The National Approach to Single Ethical Review of Multicentre Research was set up to enable a single ethics review for multi-site research undertaken in Australian, including across jurisdictions.
Cancer Australia, n.d. [267]	Clinical Trials	Cancer Australia supports several multi-site Collaborative Clinical Trials Groups. Program aims to increase number of, and participation in, clinical trials in Australia, and increase involvement of consumers, clinicians, researchers and policy makers in trial development. Cancer Australia also supports the Australian Cancer Trials portal in partnership with ANZCTR.
Cancer Australia, n.d. [18]	National Cancer Control Indicators	Adult clinical trial participation ratio' is one of the nominated National Cancer Control Indicators. 'The number and proportion of adult cancer patients enrolled in clinical trials is currently not known in Australia. As a result, an understanding of the unwarranted variation in clinical trial participation between population groups is also not known.' There is not 'a strong evidence base' for policy to increase participation. Under Data Availability: 'There are currently no national data available for this indicator. Cancer Australia is progressing the development of this indicator.
Psycho-oncology Co-operative Research Group, n.d. [19]	Cancer Australia evaluation framework for National Cancer Collaborative Trials Groups	Minimum Dataset page refers to Cancer Australia's evaluation framework for National Cancer Collaborative Trials Groups (CCTGs) which requires demonstrating the participation of patients from private sector sites, non-metropolitan locations, Aboriginal, Torres Strait Islander and Culturally and Linguistically Diverse backgrounds in clinical trials: "As part of the Australian Government's commitment to rural and remote, Aboriginal and Torres Strait Islander (ATSI) and Culturally and Linguistically Diverse (CALD) health, it is requested that the Multi-site Collaborative National Cancer Clinical Trials Groups which Cancer Australia funds record for each clinical trial participant: post code, ATSI status, country of birth, and language spoken at home. These populations have distinct issues relating to cancer, for example increased incidence of specific co-morbidities, difficulties in treatment adherence and delays in diagnosis. This information will allow for improved understanding of the study population and the coverage of clinical trials. Only summative

		information on remoteness, ATSI and CALD status will be reported from this data in order to protect individual’s identities. In the future the collection of this information, subject to additional ethics approval, will also enable the aggregation of data across trials, allowing further research into specific issues relating to these at risk populations.”
Australian Commission on Safety and Quality in Health Care, n.d. [7]	National Clinical Trials Governance Framework consultation	Development and consultation under way. Final Framework expected nid-2019. Clinical trials must be: high-quality, integrated, consumer-focused, undertaken in a safe environment. Improved governance will result in improved trial start up times, greater transparency, more cohesion, and greater productivity across the sector.
McInerney, 2019 [8]	National Clinical Trials Governance Framework consultation	Discusses the context and rationale for the proposed National Clinical Trials Governance Framework (see above). Key point: 'The draft framework also aims to embed processes to ensure that Aboriginal and Torres Strait Islander people and those from culturally and linguistically diverse (CALD) backgrounds are not disadvantaged in research, either by being excluded or through a lack of cultural safety.' Also: The standards in the framework will be requirements under the National Safety and Quality Health Service Standards for hospitals (public and private) that do clinical trials.
Wardliparingga, 2017 [75]	National Safety and Quality Health Service Standards as they apply to Aboriginal and Torres Strait Islander people	Six actions to specifically meet the needs of Aboriginal and Torres Strait Islander people. 1) 'The health service organisation works in partnership with Aboriginal and Torres Strait Islander communities to meet their healthcare needs'; 2) 'The governing body ensures that the organisation's safety and quality priorities address the specific health needs of Aboriginal and Torres Strait Islander people'; 3) ' The health service organisation implements and monitors strategies to meet the organisation's safety and quality priorities for Aboriginal and Torres Strait Islander people'; 4) The health service organisation has strategies to improve the cultural awareness and cultural competency of the workforce to meet the needs of its Aboriginal and Torres Strait Islander patients'; 5) The health service organisation demonstrates a welcoming environment that recognised the importance of cultural beliefs and practices of Aboriginal and Torres Strait Islander people'; 6) The health service organisation has processes to routinely ask patients if they identify as being of Aboriginal and/or Torres Strait Islander origin, and to record this information in administrative and clinical information systems'. No specific mention about clinical trials or research more broadly.

Cancer Australia, 2018 [9]	Optimal Care Pathway for Aboriginal and Torres Strait Islander people	In several places in the OCP, there is mention of clinical trial participation. For example, 'Where practical, patients should be offered the opportunity to participate in research or clinical trials at any stage of the care pathway' (p.17) and 'To achieve equity in the participation rate of Aboriginal and Torres Strait Islander people in clinical trials, clinicians should use culturally appropriate resources to better inform patients about the benefits of trials.' (p.17) There is recognition of the special ethical requirements for research involving Aboriginal and Torres Strait Islander people ('that protect the cultural needs...'), and reference is made to the need to provide 'fair opportunity' for participation in trials by Aboriginal and Torres Strait Islander people (p.41). It is noted that tele-trials may be a means of improving access. There is a list of topics that should be included in communication between the lead clinician and the patient's GP, one of which is 'enrolment in research or clinical trials' (p.50).
Clinical Oncology Society of Australia, 2016 [14]	Australasian Tele-trial Model	Describes the model and implementation considerations for tele-trials using the established tele-oncology approach. Core principles are to increase accessibility especially, but not exclusively, for rural and remote patients (trials closer to home); develop collaboration and networking to enhance clinical trials activity; and create relationships between sites to establish trial clusters. The additional ethics requirements for special populations (including Aboriginal and Torres Strait Islander people) are noted.
VICTORIA		
Dept of Health and Human Services, Victoria, 2016 [10]	Victorian Cancer plan, 2016-2020	Improving access to clinical trials is a priority under the Plan. Stated focus for 2016-2020 includes: 'Improve equity of access to clinical research." The page on improving outcomes for Aboriginal Victorians does NOT mention clinical trials. The plan does mention better understanding of the barriers to participation and improving patient and GP awareness of clinical trials, as well as the need to focus on system-wide improvements and infrastructure.
Dept of Health and Human Services, Victoria, 2018 [91]	Victorian Cancer plan monitoring and evaluation framework, 2016-2020	see 'Report' below
Dept of Health and Human Services, Victoria, 2018 [11]	Victorian Cancer plan monitoring and evaluation framework: Report	Number of new enrolments in cancer intervention clinical trials is one of three measures under the indicator "Embedded research into the health system". (Others under this indicator are "Number of recruiting cancer intervention clinical trials" and "Number of human research ethics committee approved cancer-related studies".) BUT all are listed as Not Applicable with respect to disaggregation by Aboriginal status.

Dept of Health and Human Services, Victoria, 2018 [12]	Healthier Lives, Stronger Economy: Victoria’s Health and Medical Research Strategy, 2016-2020	Enhancing a world-leading clinical trials system' is one of 6 key strategic directions. Objective is to 'optimise performance …by improving timeliness, reliability and efficiency of clinical trial processes'. (p.vi) Cancer is named as a recognised area of research strength in Victoria, which will be enhanced through investment. This includes funding a "Streamlining Clinical Trial Research Program" in DHHS to 'consolidate administrative functions of clinical trials'. Key areas to address in order to meet the objective 'optimise the performance of the Victorian clinical trials sector and position the state as the premier destination for clinical trials in the Asia-Pacific region' include: 'streamlined and timely ethics approval; support for common approaches within and between institutions; reliability in meeting participant recruitment targets and completing a trial within the agreed timeframe; accuracy in data collection and a process for reporting clinical trial performance across the state.'
Victorian Comprehensive Cancer Centre, n.d. [15]	Tele-trials	VCCC Tele-trial Program base on COSA Tele-trials model, taking into account specific of Victorian requirements. "regional consumers have been consulted throughout the tele-trial implementation…' - no mention about Aboriginal people. Initial trial involving a cluster with one metro site and two regional sites (Albury-Wodonga and Bendigo) will be evaluated. 'Tele-tools are a key tool for reducing barriers, such as time, cost and social disruption, for regional patients' access to cancer clinical trials.' 12 December 2018 News item: implementation under way in Albury Wodonga and Bendigo.
Cancer Council Victoria, n.d. [17]	Victorian Cancer Trials Link, Trial Connect	VCTL is a searchable database of Victorian cancer clinical trials. It commenced in 2009. Trial Connect is a peer support program that matches trained volunteers with people wanting information about being in a trial. Volunteers must have participated in at least one trial.
Cancer Trials Australia, n.d. [13]	Victorian Regional Cancer Clinical Trials Network	Victorian Regional Cancer Clinical Trials Network established in 2017, includes 6 regional sites: Ballarat Health-BRICC; Barwon Health - Andrew Love Cancer Centre; Bendigo Health - Bendigo Cancer Centre; Border Medical Oncology; Goulburn Valley Health - Peter Copulos Cancer and Wellness Centre; South West Healthcare - SWRCC. Supported by Cancer Council Victoria in partnership with Cancer Trials Australia.
Commonwealth Health Department, n.d. [16]	new funding announced by the Health Minister (media release 22 March 2019)	$24.6m Commonwealth government funding to support the Australian Clinical Trials Network's TrialHub. Partnerships between Alfred/Monash and regional hospitals to extend reach. First hospitals to participate will be Rosebud, Casey and Bendigo. Initial focus on rare cancers, melanoma and prostate cancer.
McCarthy, 2017 [21]	Barriers and enablers for access to cancer clinical trials for cancer patients in the Loddon	Loddon Mallee Region is about 57K sq km, with about 300k people, and about 2000 new cancer cases per year. Clinical trials 'a component of gold-standard health care with well-described benefits for both patients and the health system.' (p.1) Trials for patients in the region are mostly conducted in Bendigo and Melbourne. This report looked at medical oncology and radiotherapy trials. Main barriers to participation included distance

	Mallee Region. Interviews with key stakeholders, data from Vic Cancer Registry and data from relevant clinical trials centres (Peter Mac, Royal Melbourne, Bendigo Health)	and travel. Differences in participation rates by area: Macedon Ranges LGA and Bendigo LGA much higher than Mildura LGA and Swan Hill LGA. Clinicians identified a range of other barriers including: lack of patient awareness, higher workload, poor communication from Melbourne trial sites, trial design and eligibility criteria, lack of resources. Enablers included: clinician interest, engagement and activity, more information becoming available, multi-disciplinary meetings, champions, local conditions. Given greater complexity re: eligibility, increased awareness may not lead to increased participation. A 2012 assessment indicated lower participation rates for patients in regional integrated cancer services than in metropolitan ones (3% vs 10% - with 20% for WCMICS). Possible solutions include improved travel options, increased awareness, new trial models (e.g. telehealth), sufficient resourcing, referral systems, better communication, better identification of eligible patients. NOTE: NO mention of Aboriginal patients in the report.
OTHER		
Cancer Institute NSW, n.d. [20]	Cancer clinical trials participation	In 2017-18, there were 9 enrolments into cancer clinical trials for every 100 people newly diagnosed with cancer during the same year (up from 8/100 in 2016-17). Huge variation in trial participation rates by Local Health District. Performance Indicators for clinical trials do NOT include reporting of Indigenous status.
Carey et al., 2017 [23]	Cross-sectional survey of medical oncology patients on invitations and consent to participate in a trial	383 patients from 3 centres completed the survey.38% reported they had been invited to participate in a trial, 93% of whom said they consented. Of those who said they had agreed, 89% would do so again. Among 5 Aboriginal/Torres Strait Islander participants, 3 said they had been invited to participate (60%); no figures on consent.
McMahon et al., 2011 [272]	Literature review on willingness of patients, especially rural, to participate in clinical trials - personal characteristics, enabling factors and barriers	Relevant personal characteristics may include age, health status, race/ethnicity, but conflicting evidence about these. No information about Aboriginal participation/recruitment. Personal characteristics of treating doctors may also play a role. Enabling factors include perceived health benefit (versus dislike of randomisation, satisfaction with current treatment), provision of detailed information/knowledge about trial, active recommendation by physician, altruism (so especially important to report trial results). Barriers include dislike of research process, randomisation (gamble), experimentation, understanding informed consent, demanding study protocols, wanting to pick treatment, discouragement by doctor, poor communication, concern re: Quality of Life, side effects. Many of these barriers are amenable to good information process. Unique challenges for rural/remote patients: distance, few trials available. Cites results of Sabesan study on attitudes, knowledge, barriers to participation in North Qld.

Sabesan et al., 2011 [22]	Survey of attitudes, knowledge and barriers to cancer clinical trials among rural and remote cancer patients in Townsville and Mt Isa, 2007-08.	178 participants. Self-completed Qs on patient characteristics, knowledge of clinical trials, willingness to participate in RCTs, possible reasons. Indigenous status not recorded, but study setting suggests it would include a reasonable proportion of Indigenous patients. Rural and remote patients had limited knowledge about clinical trials. Rural and remote similar to regional centre re: willingness to participate. Travel a concern especially for rural/remote. Travel costs and need for family members to accompany patient need to be factored in to trial budget.
Stanaway et al., 2017 [33]	Language-based exclusions in Australian clinical trials	WHO International Clinical Trials Registry Platform data for trials registered in June-August 2015. 21% of Australian-based trials registered in a 3-month period (71 of 342) explicitly excluded people with low English proficiency. (Other trials that did not explicitly state this as an exclusion criterion may still exclude at the consent stage.) Only 1 trial specified the provision of translated materials. Explicit exclusion more likely in mental health, pain trials than in cancer trials.

Table 1.1.2 Reviews of RCTs addressing Aboriginal health needs.

Author	Jurisdiction	Population group	Description	Data sources	Dates	Key findings
Morris, 1999 [24]	Australia	Aboriginal people	Systematic review: describes frequency and design of controlled clinical trials addressing health needs of Aboriginal Australians	Medline, Australasian Medical Index, Aboriginal and Torres Strait Islander health bibliographic database, Aboriginal Health: an annotated bibliography	to 1997	Only 13 RCTs - 12 involving children. The only adult trial had only 11 participants. No evidence of increase in number of published trials over time, or of the establishment of long-term applied clinical research programs which are needed.
Saini & Quinn, 2013 [25]	Canada and other countries	Aboriginal peoples	Systematic review: explores extent to which RCTs have been used, types of interventions, and relevance/applicability of RCTs within Aboriginal communities. Builds on Morris 1999.	Medline, PsycInfo, PsychLit, ClinPsyc, Embase, ASSIA, ERIC, CINAHL, Social Work Abstracts, Social Sciences Abstracts, DAI, Bibliography of Native North Americans, America: History and Life, CSA FRANCIS, IBSS, Library and Archives Canada: Aboriginal Peoples	1999 to 2010	22 studies, most in US and Australia (n=6). 13 of 22 involve children. Obesity, diabetes, mental health and substance abuse, child health, etc. Some interventions were culturally adapted. Findings suggest that Aboriginal people are underrepresented in RCTs. Recommends using participatory methods to increase cultural relevance, enhancing methods to maximise recruitment and retention. Consider how to do research that is consistent with Aboriginal values, expectations, traditions.

Table 1.1.3 Australian trials involving Aboriginal and Torres Strait Islander people and organisations (Source: ANZCTR; Accessed 30 April 2019)

1. Completed trials (N=47)

Scientific Title (Acronym) – Trial Reg. No.	Principal Investigator /Scientific Contact	Intervention codes	Health Conditions	Age range*	Gender	RCT?**	Start Year	End Year	Sample size***
Amoxycillin Versus Placebo for Resolution of Otitis Media with Effusion and Prevention of Acute Otitis Media with Perforation in Aboriginal Infants: A Randomised Controlled Trial. (COMIT1) NCT00539149	John Mathews (MSHR)	Prevention	Otitis Media	0-12 mos	Both	Yes	1996	2001	126
In Indigenous children aged 6 months to 6 years with a diagnosis of acute otitis media, does Azithromycin given as a single dose (compared to 7 days of standard dose amoxicillin) result in a reduction in the proportion of children with signs of persistent disease after treatment? (AATAAC) ACTRN12609000691246	Amanda J Leach (MSHR)	Treatment: Drugs	Acute otitis media in Indigenous children aged 6 months to 6 years	6 mos-6 yrs	Both	Yes	2002		330
Australian Integrated Mental Health Initiative - Evidence based health promotion strategies to people with chronic or recurring mental disorders (CRMD) to improve mental health outcomes, reduce physical risks and promote social and community functioning - NHMRC Health Research	David Kavanagh (IHBI)	Other interventions	Chronic or Recurring Mental Disorders	18+	Both	No	2003		1000

Partnership. (AIMhi) ACTRN12605000531617									
A Clinical Trial of Fish and Fruit to Improve Survival of Aboriginal People with End Stage Renal Disease. NCT00192543	Kerin O'Dea (MSHR)	Behaviour	Cardiovascular Diseases	18+	Both	Yes	2004	2008	152
The effect of a multifaceted high intensity culturally specific intervention incorporating advice, support and nicotine replacement on smoking cessation rates in pregnant Indigenous women: a randomised controlled trial. ACTRN12609000929202	Sandra Eades (Baker IDI Heart and Diabetes Institute)	Behaviour; Lifestyle; Prevention	Smoking in pregnancy	16-50	Females	Yes	2005		270
A quasi-experimental multi-level intervention demonstration project with comparison group to increase community capacity to promote healthy eating and physical activity, measured by changes in community capacity, environments, health behaviours and anthropometry. (HPC: BAEW) ACTRN12609000892213	Michelle Haby (VIC Dept of Health)	Prevention	Overweight and obesity	no limit	Both	No	2006		4500
Among children living in remote communities does a comprehensive primary health care intervention (including fluoride varnish) compared to usual care reduce the incidence of new caries? (STLK: Strong Teeth for Little Kids) ACTRN12609001000291	Peter S Morris (MSHR)	Other interventions; Prevention	Early childhood caries	18 mos - 4 yrs	Both	Yes	2006		700
A randomised trial of nortriptyline, nicotine replacement therapy, and brief cognitive behavioural therapy (CBT) vs.	Robyn Richmond (UNSW)	Prevention	Tobacco Addiction	18+	Males	Yes	2006	2009	425

placebo, nicotine replacement therapy, and brief cognitive behavioural therapy for smoking cessation among prison inmates. ACTRN12606000229572									
PneuMum: A Randomised Controlled Trial of Pneumococcal Polysaccharide Vaccination for Aboriginal and Torres Strait Islander Mothers to Protect Their Babies from Ear Disease. (PneuMum) NCT00714064 / NCT 00310349	Ross Andrews (MSHR)	Other interventions	Acute Otitis Media; Middle Ear Effusion; Pneumococcal Infections; Tympanic Membrane Perforation	17-39	Females	Yes	2006	2011	227
A randomised controlled trial in Indigenous Australian clients of primary health care services of a twelve month intensive multidimensional smoking cessation intervention with a primary end point of sustained cessation at twelve months from the beginning of the intervention. (BOABS Study) ACTRN12608000604303	Julia Marley (UWA/KAMSC Inc	Behaviour; Other interventions	Tobacco smoking	16+	Both	Yes	2008	2011	360
An intervention study for bronchiolitis in Darwin and Townsville - Comparing severity of disease and readmission of infants given azithromycin or placebo. (ABIS) ACTRN12608000150347	Anne Chang (MSHR)	Treatment: Drugs	Bronchiolitis	0-18 mos	Both	Yes	2008	2011	97
Among Indigenous children with bronchiectasis, does weekly azithromycin (compared to weekly placebo) reduce rates of exacerbation? (BIS (Bronchiectasis Interventional Study)) ACTRN12610000383066	Peter Morris (MSHR)	Treatment: Drugs	Bronchiectasis in Indigenous children	12 mos - 8 yrs	Both	Yes	2008	2010	68

In Aboriginal children in remote communities, is oral cotrimoxazole as safe and efficacious as intramuscular benzathine penicillin, in achieving resolution of skin sores? ACTRN12607000592448	Steven Tong (MSHR)	Treatment: Drugs	Impetigo	2 mos - 16 yrs	Both	Yes	2008		30
A randomised controlled trial of a family-centred tobacco control program about environmental tobacco smoke (ETS) to reduce respiratory illness in Indigenous infants. ACTRN12609000937213	David Thomas (MSHR/ Lowitja)	Behaviour	Prevention of environmental tobacco smoke exposure of Indigenous infants; Prevention of respiratory illness among Indigenous infants	0-5 wks	Both	Yes	2009	2012	420
A randomised controlled trial looking at the effects of swimming on chronic suppurative otitis media in Aboriginal aged 5-12 years living in the Northern Territory. (SSSOM) ACTRN12613000634774	Anna Stephen (MSHR)	Treatment: Other	Otitis Media	5-12	Both	Yes	2009	2009	100
A randomised controlled trial of a fixed dose combination medication (Polypill) versus usual care for improved adherence to indicated pharmacotherapy among Indigenous and Non-Indigenous people at high risk of a cardiovascular event. (Kanyini GAP) ACTRN12608000583347	Anushka Patel (George Institute)	Prevention; Treatment: Drugs	Cardiovascular disease; High Risk Cardiovascular Disease; Medication Adherence	18+	Both	Yes	2009		1000

An open label randomised controlled trial to determine if 5 days of once-daily oral trimethoprim-sulfamethoxazole or three days of twice-daily oral trimethoprim-sulfamethoxazole will lead to non-inferior cure rates of impetigo compared to a single dose of intramuscular benzathine penicillin G (the current gold standard treatment) in children living in remote Aboriginal communities between the age of 12 weeks to less than 13 years. ACTRN12609000858291	Jonathan Carapetis (Telethon Institute for Child Health Research)	Treatment: Drugs	Impetigo in Aboriginal children	12 wks - 13 yrs	Both	Yes	2009	2012	663
The effect of lapband surgery on weight loss in diabetic Indigenous Australians. ACTRN12609000319279	Kristine Egberts (Monash Uni)	Treatment: Surgery	Type 2 diabetes	20-60	Both	Yes	2009	2010	30
Pilot study investigating psychometric assessments and feasibility of omega-3 fatty acid supplementation in indigenous children from 2-3 remote Northern Territory schools. ACTRN12609000753257	Natalie Parletta (UniSA)	Treatment: Other	Learning and behaviour in indigenous children from 2-3 remote community schools	4-12	Both	No	2009	2010	47
A randomised controlled trial to determine whether an intervention of annual chlamydia testing in general practice for sexually active men and women aged 16 to 29 years can lead to a reduction in chlamydia prevalence. (ACCEPt) ACTRN12610000297022	Jane Hocking (Melbourne Uni)	Early detection / Screening	Infection with Chlamydia trachomatis	no limit	Both	Yes	2010	2012	52

A randomized, two-arm parallel dietary intervention study to compare the effects of consuming a low glycemic diet or wholegrain high fibre diet on infant birth weight and body composition, complications related to Gestational Diabetes Mellitus (GDM) and progression to GDM diagnosis in women at high-risk of GDM. (GI Baby 3) ACTRN12610000681055	Jennie Brand Miller (Sydney Uni)	Prevention	Gestational Diabetes Mellitus	no limit	Females	Yes	2010	2012	147
Sexually Transmitted Infections (STI) in Remote communities: ImproVed & Enhanced primary health care - A randomised community trial to reduce STIs in remote Aboriginal and Torres Strait Islander communities, comparing clinical care enhanced with a Sexual Health Quality Improvement Program with standard clinical care. (STRIVE) ACTRN12610000358044	John Kaldor (Kirby Institute, UNSW)	Other interventions; Prevention	Sexually transmitted infections	16-34	Both	Yes	2010		21
A group based 12-week physical activity and nutrition program for overweight Aboriginal and Torres Strait Islander women, comparing waist circumference to Aboriginal and Torres Strait Islander women who are wait listed for the program. ACTRN12610000224022	Robyn McDermott (UniSA)	Lifestyle	Obesity. Waist circumference >80cm.	18-64	Females	Yes	2010	2012	100
Amongst hospitalised Indigenous infants with bronchiolitis, does azithromycin (compared to placebo) improve clinical outcomes (length of stay in hospital and duration of oxygen supplementation)? (ABIS2) ACTRN12610000326099	Anne Chang (MSHR)	Treatment: Drugs	Bronchiolitis	0-24 mos	Both	Yes	2010	2013	219

Associations between periodontal disease and cardiovascular surrogate endpoints following periodontal treatment in an adult Indigenous population with moderate/severe periodontal disease. ACTRN12610000817044	Lisa M Jamieson (ARCPOH, Adelaide Uni)	Prevention; Treatment: Other	Cardiovascular surrogate endpoints; periodontal disease	25+	Both	Yes	2010	2012	200
Effects of omega-3 fatty acids on learning and behaviour of children in Indigenous Northern Territory schools: a randomised controlled trial with one-way crossover. ACTRN12611000017921	Natalie (Sinn) Parletta (UniSA)	Lifestyle; Treatment: Other	Attention, learning and behaviour	6-16	Both	Yes	2010	2011	409
Getting better at chronic care in North Queensland: A cluster randomized trial of patient-centred care delivered by Indigenous health professionals to Indigenous clients. ACTRN12610000812099	Robyn McDermott	Behaviour; Lifestyle; Other interventions	Chronic Obstructive Pulmonary Disease; Coronary Heart Disease; Diabetes; Hypertension; Renal Disease	18-65	Both	Yes	2010	2011	213
Do high need primary care patients (those attending an Aboriginal Community Controlled Health Service) rate tailored health risk feedback provided before their GP appointment as more acceptable (in terms of easy to understand, relevant and will help improve health) than generic feedback, and is tailored feedback more effective in terms of being shown and discussed with the patient's GP than generic health risk feedback? ACTRN12614001205628	Christine Paul (Newcastle Uni)	Behaviour; Lifestyle; Prevention	Cancer; Cardiovascular disease	18+	Both	No	2011	2012	200

The TORPEDO study: Use of the HealthTracker Electronic Decision Support System General Practice and Aboriginal Community Controlled Health Services to improve adherence to guideline recommended screening for absolute cardiovascular disease risk and guideline recommended prescribing to individuals at high cardiovascular risk. (The TORPEDO Study) ACTRN12611000478910	David Peiris (George Institute)	Early detection / Screening; Prevention; Treatment: Drugs; Treatment: Other	Cardiovascular diseases and their risk factors; Chronic kidney disease; Diabetes	35+	Both	Yes	2011	2012	38725
Reducing disease burden and health inequalities arising from chronic dental disease among Indigenous children: an early childhood caries intervention. ACTRN12611000111976	Lisa M. Jamieson (ARCPOH, Adelaide Uni)	Prevention; Treatment: Other	Early Childhood Caries	no limit	Females	Yes	2011	2012	446
The effectiveness of a sustained nurse home visiting intervention for Aboriginal infants compared with non-Aboriginal infants and with Aboriginal infants receiving usual child health care: a quasi-experimental trial. (Bulundidi Gudaga) ACTRN12616001721493	Lynn Kemp (Ingham Institute)	Behaviour; Prevention	Body mass index; Breastfeeding; Child development; Child vocabulary development	15-50	Females	No	2011	2013	231
Evaluation of participation of Tasmanian Aborigines in a cardiopulmonary rehabilitation program: a comparison of pre and post measures of physical fitness and quality of life. ACTRN12614000842662	Maureen Davey (Tasmanian Aboriginal Centre)	Rehabilitation	Chronic cardiovascular disease; Chronic obstructive pulmonary disease	18+	Both	No	2011	2013	100

A randomised trial to assess the impact of a price reduction with and without an in-store nutrition education strategy on purchasing of fruit, vegetables, water and diet soft-drinks in remote Northern Territory Aboriginal communities. (SHOP@RIC) ACTRN12613000694718	Julie Brimblecombe (MSHR)	Behaviour	Dietary intake of remote Northern Territory Aboriginal communities	no limit	Both	Yes	2012		20
A randomised, double blind trial of Azithromycin versus Amoxycillin-Clavulate to treat mild to moderate respiratory exacerbations in children with non-Cystic Fibrosis bronchiectasis, Study Two. (BEST - 2) ACTRN12612000010897	Anne Chang (MSHR)	Treatment: Drugs	Bronchiectasis	0-19	Both	Yes	2012	2016	178
A randomised, double blind, placebo controlled trial of Azithromycin versus Amoxycillin-Clavulanic Acid to treat mild to moderate respiratory exacerbations in children with non-Cystic Fibrosis bronchiectasis, Study One. (BEST - 1) ACTRN12612000011886	Anne Chang (MSHR)	Treatment: Drugs	Bronchiectasis	0-19	Both	Yes	2012	2017	197
Does culturally appropriate low back pain information improve the beliefs and perceptions of Aboriginal adults when compared to conventional low back pain information: the My Back on Track, My Future project. ACTRN12613001319763	Ivan Lin (Combined Unis Ctre for Rural Health)	Other interventions	low back pain	18+	Both	Yes	2013	2014	20
Improving delivery of secondary prophylaxis for rheumatic heart disease: a stepped-wedge, community-randomised trial to increase proportion of clients receiving 80% or more of	Jonathan Carapetis (Telethon Institute for	Prevention	Acute Rheumatic Fever;	no limit	Both	Yes	2013	2016	403

scheduled benzathine penicillin G injections. (RHD SP) ACTRN12613000223730	Child Health Research)		Rheumatic Heart Disease						
A controlled pilot trial to evaluate the effect on suicidal ideation and mental health of a self-managed acceptance and commitment therapy based app delivered on tablets for youths with suicidal ideation compared against wait list control. ACTRN12613000104752	Helen Christensen (Black Dog Institute)	Behaviour; Treatment: Devices	Suicidal ideation	18-25	Both	Yes	2013	2014	150
An Evaluation of Telehealth in the Facilitation of Diabetes and Cardiovascular Care for improving disease management in three Aboriginal-Controlled Community Health Organisations in the Northern Territory, Australia. (TEAMSnet (Telehealth Eye and Associated Medical Services network)) ACTRN12616000370404	Sven-Erik Bursell (NHMRC Clinical Trials Centre,)	Treatment: Other	Cardiovascular; Diabetes; Diabetic retinopathy	18+	Both	No	2013	2015	600
A cluster randomised trial to examine the whether the “Ways of Thinking and Ways of Doing (WoTWoD)" Program and Toolkit improves cultural respect and delivery of culturally and clinically appropriate health care to Aboriginal patients in Australian general practice. (WoTWoD Project) ACTRN12614000797673	Siaw-Teng Liaw (Ingham Institute)	Early detection / Screening; Lifestyle; Prevention	Health inequities and culturally inappropriate health care in general practices for Aboriginal Australians.	18+	Both	Yes	2014	2017	58
The effect of omega-3 supplementation on adverse cardiovascular (CV) events among Indigenous Australians with stable coronary artery disease: A	Alex Brown (SAHMRI)	Treatment: Drugs	Atherosclerosis; Coronary Artery Disease; factors associated with thrombus	18+	Both	Yes	2014	2017	89

randomized controlled trial. ACTRN12614000732684			formation; heart rate variability						
A telephone-delivered social well-being and engaged living intervention, compared to a manualised control or a single-session psychoeducation intervention, for improving level of engagement in education, training or employment for disengaged youth. ACTRN12614001212640	Leanne Hides (UQ)	Behaviour; Treatment: Other	Emotional well-being; Social engagement	12-25	Both	Yes	2014	2017	273
Effect of the Alert Program on measures of self-regulation and executive function in primary school aged children in the Fitzroy Valley with fetal alcohol spectrum disorders compared to those without fetal alcohol spectrum disorders. ACTRN12615000733572	James Fitzpatrick (Telethon Kids Institute)	Behaviour	Executive functioning; Fetal alcohol spectrum disorders; Self-regulation	6-13	Both	No	2015	2017	271
A trial to assess the effect of reducing salt in bread on sales and overall salt intake in remote Indigenous Australian communities. ACTRN12616001585415	Emma McMahon (MSHR)	Other interventions	Excess salt intake	no limit	Both	No	2015	2015	26
Model of enhanced clinical governance and peer led targeted support for antenatal care for improving iron deficiency anaemia rates in Aboriginal infants aged six months in the Kimberley region. ACTRN12615001060538	Karen Edmond (UWA)	Behaviour; Prevention	All cause hospitalisation; Child neurodevelopment; Iron deficiency anaemia	no limit	Both	Yes	2015	2018	800
A pilot study to investigate the efficacy, feasibility and safety of once weekly injection of exenatide-LAR in addition to standard diabetes care on blood glucose	Neale Cohen (BakerIDI Heart and	Treatment: Drugs	Type 2 Diabetes	18+	Both	Yes	2016	2017	37

control in indigenous Australians with type 2 diabetes living in remote communities. (LOWER-SUGAR: Long acting Once Weekly Exenatide laR-SUGAR study) ACTRN12615000913572	Diabetes Institute)								
Using behavioural communication to optimise flu vaccination in infant indigenous populations in Victoria. ACTRN12617001315303	Peter Bragge (Monash Uni)	Behaviour; Prevention	Influenza	16+	Both	Yes	2017	2017	6499

* In years, unless otherwise stated. ** RCT, Randomised controlled trial. *** Final if recorded; otherwise target.

2. Trials listed as ‘Stopped early’ (N=8)

Scientific Title (Acronym) – Trial Reg. No.	Principal Investigator /Scientific Contact	Intervention codes	Health Conditions	Age range*	Gender	RCT?**	Start Year	End Year	Sample size - final (target)	Reasons for stopping***; comments
A pragmatic, multi-centre, parallel design (1:1:1), open, randomised controlled trial to evaluate the effectiveness of a simple short message service (sms) vs tailored sms and home visiting compared to usual parent/carer practice to improve the uptake and timeliness of the primary immunisation series in children aged less than 2 years. (PRICKLE BABES STUDY) ACTRN12616000204448	Kerry-Ann O'Grady (Centre for Children's Health Research, QLD)	Behaviour	Immunisation Coverage; Immunisation Delivery; Vaccine Preventable Diseases	12-45	Females	Yes	2016	2018	322 (516)	1,3; Data collected is being analysed; Results of interim analysis indicated early stopping was acceptable.
In patients frequently admitted to hospital does a multi-dimensional transitional care package, compared with usual care, reduce hospital readmission. (ASH RAPP) ACTRN12615000808549	Graeme Maguire (Baker IDI Central Australia)	Prevention	Aboriginal Australian health; chronic non-communicable diseases; Frequent hospital readmission	18+	Both	Yes	2015	2017	113 (210)	1,2,3; Data analysis is complete; Positive results from interim analysis; potential survival benefit identified.

"Gotta be sit down and worked out together"- using participatory action research to test an empowerment intervention addressing the needs of unpaid family carers of Aboriginal older people. (SCSC) ACTRN12614000415606	Dina LoGiudice (Melbourne Health)	Treatment: Other	carer burden; depression; empowerment	18+	Both	Yes	2014	2016	140 (304)	1,2; Data collected is being analysed.
A randomised controlled study of the Health Intervention "SNAP" in Northern Territory prisons- where smoking is banned- to prevent relapse to smoking. (SNAP) ACTRN12617000217303	Kate Dolan (NDARC UNSW)	Behaviour; Lifestyle; Prevention	Alcohol Use; Nutrition; Physical Activity levels; Tobacco Smoking	18+	Both	Yes	2017	2018	557 (824)	1,2; Data collected is being analysed.
The ASQ-TRAK developmental screening tool for Australian Aboriginal children. Determining the reliability and face validity of the ASQ-TRAK and exploring the characteristics of developmental delay in Aboriginal children in urban, regional and remote areas of South Australia. ACTRN12617000553370	Deepa Jeyaseelan (Women's and Children's Hospital, SA)	Early detection / Screening	Developmental delay	1 mos - 4 yrs	Both	No	2017	2018	100 (160)	1; Data collected is being analysed.
Can't Even Quit - A pilot randomised, controlled trial of an mHealth intervention to promote smoking abstinence for Aboriginal and Torres Strait	David Peiris (George Institute)	Behaviour; Treatment: Other	Tobacco use	16+	Both	Yes	2016	2017	49 (200)	2; Data analysis is complete.

Islander people. ACTRN12616001550493										
Evaluating the efficacy and adherence of administration of a PCSK9 inhibitor Alirocumab in Aboriginal participants with hypercholesterolaemia. (IMPACT-LDL) ACTRN12616000871448	Stephen Nicholls (SAHMRI)	Treatment: Drugs	Hyper-cholesterol-aemia	18+	Both	Yes	2016	2018	3 (200)	2; No data analysis planned.
Strengthening health literacy among Indigenous people living with cardiovascular disease, their families, and health care providers. ACTRN12612001309875	Sue Crengle (U Otago)	Prevention	Cardio-vascular disease	20+	Both	No	2013	2013	171 (440)	Partic. size reduced as pool of eligible people at sites was smaller than anticipated; data analysis complete.

* In years, unless otherwise stated. ** RCT, Randomised controlled trial. *** Reasons: 1= Lack of funding /staff /facilities; 2= Participant recruitment difficulties; 3= Other reasons /comments.

3. Trials listed as ‘Active, not recruiting’ (N=6)

Scientific Title (Acronym) – Trial Reg. No.	Principal Investigator /Scientific Contact	Intervention codes	Health Conditions	Age range*	Gender	RCT?**	Start Year	End Year	Sample size***
In Aboriginal children with acute or chronic suppurative otitis media (CSOM), do additional text messaging or phone calls (compared to standard care) improve clinic attendance for ear health checks, a pilot randomised controlled trial. (MOP-UP) ACTRN12610000972022	Amanda Leach (MSHR)	Behaviour; Other interventions; Treatment: Other	Otitis media with perforation of the tympanic membrane.	0-13	Both	Yes	2010		70
Pneumococcal Conjugate Vaccine (PCV) Schedules for the Northern Territory: Randomised Controlled Trial of Booster Vaccines to Broaden and Strengthen Protection from Invasive and Mucosal Infections. (PREV-IX_B) NCT01735084	Amanda Leach (MSHR)	Other interventions	Cough; Febrile Illness Lower Respiratory Tract Infection; Otitis Media; Upper Respiratory Tract Infection	9 mos-3 yrs	Both	Yes	2013	2020	261
A randomised controlled trial of a consumer focussed e-health strategy for cardiovascular risk management in General Practice and Aboriginal Community Controlled Health Services. (CONNECT (Consumer Navigation of electronic cardiovascular Tools)) ACTRN12613000715774	Julie Redfern (George Institute)	Lifestyle; Prevention; Treatment: Other	Cardiovascular disease	18+	Both	Yes	2013	2017	934

Effectiveness, cost-effectiveness and cost-benefit of a single annual professional intervention for the prevention of childhood dental caries in a remote rural Indigenous community. ACTRN12615000693527	Newell W Johnson (Griffith Uni)	Prevention; Treatment: Other	Dental Caries	4-17	Both	No	2015	2015	434
Increasing uptake of evidence-based management of unhealthy alcohol use in Aboriginal primary health care services: a cluster randomised controlled trial. ACTRN12618001892202	Katherine Conigrave (Sydney Uni)	Other interventions	alcohol use disorders; hazardous alcohol use	16+	Both	Yes	2016	2017	22
Healthy Stores 2020: Reducing retail merchandising of discretionary food and beverages in remote Indigenous community stores. (HS 2020) ACTRN12618001588280	Julie Brimblecombe (MSHR)	Behaviour	Obesity; Overweight; Risk of cardiovascular disease; Risk of renal disease; Risk of type 2 diabetes	no limit	Both	Yes	2018	2018	20

* In years, unless otherwise stated. ** RCT, Randomised controlled trial. *** Final if recorded; otherwise target.

4. Trials listed as ‘Recruiting’ (N=44)

Scientific Title (Acronym) – Trial Reg. No.	Principal Investigator /Scientific Contact	Intervention codes	Health Conditions	Age range*	Gender	RCT?**	Start Year	End Year	Sample size***
A randomised controlled study on education intervention for childhood asthma by Aboriginal and Torres Strait Islander Health Workers aiming at reducing the number of unscheduled hospital/doctor visits due to asthma exacerbation during the 12 months follow up period. ACTRN12605000718640	Patricia C Valery (QIMR)	Treatment: Other	Asthma	0-18	Both	Yes	2005		100
A triple-blind, placebo controlled clinical trial which is designed to determine whether a weekly dose of 1 gram oral azithromycin for one year will reduce acute infective exacerbations in adult Aboriginal Australians adults with chronic obstructive pulmonary disease (COPD). ACTRN12605000229673	Graeme Maguire (WACHS)	Treatment: Drugs	Chronic Obstructive Pulmonary Disease (COPD)	18+	Both	Yes	2005		130
Hepatitis B immunity and response to a booster dose of hepatitis B vaccine in Indigenous children who received hepatitis B vaccines in infancy. ACTRN12606000396527	Nicholas Wood (NCIRS)	Prevention	Hepatitis B immunity in healthy subjects	16-19	Both	No	2006		450
A double blind placebo-controlled randomized clinical trial of the use of oral azithromycin in Aboriginal children between 6 months and 30 months of age presenting with asymptomatic acute otitis media	Andre Wattiaux (MSHR)	Treatment: Drugs	Acute otitis media without perforation	6-30 mos	Both	Yes	2007		300

without perforation. (AAAOM) ACTRN12608000424303								
A Randomised Controlled Trial of Medical Prophylaxis for the Prevention of Hypertension, Renal Disease and Diabetes in Australian Aborigines. (Tiwi-PPPP) ACTRN12608000371392	Wendy Hoy (UQ)	Prevention	Diabetes; Hypertension; Renal Disease	18+	Both	Yes	2008	200
The effectiveness of a clinical practice change intervention in increasing, on a health service wide basis, community health clinician adherence to preventive care guidelines; a multiple baseline trial. ACTRN12611001284954	John Wiggers (HNE Pop Health)	Early detection / Screening; Lifestyle; Prevention	Alcohol overconsumption; Clinician delivery of preventive care; Physical inactivity; Poor nutrition; Smoking	18+	Both	No	2009	13500
A before and after study of scabies and strongyloidiasis prevalence in a remote Aboriginal community following the introduction of an ivermectin mass drug administration (MDA) delivered at months 0 and 12. ACTRN12609000654257	Therese Kearns (MSHR)	Early detection / Screening; Prevention; Treatment: Drugs	scabies; strongyloidiasis	0-85	Both	No	2010	2500
Reducing alcohol related facial trauma patients with high risk drinking using Motivational Care Planning START Interventions. (START Brief Interventions project) ACTRN12611000135910	Tricia Nagel (MSHR)	Early detection / Screening; Treatment: Other	Alcohol abuse; Facial Trauma	12+	Both	Yes	2010	154
In Aboriginal and Torres Strait Islander Peoples can an Aboriginal Primary Health Service collaborative intervention increase screening and management of type 2	Chris Paul (Newcastle Uni)	Early detection / Screening; Treatment: Other	Type 2 diabetes	35+	Both	Yes	2011	20

diabetes when compared with usual care. (ADACC) ACTRN12611000518965									
In high-risk Indigenous infants does an early combination schedule of two pneumococcal conjugate vaccines Synflorix and Prevenar13 provide greater pathogen protection than standard single vaccine schedules. (PREVIX_COMBO) ACTRN12610000544077/NCT01174849	Amanda Leach (MSHR)	Prevention	Non-typeable Haemophilus influenzae disease; Otitis media in Indigenous infants; Pneumococcal disease	4 wks-6 wks	Both	Yes	2011		425
The Central Australian Heart Protection Study: A Randomised Trial of Nurse-Led, Family Based Secondary Prevention of Acute Coronary Syndromes. (CAHPS) ACTRN12614000284662	Alex Brown (SAHMRI)	Lifestyle; Prevention; Rehabilitation	Acute Coronary Syndromes	18+	Both	Yes	2011	2013	360
Children in remote Aboriginal communities with silver fluoride applications compared with conventional atraumatic restorative technique in managing deciduous dental caries. ACTRN12611000473965	Kaye Roberts-Thomson (ARCPOH, Adelaide Uni)	Prevention; Treatment: Other	Dental caries	4-8	Both	Yes	2011		304
A Phase II Clinical Trial of a Dental Health Education Program Delivered by Aboriginal Health Workers to Prevent Early Childhood Caries. (Smiles not Tears) ACTRN12612000712808	Anthony Blinkhorn (Westmead)	Early detection / Screening; Lifestyle; Prevention	Early Childhood Caries	5-7 mos	Both	No	2012		250
A randomised trial to evaluate whether point-of-care testing for chlamydia and gonorrhoea in remote Aboriginal communities can reduce repeat positivity at three months after treatment, among people with chlamydia or gonorrhoea	Rebecca Guy (Kirby Institute)	Diagnosis / Prognosis; Early detection / Screening	Chlamydia; Gonorrhoea	16-29	Both	Yes	2013		1800

infection. (TTANGO) ACTRN12613000808741									
In patients having an Exercise Stress Test (EST) does a culturally and linguistically appropriate education tool, in comparison to a placebo Coronary Heart Disease (CHD) education video, reduce inconclusive EST. (BEST study) ACTRN12614001184662	Graeme Maguire (Baker IDI)	Other interventions	Coronary Artery Disease	18+	Both	Yes	2014	2015	100
A multi-centre open label randomised non-inferiority study to compare the efficacy of antibiotics versus watchful waiting for Acute Otitis Media without perforation in low-risk urban Aboriginal and Torres Strait Islander children. (WATCH) ACTRN12613001068752	Jennifer Reath (Western Sydney Uni)	Treatment: Other	Acute Otitis Media; Health of Urban Aboriginal children	18 mos - 16 yrs	Both	Yes	2014	2020	495
Optimum Thiamine Intervention for Treatment and Prevention of Wernicke-Korsakoff Syndrome (WKS): A Randomised Controlled Trial. (OpT In) ACTRN12614000327684 / NCT02788552	Kylie Dingwall (Ctr for Remote Health)	Prevention; Treatment: Drugs	Wernicke-Korsakoff Syndrome (WKS)	18+	Both	Yes	2014	2018	450
A 12 month, multi-centred, randomized trial to compare the outcomes of two surgical and one medical intervention on chronic Otitis Media in Indigenous children living in remote communities of Australia. (OM medicine V surgery sub-study) ACTRN12611001073998	Stephen O'Leary (RVE&E Hospital, VIC)	Treatment: Surgery	Chronic Otitis Media	3-10	Both	Yes	2014		200
This 12 month, surgical sub-study is a multi-centred, randomized trial to compare the outcomes of two surgical interventions on chronic Otitis Media in Indigenous children living in remote communities of	Stephen O'Leary (RVE&E Hospital, VIC)	Treatment: Surgery	bilateral grommet tube insertion with adenoidectomy; myringotomy	3-10	Both	Yes	2014	2018	280

Australia. (OM, surgical sub-study) ACTRN12613000102774			with adenoidectomy; otitis media						
In Australian indigenous children, what is the effect of oral nitazoxanide versus placebo on acute gastroenteritis? (NICE-GUT) ACTRN12614000381684 / NCT02165813	Tom Snelling (Telethon Kids Institute)	Treatment: Drugs	Acute Gastroenteritis	3 mos - 5 yrs	Both	Yes	2014	2019	300
Assessment of the acceptability, feasibility and impact on smoking cessation, of an intensive smoking cessation intervention, including financial incentives, among pregnant Indigenous women reporting daily smoking and receiving maternity care through the Birthing in Our Community program. ACTRN12615001278527	Sue Kildea (Mater Research, QLD)	Behaviour; Lifestyle; Treatment: Other	Reduction in smoking; Smoking cessation	14+	Females	No	2015	2018	140
A randomised controlled trial to evaluate the efficacy of an evidence based cough algorithm compared to standard care in reducing cough duration in children aged < 15 years who develop chronic cough (> 4 weeks) following acute respiratory infection. (RICCi Kids Study) ACTRN12615000132549	Kerry-Ann O'Grady (Centre for Children's Health Research, QLD)	Treatment: Other	Acute respiratory infection; Cough	0-14	Both	Yes	2015	2018	700
The effect of a periodontal intervention on renal health in Aboriginal Australian adults with kidney disease. ACTRN12614001183673	Lisa Jamieson (Adelaide Uni)	Treatment: Other; Treatment: Surgery	Periodontal disease; Renal disease	18+	Both	Yes	2015	2017	600
The Indigenous Birthing in an Urban Setting (IBUS) Study: Improving maternal infant health care for Aboriginal and Torres Strait	Sue Kildea (Mater Research, QLD)	Treatment: Other	infant health; preterm birth	no limit	Both	No	2015	2019	770

Islander women and infants through a multi-agency partnership. (IBUS) ACTRN12618001365257									
NSW Dried Blood Spot Self-Sampling HIV Testing Pilot Program. ACTRN12616000673448	Jo Holden (NSW Ministry of Health)	Early detection / Screening	Hepatitis C; HIV	16+	Both	No	2016	2020	860
The Indigenous Counselling and Nicotine (ICAN) QUIT in Pregnancy Step-Wedge Pilot Study: feasibility of training health providers in evidence based smoking cessation care for Australian Indigenous pregnant smokers. (ICAN QUIT in Pregnancy - pilot) ACTRN12616001603404	Gillian S Gould (Newcastle Uni)	Behaviour; Treatment: Other	Management of smoking during pregnancy in Aboriginal and Torres Strait Islander women	16+	Both	No	2016	2017	80
An enhanced model of targeted support and early infant primary care coordination, compared to current practice, for the reduction of all cause hospitalisation in Aboriginal and Torres Strait Islander infants less than 3 months of age. ACTRN12615000976583	Karen Edmond (UWA)	Prevention	All cause hospitalisation; Child health screening; Immunisation coverage	14+	Females	Yes	2016	2018	4300
A multi-centre double-blind randomised controlled trial to determine if a longer duration of amoxicillin-clavulanic acid (compared to shorter duration) improves the short and long term clinical outcomes of children hospitalised with community-acquired pneumonia, in Indigenous children and a developing country. (HOPE Study) ACTRN12616000046404/NCT02783859	Anne Chang (MSHR)	Treatment: Drugs	Pneumonia in children	3 mos - 6 yrs	Both	Yes	2016	2019	314

A pragmatic trial of an 8-week physical activity program for Australian Indigenous adults with/ or at risk of chronic disease, to improve functional capacity. ACTRN12616000497404	Ashleigh Sushames (JCU)	Lifestyle; Prevention; Treatment: Other	Chronic disease; Functional capacity; physical inactivity	18-45	Both	No	2016		100
A randomised controlled trial to evaluate the effect of a self-managed acceptance and commitment therapy based app for Indigenous youths with suicidal ideation compared against wait list control. ACTRN12614000686606	Fiona Shand (Black Dog Institute)	Behaviour; Prevention; Treatment: Devices	Suicidal ideation	16-35	Both	Yes	2016		570
A cluster randomised trial of a school-based health promotion intervention: Shake-a-Leg. ACTRN12616001685404	Karen Gillham (HNE Pop Health)	Behaviour; Lifestyle; Prevention	Inadequate Nutrition; Physical Inactivity	9-12	Both	Yes	2017	2018	466
The effectiveness and acceptance of an ecologically adapted eye movement desensitisation and reprocessing (EMDR) standard protocol to treat post traumatic symptoms with remote Aboriginal Australian adults. ACTRN12617000316303	Gene Hodgins (CSU)	Treatment: Other	Post-traumatic stress disorder	18-70	Both	No	2017	2017	20
A randomised active-controlled non-inferiority trial of OZURDEX® intravitreal implant versus Avastin® intravitreal injection in Indigenous patients with or at risk of diabetic macular oedema, at the time of or following cataract surgery. (The OASIS Study) ACTRN12618000202268	Hessom Razavi (Lions Eye Institute, WA)	Treatment: Drugs	Diabetic Macular Oedema	18+	Both	Yes	2017		72

Wellbeing Intervention for Chronic Kidney Disease (WICKD): A Trial of the Aboriginal and Islander Mental Health Initiative (AIMhi) Stay Strong App. (WICKD) ACTRN12617000249358	Kylie Dingwall (MSHR)	Treatment: Devices; Treatment: Other	Chronic Kidney Disease; Psychological distress	18+	Both	Yes	2017	2018	156
Minimally invasive approach to manage early childhood caries in Aboriginal preschoolers. ACTRN12616001537448	Peter Arrow (WA Dental Health Services)	Behaviour; Prevention; Treatment: Surgery	dental decay	0-72 mos	Both	Yes	2017	2018	440
A model of integration of diabetic retinopathy screening (DRS) into a diabetes education (DE) service to improve patient engagement with diabetes self-management and to increase diabetic retinopathy screening rates among Indigenous Australians. ACTRN12618001204235	Laima Brazionis (Melbourne Uni)	Early detection / Screening	Diabetic retinopathy; Type 2 Diabetes Mellitus	18+	Both	No	2018	2018	250
Improved medication management for Aboriginal and Torres Strait Islanders through pharmacist advice and culturally appropriate services: a feasibility study. (IMeRSe) ACTRN12618000188235	Amanda Wheeler (Griffith Uni)	Other interventions; Prevention	Medication Review Services	18+	Both	No	2018	2019	540
The ORVAC Trial: A Phase IV, Double-blind, Randomised, Placebo-controlled Clinical Trial of a Third Scheduled Dose of RV1 Rotavirus Vaccine in Australian Aboriginal Infants to Improve Protection Against Gastroenteritis. (ORVAC) NCT02941107	Tom Snelling (Telethon Kids Institute)	Treatment: Drugs	Viral Gastroenteritis Due to Rotavirus	6-12 mos	Both	Yes	2018	2020	1000

The SToP (See, Treat, Prevent) Skin Sores and Scabies Trial: A cluster randomised, stepped-wedge trial for skin disease control in remote Western Australia. (SToP (See Treat Prevent) Trial) ACTRN12618000520235	Asha Bowen (Telethon Kids Institute)	Early detection / Screening; Prevention; Treatment: Drugs	crusted scabies; impetigo; scabies	no limit	Both	Yes	2018	2020	400
Double blind randomised controlled trial (RCT) on the utility of personalised bronchiectasis action management plans (BAMP) for children with bronchiectasis. (BAMP Study) ACTRN12618000604202	Gabrielle McCallum (MSHR)	Treatment: Other	Bronchiectasis	0-18	Both	Yes	2018	2019	198
Yeddung Gauar (Good Heart): Feasibility of an Aboriginal and Torres Strait Islander female Cardiac Rehabilitation program delivered in a non-Indigenous health service. (GoodHeart-CR) ACTRN12618000581268	Nicole Freene (Canberra Uni)	Lifestyle; Rehabilitation; Treatment: Other	Heart Attack; Ischaemic Heart Disease; Medium-high risk of a cardiac event	18+	Females	No	2018	2018	20
A multi-centre randomised controlled trial to compare nasal balloon autoinflation versus no nasal balloon autoinflation for otitis media with effusion in Aboriginal and Torres Strait Islander children. (INFLATE) ACTRN12617001652369	Penelope Abbott (Western Sydney Uni)	Treatment: Devices	Health of Aboriginal Children; Otitis Media with Effusion	3-16	Both	Yes	2018	2019	400
Integrating Pharmacists within Aboriginal Community Controlled Health Services to improve Chronic Disease Management (IPAC) Project. (IPAC Project) ACTRN12618002002268	Sophia Couzos (JCU)	Treatment: Other	Cardiovascular disease; Chronic kidney disease; Coronary heart disease; Dyslipidaemia; Hypertension; Polypharmacy; Stroke; Type 2	18+	Both	No	2018	2019	1500

			diabetes mellitus						
Improving mental health screening for Aboriginal and Torres Strait Islander pregnant women and mothers of young children. ACTRN12619000580178	Julia Marley (UWA)	Early detection / Screening	Perinatal mental health	16+	Females	No	2019	2021	1246

* In years, unless otherwise stated. ** RCT, Randomised controlled trial. *** Target sample size.

5. Trials listed as ‘Not yet recruiting’ (N=31)

Scientific Title (Acronym) – Trial Reg. No.	Principal Investigator /Scientific Contact	Intervention codes	Health Conditions	Age range*	Gender	RCT?**	Start Year	End Year	Sample size***
Drug naïve Indigenous Australians with Type 2 Diabetes, enrolled in a randomised controlled trial of pioglitazone versus metformin monotherapy to assess the effects on metabolic and cardiovascular parameters. ACTRN12607000135415/NCT00437970	Louise Maple Brown (MSHR)	Treatment: Drugs	Type 2 Diabetes	18+	Both	Yes	2008		60
The efficacy of daily versus depot vitamin D3 supplementation on vitamin D deficiency in Aboriginal children and adolescents in metropolitan and rural Western Australia. ACTRN12609000269235	Jason Tan (Princess Margaret Hospital)	Treatment: Other	Vitamin D deficiency	0-16	Both	Yes	2009		120
Preparing culturally competent physical education teachers: Can they increase the physical activity levels of Indigenous students participating in a Sporting Chance Program. ACTRN12612000127808	Louisa Peralta (Sydney Uni)	Prevention	Academic deficits in extremely preterm children	11-17	Both	No	2012		70
A partnership with Bindjareb Nyungar women in Pinjarra aimed at developing the Bindjareb Yorgas Health Program; a sustainable suite of health promotion activities aimed at establishing health literacy, self-determination and individual,	Paul Morrison (Murdoch Uni)	Behaviour; Lifestyle; Prevention	Mental well-being; Obesity; Poor nutrition; Sedentary lifestyle behaviours	18+	Females	No	2012		30

social and community capacity. ACTRN12612000292875								
Effect of delayed cord clamping on the haemoglobin levels of term newborn Aboriginal infants from remote Aboriginal communities: a pilot randomized controlled trial. (ACDC) ACTRN12612000071820	Peter Morris (MSHR)	Other interventions	neonatal health; Term birth	18+	Females	Yes	2012	72
The impact of a multi-component intervention (including strategies for engagement, education and skill development, personal development and empowerment, and case management support) on high-risk Indigenous and non-Indigenous young people. ACTRN12613001152718	Anthony Shakeshaft (NDARC UNSW)	Behaviour; Lifestyle	Alcohol and other drug use; Educational attainment and/or skills training; Involvement in crime related activities; Mental health and resilience	12-22	Both	No	2013	60
For speech pathology students from Culturally and Linguistically Diverse (CALD) background, does an intensive pronunciation intervention targeting prosody and articulation improve speech intelligibility and acceptability? ACTRN12614000855628	Alison Purcell (Sydney Uni)	Treatment: Other	Speech impairment	18+	Both	No	2014	10
Randomised Controlled Trial of a Traditional and Modified Healing Program for Enhancing Social Emotional Well-Being in Indigenous Australian Children. ACTRN12611001237976	Richard Bryant (UNSW)	Behaviour	Social emotional well-being	11-17	Both	Yes	2014	120

Randomised Controlled Trial of a Traditional and Modified Healing Program for Enhancing Social Emotional Well-Being in Indigenous Australians. ACTRN12611001219976	Richard Bryant (UNSW)	Behaviour	Social emotional well-being	18-80	Both	Yes	2014		120
Far North Queensland Hospital Avoidance Trial - chronic disease case management compared with usual care in reducing avoidable hospital and Emergency Department admissions. (FNQHAT) ACTRN12614000219684	Robyn McDermott (JCU)	Treatment: Other	Cardiovascular Disease; Chronic Disease; Chronic Kidney Disease; Chronic Obstructive Pulmonary Disease; Diabetes	18-75	Both	Yes	2014		530
Among Aboriginal children (2 months of age and up to 17 years of age) with chronic suppurative otitis media, is 4 months of povidone-iodine ear wash and/or oral cotrimoxazole in addition to standard treatment (cleaning and dry mopping with tissue spears plus topical ciprofloxacin) superior to standard treatment alone for resolving ear discharge? A 2x2 factorial randomised controlled trial. (I HEAR BETA (Indigenous Healthy EARs- BEtadine, Tissues and Antibiotics)) ACTRN12614000234617	Peter Morris (MSHR)	Treatment: Drugs	chronic suppurative otitis media (CSOM)	2 mos - 17 yrs	Both	Yes	2015	2016	280

Is opportunistic screening appropriate for identifying arrhythmias and establishing effective clinical pathways for Aboriginal Australians? (AAiECG) ACTRN12616000459426	Kylie Gwynne (Sydney Uni)	Early detection / Screening	atrial fibrillation; cardiovascular disease; stroke	45+	Both	No	2016	2017	1500
Does application of the sepsis scoring system qSOFA and early notification to senior medical staff in a Remote Australian Emergency Department improve the outcomes of patients presenting with sepsis. ACTRN12617000334303	Richard Johnson (Alice Springs Hospital)	Diagnosis / Prognosis; Early detection / Screening	sepsis	18+	Both	No	2017	2017	786
Exploring a better treatment option for scabies using tea tree oil-based gel formulation in remote-dwelling Aboriginal and Torres Strait Islander children – Protocol for a pilot, randomised, permethrin controlled trial. ACTRN12617000902392	Jackson Thomas (U Canberra)	Treatment: Drugs	Scabies infestation	5-16	Both	Yes	2017	2018	200
Implementing evidence into practice to improve chronic lung disease management in Indigenous Australians: the Breathe Easy, Walk Easy - Lungs for Life (BE WELL) project. ACTRN12617001337369	Jennifer Alison (Sydney Uni)	Rehabilitation	Chronic obstructive pulmonary disease	40-90	Both	No	2017	2020	97
Rapid ferric carboxymaltose infusion (Ferinject) for Iron Deficiency Anaemia in Aboriginal children: a randomised controlled trial. (RIIS) ACTRN12617001273370	Peter Morris (MSHR)	Treatment: Drugs	Childhood Iron Deficiency Anaemia	0-6	Both	Yes	2017	2019	226

Let's CHAT (Community Health Approaches To) Dementia in Indigenous Communities. (Let's Chat - Dementia) ACTRN12618001485224	Dina LoGiudice (Melbourne Health)	Other interventions	Cognitive Impairment Not Dementia; Dementia	50+	Both	Yes	2018	2021	180
Enhancing rehabilitation services and quality of life for Aboriginal Australians after brain injury: Healing Right Way. ACTRN12618000139279	Elizabeth Armstrong (ECU)	Rehabilitation	brain injury	18+	Both	Yes	2018	2021	312
SISTAQUIT (Supporting Indigenous Smokers to Assist Quitting) - A Cluster Randomised Controlled Trial to Improve Strategies for the Management of Smoking Cessation in Pregnant Aboriginal and/or Torres Strait Islander Women. (SISTAQUIT) ACTRN12618000972224	Gillian Gould (Newcastle Uni)	Behaviour; Prevention	Management of smoking during pregnancy for Aboriginal and Torres Strait Islander women; Respiratory health of babies from birth to 6 months of age; Tobacco smoking during pregnancy	16+	Females	Yes	2018	2019	450
A multi-centre, observer blinded, randomised controlled trial to evaluate the efficacy of the 10 valent pneumococcal-Protein D conjugate (PHiD-CV) vaccine administered during pregnancy in preventing acute lower respiratory infection (ALRI) in Australian Indigenous and Malaysian infants up to 12 months of age, compared to infants whose mothers	Anne Chang (MSHR)	Prevention	Acute Lower Respiratory Infection	17-40	Females	Yes	2018	2021	292

were not vaccinated in pregnancy. (PneuMatters) ACTRN12618000150246									
Alternative Pathway for the National Bowel Cancer Screening Program for Indigenous Australians: A randomised cluster trial of implementation models. ACTRN12618001555246	Gail Garvey (MSHR)	Early detection / Screening	Bowel Cancer	50-74	Both	Yes	2018	2018	900
A randomised controlled trial of telephone call versus letter recalls for cervical screening and mammography for Aboriginal women to improve uptake of screening. (IAMS CCT Recall Project) ACTRN12618001652268	Rowena Ivers (Illawarra AMS)	Early detection / Screening	breast cancer; cervical cancer	25-74	Females	Yes	2018	2018	80
Women's action for Mums and Bubs (WOMB): a pragmatic, cluster-randomized stepped wedge trial of participatory women's groups to improve Indigenous maternal and child health. (WOMB) ACTRN12618000945224	Sarah Larkins (JCU)	Treatment: Other	Antenatal care	no limit	Females	No	2018	2020	200
The Hearing for Learning Initiative - an Innovative Community-based Service-enhancement Model to Address the Crisis in Ear and Hearing Health of Aboriginal Children in the Northern Territory: a Stepped-wedge Cluster Randomised Trial. (HfLI) NCT03916029	Amanda Leach (MSHR)	Behaviour	Conductive Hearing Loss; Otitis Media	no limit	Both	Yes	2019	2024	20
Cockburn Ear Portal: An ENT and Audiology referral portal to reduce time to assessment for ear health services for Aboriginal children in metropolitan areas using telehealth. ACTRN12619000040167	Chris Brennan-Jones (Perth Children's Hospital)	Diagnosis / Prognosis; Early detection / Screening; Prevention	Otitis Media	0-6	Both	No	2019		120

PCH Ear Portal: An urban-based ENT and Audiology referral telehealth portal to reduce time to assessment for specialist ear health services for children. ACTRN12619000039189	Chris Brennan-Jones (Perth Children's Hospital)	Diagnosis / Prognosis; Early detection / Screening; Prevention	Otitis Media	6 mos - 6 yrs	Both	No	2019		120
Vitamin D supplementation to prevent acute respiratory infections among Indigenous children in the Northern Territory: a randomised controlled trial. (D-Kids) ACTRN12618001174279	Michael Binks (MSHR)	Prevention; Treatment: Drugs	Acute Respiratory Infection	0-40	Both	Yes	2019	2021	440
Preventing Falls in Older Aboriginal People through exercise and yarning circles: Ironbark trial. ACTRN12619000349145	Rebecca Ivers (UNSW)	Behaviour; Lifestyle; Prevention	Social and emotional wellbeing; Central obesity; Falls; Functional mobility; Health related quality of life; Healthy ageing; Mental health; Physical activity	45+	Both	Yes	2019	2021	600
A multi-centre double-blind randomised controlled trial to determine if long-term once-weekly azithromycin (compared to placebo) reduces recurrent respiratory-related acute lower respiratory infections in young Indigenous children hospitalised with an acute lower respiratory infection. (PETAL Study) ACTRN12619000456156	Gabrielle McCallum (MSHR)	Treatment: Drugs	Acute lower respiratory infection in children	0-2	Both	Yes	2019	2021	306

Novel Interventions to Address Methamphetamine Use in Aboriginal and Torres Strait Islander People (NIMAC). Phase 4: Effectiveness of a Culturally Appropriate Web-based Intervention for Methamphetamine Use. ACTRN12619000134123	James Ward (SAHMRI)	Behaviour	Methamphetamine use	16+	Both	Yes	2019	2019	288
Indigenous Model of Mental Health Care: A randomised controlled trial based on a trans-diagnostic Cognitive Behavior Therapy program co-designed with Community, targeting participants with depression. (IMMHC) ACTRN12618001746224	Maree Toombs (Rural Clinical School Research Centre, QLD)	Treatment: Other	Depression	18+	Both	Yes	2019		110

* In years, unless otherwise stated. ** RCT, Randomised controlled trial. *** Target sample size.

6. Trials with other listed status (N=3)

Scientific Title (Acronym) – Trial Reg. No.	Principal Investigator /Scientific Contact	Intervention codes	Health Conditions	Age range*	Gender	RCT?**	Start Year	End Year	Sample size***	ANZCTR status
A Pilot Study to Evaluate the Impact of Adapted Compassion Focused Therapy on Psychological Distress in Aboriginal and Torres Strait Islander Groups from 3 Different Services. ACTRN12618000008224	James Bennett-Levy (Uni Ctre for Rural Health, Lismore)	Behaviour; Treatment: Other	Psychological Distress; Social and Emotional Wellbeing	18+	Both	No	2018	2020	35	Suspended
Relapse Prevention Trial in Top End Aboriginal People with Chronic Mental Illness. (AIMHINTRPT) NCT00192582	Tricia Nagel (MSHR)	Behaviour	Bipolar Disorder; Depression; Psychoses, Substance Induced; Schizoaffective Disorder; Schizophrenia	18+	Both	Yes	2005	2007		Unknown status
Randomised Controlled Trial of a Health Broker Intervention to Improve Adherence to the Primary Healthcare Practitioner's Care plan for otitis media in Aboriginal children. (SEARCH) ACTRN12608000073303	Jonathan Craig (Sydney Uni)	Behaviour	Otitis media	0-12	Both	Yes	2010		400	Withdrawn

* In years, unless otherwise stated. ** RCT, Randomised controlled trial. *** Target sample size.

Table 1.3.1 Barriers and enablers to, and strategies to increase, participation in clinical trials for Indigenous peoples, ethnic minorities, and underserved populations.

Author	Population group(s)	Description	Data sources	Dates	Key findings
INDIGENOUS AUSTRALIANS (+/- others)					
Glover et al., 2014 [35]	Indigenous people in Australia, NZ, Canada, US	Systematic review of identification of barriers and facilitators relating to participation of Indigenous people in health-related RCTs (excludes reviews)	Scopus, Medline, EMBASE.	up to March 2012	46 papers included, 20 with info on barriers, 37 on facilitators, 11 on both. Includes 5 papers from Australia - 2 on barriers, 2 on facilitators, 1 on both. Barriers: a) lack of access, especially due to disadvantage (e.g. no phone, place of residence far away); b) distrust of/unfamiliarity with research (e.g. confidentiality and privacy concerns); c) problems with research materials/procedures (e.g. not consistent with Indigenous knowledge, culturally inappropriate); d) loss to follow up (e.g. through high mobility or length of study). Facilitators: a) partnership and relationship building (including early engagement, community-identified priorities/needs, Indigenous leadership/guidance); b) culturally appropriate study design and culturally appropriate study materials (appropriate language(s), drawing on Indigenous traditions, incorporating Indigenous worldview/knowledge systems into intervention design, input from community/Indigenous staff on materials); c) employing Indigenous staff; d) targeted recruitment (Indigenous-led, through Indigenous health services, through Indigenous schools, via Indigenous media).

Guillemin et al., 2016 [36]	Victorian Aboriginal and non-Aboriginal people who had previously participate in research	Qualitative study of reasons for participating in research, decision-making process	interviews	Not stated	8 Aboriginal participants indicated their main reason for participating in research was community benefit (their own community) rather than personal benefit. For non-Indigenous participants, focus was on personal interest in the topic, altruism/contributing to knowledge, 'no reason to say no'', trust in the GP who recruited them. Decision-making process for Indigenous participants was thoughtful and considered: 'we're checking them out'. Researchers' motivations/commitment, honesty, integrity, respect, transparency, etc. all being ‘checked out’. Aboriginal people started from a position of caution/distrust rather than a position of trust (in non-Indigenous people). Privacy and confidentiality also key issues. Non-Indigenous participants didn't seem to take much time or thought in decision-making.
CULTURALLY AND LINGUISTICALLY DIVERSE (CALD)					
Hughson et al., 2016 [45]	No restriction - CALD	Review of recruitment barriers and strategies, informed consent, efficacy of innovative approaches including multimedia	Medline search	up to May 2015	Major barriers: mistrust; communication, including literacy/health literacy, English proficiency, perceived lack of benefit; cultural factors including different beliefs/practices, lack of staff diversity, inappropriate materials; economic and time constraints; mobility/health status; lack of opportunity (gatekeeping; CALD seen as 'too hard'). Some evidence in favour of multimedia approaches to aid informed consent. Importance of educating researchers to address preconceptions, improve understanding of cultural concerns. Specific strategies relate to: building relationships with community; initial and ongoing communication; cultural sensitivity; facilitating access to research, raising stakeholder awareness. Use multimedia in relevant language(s).
Lwin et al., 2014 [46]	CALD glioma patients	Review of key challenges and implications for improving CALD patient participation in glioma research	not stated	not stated	Barriers relating to recruitment (e.g. lack of knowledge, communication difficulties, gatekeeping, difficulties navigating health system, mistrust, increased costs of needing to use interpreters), enrolment & participation (informed consent given language barriers, problems using patient-reported outcomes measures across culture/language) and cognition (language versus cognitive function) reviewed. Suggested interventions include improving investigator understanding, cultural competence, communication skills; involving CALD communities (e.g. community

					organisations). Of particular importance is cultural differences in whether carers/families want patient to know prognosis - important to have culturally appropriate educational interventions not only for patients but for families/carers and communities as well.
Smith et al., 2017 [34]	Southwest Sydney - cancer patients - CALD and non-CALD	Retrospective analysis of de-identified admin and clinical data on factors associated with trial enrolment for CALD vs non-CALD cancer patients	Local Health District - oncology info mgmt system	Jan 2006-July 2016	CALD with preferred language English were similar to non-CALD (7.7% vs 8.4%), but CALD with preferred language not English had lower participation (3.9%). This suggests language rather than cultural background is major barrier. This could be due to specific exclusion, or to failure to actively cater for language differences. Interpreters may not completely address this, due to issues of health literacy. Improving access more important than focusing on patient attitudes to trials. Make sure CALD patients are not routinely excluded, translate materials and make them suitable for low health literacy levels. Use innovative approaches such as multimedia delivered electronically. Employ appropriate staff (bilingual, bicultural).
MAORI					
Selak et al., 2013 [56]	NZ Maori	Description of process of recruiting equal numbers of Maori and non-Maori participants in an RCT			Primary-care-based polypill trial to improve CVD prevention. Important to recruit sufficient numbers of Maori participants; specific strategies implemented, oversampling required. Strategies: governance (Steering Committee included experienced Maori researchers involved at all stages, explicit commitment for equal recruitment of Maori participants); staffing (Maori nurses or nurses with substantial experience with Maori population, more time allowed for culturally appropriate recruitment of Maori participants including family discussion), trial practices (primary care practices with high Maori enrolment were identified and targeted), participant screening (oversampling, longer time frame), contact (face-to-face at a location of participant's choosing, developing trust and rapport over multiple visits, staff continuity, involvement of family). Maori represented 50% of final study recruitment.
NATIVE AMERICANS					

Hodge et al., 2000 [52]	US American Indians/ Alaska Natives (AI/AN)	Review/ commentary on challenges relevant to recruitment into trials; recommendations to address these.		Up to 2000	Similar to Australia: AI/AN comprise very small % of US population (<1%); diverse, rural (but urban migration), disadvantaged; cancer 2nd leading cause of death (previously less common); smoking-related cancers, screen-detectable, poorer survival. Indian Health Service not fully funded, cancer care largely outside IHS due to highly technical nature of diagnosis and care. IHS reimburses for external care, but not for 'experimental' treatments, so not trials. Urban AI/AN often choose to go home for treatment, so no longer in the right place to access trials. Barriers to participation include cultural, physical and social factors. Barriers faced by researchers: past negative experiences of research mean suspicion, reluctance to participate. Researchers need to work with tribal IRB (Institutional Review Board) as well as IHS IRB. Tribal Council approval may also be needed. Need to be clear benefits to community, proposal needs to be expressed clearly in understandable language. Need to be aware of cultural differences, nuances. Hard to identify urban populations. Issues relating to transport, phones, transience, importance of extended family, social networks, migration patterns, validity and reliability of instruments, meanings. Barriers faced by care providers: patient/provider communication styles, health/illness beliefs, family orientation, physical barriers (including body language, modesty/ privacy), belief by many that cancer is a death sentence, cancer as contagious. Treatment away from country is disturbing. Central role of family - their needs take priority. Must include them in education and decision making. Mismatch between trials and patient centred care model. Need for education, advocacy, networking, outreach. Recommendations for researchers: involve tribal and health service leaders; learn about local community; provide understandable information, answer all questions, be flexible; involve community members in all phases; assess suitability of instruments; review content with community to assess meanings; be creative about selection methods; employ community members; negotiate what is provided to non-treatment group to ensure benefit; offer appropriate incentives; provide transport; present results to community; for trials not Indian-specific, ensure recruiters can communicate effectively and do not rule out AI/AN inappropriately due to bias; develop appropriate recruitment materials with key informants. Recommendations for providers: be aware of community beliefs about illness; modify patient communication style; include family in decision-making; understand tribal customs relating to

					illness and death; insure understanding of consent forms, through wording, interpreters, oral presentation; respect preferences re: provider gender/privacy; allow adequate time; avoid scheduling appointments during important community events.
LaVallie et al., 2008 [54]	US – Native Americans	Cross-sectional survey on factors associated with willingness to participate in a hypothetical cancer clinical trial	112 elders aged 40-84		37 factors assessed. Decreased willingness to participate in cancer clinical trials if the trial is far away (more than 20 miles), if the person thought confidentiality might be compromised. Increased willingness if: study physician experienced in treating AI/AN; personal experience with cancer being studied; belief/hope that trial would result in new treatments; AI/AN investigator; family supportive of participation. Importance of overcoming community mistrust, building partnerships, providing adequate information, maintaining confidentiality, including family in decision-making, overcoming distance, involving AI/AN researchers, and cultural competence of researchers.
Sprague et al., 2013 [273]	US - Native Americans	Cross-sectional survey on factors that influence willingness to participate in research	489 tribal student surveys; 112 elders previously surveyed (see LaVallie et al. 2008).	2008-2010	Logistical barriers more important than attitudinal barriers. 64% of students thought patients should be asked to participate in research; 65% said they would be willing. Most students willing to participate in hypothetical trial if study doctor was an expert, had experience treating AI/AN patients, if study would lead to new treatments, would help others in community with cancer, if family member or friend had that type of cancer. Barriers included living a long way from study site; and fearing confidentiality would not be upheld. Students and elders were generally similar in willingness, except for when long distance. Discussion mentions mismatch between where trial centres are and where AI/AN people live; ineligibility due to late stage, comorbidities.
MINORITY AND UNDERSERVED POPULATIONS (MOSTLY US)					
Ahaghotu et al., 2016 [26]	US - African Americans	Narrative review on participation in prostate cancer trials	Not stated	Not stated	Factors contributing to low participation by African Americans include low SES (competing priorities, transport, out-of-pocket costs), lack of awareness about trials, lack of education (affects information-seeking behaviour), ineligibility (comorbidities), willingness to participate (distrust, chance of benefit), 'cultural' barriers (real or perceived), type of institution providing treatment (are trials available?). Potential solutions: increased awareness, building of trust, overcome identified barriers - personal

					contact (face-to-face or patient navigators by phone), engagement through community groups, make it easier (transport, child care, appointment scheduling, etc.), overcome gatekeeping (improved communication, changed incentives, African-American investigators, improve cultural awareness), build community trust through ongoing contact, select appropriate sites, make trial design less restrictive, support involvement and training of community health centres, financial support for participation. National guidelines, infrastructure and policy reform also needed.
Bonevski et al., 2014 [43]	socially disadvantaged people	Systematic review on barriers and strategies for inclusion of socially disadvantaged people in health and medical research (not just cancer)	Medline, PsychInfo, EMBASE, Social Science Index via Web of Knowledge, CINAHL	up to May 2013	116 papers identified, most from US, but 9 from Australia. Population-based sampling not good for small sub-populations (e.g. Aboriginal people) - use oversampling or other methods (e.g. snowball, networks), or community organisations as sampling frame, or combinations. Barriers to recruitment and consent - e.g. mistrust, potential for harm, stigma, gatekeeping, lack of understanding, restrictive eligibility criteria - strategies include: community partnerships, community-driven research, community leaders, community advisory groups, peer-recruiters, culturally-relevant materials, cultural competence of study team, working with gatekeepers, flexible eligibility criteria (especially re: language, co-morbidities), outreach, incentives, social marketing, relevant media, internet, etc. Multiple strategies needed. Study materials need to be appropriate for the language and literacy level of participants. Need to ensure intervention is acceptable (e.g. some concerns re: randomisation), work with community to get this right. Alternative designs to standard RCTs are available. Retention affected by difficulty maintaining participant contact, logistical/practical difficulties (e.g. transport, child care). Use incentives, travel vouchers, have multiple forms of contact, build relationships, have flexibility in scheduling. There is no one, single solution, but overall messages include importance of community engagement throughout the process, recognition of the longer time frames and higher costs incurred, research collaborations dedicated to research with socially disadvantaged groups.

Brooks et al., 2015 [55]	US - minorities	Workshop report on practical strategies and challenges for increasing enrolment, from NRG Oncology Accrual Workshop	presentations from invited investigators, discussions	Investigators proposed interventions including: 1) address the consent process, patient and physician understanding of beliefs, cultural factors, trust; 2) develop scripts to reduce potential for bias, training module for PIs and CRAs, expand patient navigator programs (cultural competency training program developed, currently being assessed); 3) education of investigators, research staff, community groups, develop relationships with minority organisations, actively target specific populations for accrual, have cultural input during protocol development, use culturally appropriate educational info about trials; 4) develop, support, mentor minority investigators. Kaiser Permanante CHOICES Study - strong predictors of accrual include: oncologist awareness of open trials, willingness to discuss trials with eligible patients, their perception of value of clinical trials to the organisation. NCI-funded minority-based community clinical oncology programs (MB-CCOP) most successful strategies: culturally sensitive investigators and coordinators, community advisory board, partnerships (churches, community orgs, relevant media). NCI Community Oncology Research Program (starting 2014) -encourages recruitment networks, funds navigators, etc. for cancer care delivery research. Concern noted re: highly restrictive eligibility (e.g. in molecular studies). Ten 'common themes' identified, including: importance of considering diversity in protocol development stage.; changing nature of study eligibility (based on genomics); influence of payers/insurance; physician commitment to clinical research and cultural awareness; direct-to-consumer/community communication needed; adequate infrastructure and institutional commitment needed; real-time data on accrual in special populations requires better demographic data collection; IT infrastructure improvements; better recruitment, training, support of young investigators, especially from underrepresented groups; better funding for clinical cancer research needed.
Chen et al., 2014 [48]	US - minorities	EMPaCT program and the 1993 NIH Revitalization Act - reviews the case for enhancing minority participation	ClincalTrials. gov (search of NCI-sponsored trials with primary focus on	Key findings: 1) number/% of trials focused on ethnic minorities very low (less than 150 - probably about 100 - out of more than 10,000); 2) enrolment fraction generally lower for minorities (1.8% for whites, 1.3% for blacks and Hispanics, 1.7% for Asian/Pacific Islander, 2.5% for AI/AN). 60% of patients under 15 enrolled in trials, compared with 3-5% of adults with cancer. Very good participation rates for minorities in paediatric trials suggests what may be achievable for adults. 3) Only 5 studies explicitly

			minorities); PubMed; key informants from a relevant conference and 3 NIH grants.		included data on participation by race/ethnicity. Trend is good but far from optimal at present. 4) barriers persist (as described elsewhere); trial design characteristics especially important (e.g. exclusions based on comorbidities). Model programs (e.g. MB-CCOP) are seeing success. 5) increasing evidence on the benefits of trial participation (e.g. lower mortality, better understanding of ethnic diversity in pathogenesis, pharmacogenomics). Demographic change in the US means the minorities will actually be the majority. Their cancer incidence is expected to rise twice as fast as for the general population. The emphasis should be on trials aimed at ensuring adequate representation of minority groups disproportionately affected by cancer, rather than on cancer types (i.e. trials with a primary focus on minorities - currently less than 2% of NCI-sponsored trials).
Duma et al., 2018 [44]	US - minorities	trends in participation over 14 years	ClincalTrials.gov database.	2003-2016	Therapeutic cancer trials for 7 most common sites from 2003-2016. Trials with non-US sites excluded. Participation data from on-line record and from Results section of published trials. Only 31% of eligible trials on ClinicalTrials.gov reported race/ethnicity. Of those with information, recruitment of African Americans and Hispanics less than for non-Hispanic whites (AI/AN not significantly different), and minority participation has decreased from 2011. "Old challenges': mistrust, provider bias, lack of insurance, costs of participating, language barriers. 'Current and future challenges': increased complexity of trials (genetics) - concentration in larger academic centres; increased costs (targeted therapy, immunotherapy) - less available for translation, outreach, employment of multilingual research staff. Description of participant race/ethnicity should be provided for all trials. Extra effort needed to include minority groups, especially for cancers with high prevalence in those groups.
Ford et al., 2005 [27]	Under-represented populations	Systematic review commissioned by Agency for Healthcare Research and Quality, funded by NCI. Recruitment of underrepresented	Medline, Cochrane Central Register of Controlled Trials, Cochrane Database of Systematic	to March 2004	Review addresses 6 key questions relating to methods used to study strategies, measures of success, efficacy of various recruitment strategies, barriers and promoters, and physician attitudes and perceptions. 67 eligible articles. 45 on barriers and promoters; for barriers, see also Ford et al. 2008. Promoters were mostly relating to awareness, culturally relevant education, provision of transport, perceived benefits, incentives and appeals to altruism. Extremely limited info found on AI/AN, none on Asian and Pacific Islanders. Study design factors (e.g. study duration, visit structure, comorbidities, functional status) as important

	populations to cancer clinical trials	Reviews, CINAHL, PsychInfo, C2-SPECTR, hand search of 34 journals (2003-04), reference lists of eligible pubs, author search of relevant experts in Medline.		barriers. Provider attitudes, communication, awareness also important. Issues relating to quality of studies. Definitions of success were ad hoc, inconsistent. Need intervention studies linked to actual trials to assess what works. Community-based participatory research needed. Patient navigators required.

Ford et al., 2008 [42]	Under-represented populations - includes African Americans, Latinos/Hispanic, Asian American and Pacific Islanders, American Indians/Alaska Natives, adolescents, people 65+ years, low SES	Systematic review on barriers to recruitment (related to Ford et al. 2005)	Medline, Cochrane Central Register of Controlled Trials, Cochrane Database of Systematic Reviews, CINAHL, PsychInfo, C2-SPECTR, hand search of 34 journals (2003-05), reference lists of eligible pubs, author search of relevant experts in Medline.	1966-2005	Conceptual model - Trial accrual a function of: Awareness barriers/promoters; Opportunity barriers/promoters; Acceptance/Refusal barriers/promoters. 65 eligible articles: 35 on African Americans, 12 Latino/Hispanic; 6 Asian/Pacific Islander; 4 AI/AN. 8 barriers to awareness, 88 to opportunity, 44 to acceptance. 79 relevant at patient level; 37 at provider level; 25 at study design level; 8 at healthcare systems level. Most frequently reported: mistrust of research and medical system (20 studies); perceived harms (18); costs of participation (17); patient demographics (16); transport availability (15); lack of education about clinical trials (13), fear (10); time commitment (9); family issues (8). Opportunity barriers most common - these largely reflect protocol design and implementation, so investigators play a major role. Mechanisms that reduce opportunities not well understood. Suggested ways to improve opportunity: less rigid study designs, systems that facilitate participation by healthcare providers, supporting infrastructure, address costs of participation (health insurance). Awareness: culturally targeted information? Studies to date mostly qualitative; need hypothesis-driven quantitative studies specifically addressing trial enrolment as primary outcome.

Ford et al., 2013 [49]	US - minorities	Qualitative study - focus groups with community members to identify solutions	6 focus groups with African Americans (3; 32 participants) and Latinos (3 - in Spanish; 25 participants) aged 50-80	not stated	Conceptual framework based on IOM Unequal Treatment report - three key types of factors relating to trials research disparities: 1) characteristics of health care systems and study processes (e.g. timing of visits, informed consent materials, navigation of complex medical systems, tight trial timeframes); 2) perceptions and actual interactions with researchers (e.g. negative perceptions about likely adherence to protocols, difficulties in communication, importance of doctors raising participation as an option); 3) potential trial participants' preferences and attitudes (e.g. trust in health system, doctor, fear of harm, seeing participation as a burden, seeing research as negative). Solutions included: 1) compensation for out-of-pocket costs; provision of transport, holding appointments out of work hours, recruit in community contexts (e.g. churches), use word-of-mouth and/or person to person contact; 2) provide community education on trials, have training in communication skills for physicians to improve presentation of info on trials, have patients' own doctors involved in the trial, have more time for interaction; 3) provide free care for adverse effects, provide info on efficacy of the relevant drug, reassure patients about safety, focus trials on serious illness (not healthy participants/Phase I), build on people's altruism (underpinned by trust). Others: diversity in research teams, materials in the right language and literacy level, assure people that immigration status will not be documented, acknowledge past abuses, have meaningful incentives. Participants supportive of patient navigation approach. This would help overcome barriers and also make system changes. Social workers could be appropriate.

Ghebre et al., 2014 [28]		Systematic review examining how patient navigators have been used, types of barriers addressed, working models of PN in the trial process	PubMed, Medline, CINAHL	2005-2012	NCI Patient Navigation Research Program examined effectiveness of PNs in cancer care for underserved groups. PN programs increasingly being explored as a means of addressing barriers to participation in trials in underserved populations. Only 12 eligible studies on PN and trial accrual. 5 reported on curriculum development and PN training; 6 reported on enrolment as an outcome (3 of these were on the Walking Forward program). PN as bridge between cancer centre and community. PN role in increasing awareness, knowledge, access to relevant CTs. Different models relating to where PN sits in the system (e.g. inside or outside the cancer team). A range of competencies addressed in training programs. Majority of people offered a PN accepted. Early evidence of success is promising, but more, larger studies needed. Barriers to cancer care and to cancer trials co-occur. Barriers in WF include financial, psychosocial support needs. Lack of an appropriately matched, available trial remains a large stumbling block (ineligibility). Willingness to participate is not a big issue. Essential characteristics of PN programs include: community engagement; cultural competency and integration with cancer care team. Must address barriers and facilitators at individual patient-level and community-level (e.g. could be distance in one place, mistrust in another).
Hamel et al., 2016 [29]	US - minorities	Review on barriers - multi-level framework - system, individual and inter-personal levels; examples of interventions to address barriers			1) System level: Clinical trial availability and location, inadequate hospital infrastructure to support trials, costs to hospitals and patients, tight eligibility criteria, lack of community engagement. 2) Individual level: Health care professionals - lack of awareness of trials, attitudes towards trials, tensions of dual roles, implicit bias. Training in patient-centred communication needed, along with commitment to enrol minorities, cultural sensitivity, building trust. Patients and families - lack of awareness, unable to meet costs, excluded due to comorbidities, attitudes and beliefs (including mistrust of medical system). Need better education to support decision-making, community engagement to build trust. 3) Interpersonal level - importance of doctor-patient relationship, implicit bias associated with shorter, less patient-centred interactions, different topics discussed. Need to create a sense of shared purpose, increase cooperation and trust. Proposed intervention addresses patients, oncologists and patient-oncologist interactions. Focus is on clinical communication: patient- question-prompt list; doctor - skill-building in both informational and relational communication, email message prior to

					appointment with minority patients to stimulate attitude change; both - team building instructions and team-based items (e.g. pens).
Heller et al., 2014 [57]	US - minorities	Systematic review on successful community-based interventions including health care providers to address barriers to trial enrolment; multi-level approaches	Ovid Medline, EBSCO, CINAHL	2001-2013	21 studies included. Strategies categorised according to whether they would likely impact on awareness, opportunity, acceptance, as well as whether they were concerned with research system and methodology, including role of staff in overcoming barriers. and whether addressed minority perceptions of research. Key strategies: 1) Awareness: partnerships prior to, and after study start to influence study protocol and/or implementation; outreach to providers to explain study and get them on board; community research staff doing education and networking; using community members/coordinators to recruit; provision of education on clinical trials (general, specific); outreach to communities, using culturally and language appropriate materials; letters and follow-up from study staff to community providers; 2) Opportunity: recruiting at local practices that service the community of interest; consultation with patients/providers/staff re: materials and intervention; pilot testing plus adjustments; regular interactions between study staff and local providers to deal with issues; hiring researchers who are from or similar to target community; placing research nurse/coordinator at local practices to recruit and educate patients; provide patient navigators (at hospital or local practices); provide research infrastructure at local practice; incentives and/or reimbursement for patients, providers; 3) Acceptance: manage trials in community rather than in academic settings; have oncology nurse navigators/research staff take responsibility for meeting patients' needs around participation; provide transport. Critical to address recruitment during development stages, not as an afterthought, and to devote the necessary time and effort. Multiple strategies at multiple levels required. Lack of suitable trials for an individual patient remains a key barrier.
Ibrahim & Sidani 2014 [60]	People of ethnically and culturally diverse backgrounds	systematic review on strategies to recruit minorities - Not specific to cancer or clinical trials	CINAHL, Cochrane Review, PubMed, PsychInfo, Ebsco.	1995-2012	26 papers included. Most were from the US (but 2 from Australia). Most studies used multiple strategies. Both proactive (direct contact - face-to-face, including at community fairs, senior centres, etc.) and reactive (indirect contact - e.g. via newspaper ads, broadcast media (including in clinics), printed materials, community members/leaders, referrals from health professionals, snowball/word of mouth, to inform people about the study and provide contact details) recruitment strategies used. 'Effective' strategies included: snowball, community leaders, media broadcast,

					printed material, face-to-face presentations at events. Other recommendations include: compensation/incentives, flexibility, building rapport and trust, employing ethnically diverse staff. Relevance of previous unethical research, fear of experimentation/dehumanisation, on top of personal, practical and knowledge-related barriers.
Napoles et al., 2017 [61]	US minorities	Using a conceptual framework to maximise participation – analysis of case studies	Case studies	Not stated	Using Ford 2008's conceptual framework (awareness, opportunity, acceptance), presents three case studies where strategies were used to overcome barriers to participation. Strategies included: culturally appropriate videos and patient education materials, community outreach, survivors as advocates, informing clinicians at meetings/conferences, relaxing eligibility criteria, help with parking, refreshments, physician workshops, targeted grants to sites, endorsements, education about clinical trials, improving research infrastructure (staffing, administrative and regulatory load, creation of a non-profit organisation), undertaking trials in non-traditional sites (closer to home), streamlined review process, translation services. Intentional efforts needed to overcome barriers. Success of strategies was dependent on 'a culturally informed investment of resources that required stakeholder input via the establishment of genuine partnerships with the targeted populations and their providers." This takes time, attention and resources (all of which are usually underestimated).
National Academies of Sciences, Engineering, and Medicine, 2016 [53]	US - minorities	Proceedings of a workshop on strategies for ensuring diversity, inclusion, meaningful participation in clinical trials	workshop	April 2015	Barriers to meaningful participation include language and cultural differences, history of discrimination and exploitation. Personalised medicine will raise fundamental issues around inclusion in trials. Many minorities get their care from institutions that can't afford to conduct trials. Mandated inclusion (as in the US) can have drawbacks, doesn't fix the problem - the optimal population in a trial depends on the question. Personalised contact plus extra information, patient navigation help recruitment. Researchers and patients may have very different perspectives: 'Look through participants' lenses.' Researchers should ask themselves if they would/could participate in their own studies (e.g. could they attend appointments at the scheduled times?). Community partnerships, commitment to inclusion, flexibility, share results and

		democratize data. Patient-Centered Outcomes Research Institute (PCORI) comparative effectiveness trials define important patient subgroups in advance; challenges in multidisciplinary partnerships, partners lacking adequate resources, pragmatic clinical trials - minimize exclusions, reflect real-world conditions. Need to increase diversity of researchers, provide adequate support for community engagement work. Only 3-5% of eligible adult patients participate in trials. Consideration of benefits versus burdens is complex; 'informed' consent isn't always. Best practice options: community involvement throughout the process is key; adaptable study designs to include diverse but relatively small populations; oversampling; data disaggregation; greater use of IT to remove geographical barriers; improve cultural competency of researchers; don't assume, ask; allow time to build trust between researchers and communities (at least a year); identify the right community leader(s) to work with, partner with community organisation(s); ensure community benefit; build local capacity; have staff that reflect the community; support community champions; ensure culturally appropriate messaging; be visible in the community; know your audience and their lived realities; use outreach, word-of-mouth; provide appropriate and complete information; recruit minority investigators; use peer mentors; incentives for physicians to participate; use a quality improvement approach at trial centres; centralised support; develop and support minority researchers. Policy options: change funding mechanisms and infrastructure development; look at exclusion criteria; involve communities in coming up with recruitment strategies; assess return on investment for increases diversity; support for cultural competency training.
Nipp et al. 2019 [50]	overcoming barriers to clinical trials enrolment	Financial barriers and the decision-making process can act as barriers to clinical trials enrolment. 1) Those with fewer financial resources are generally less likely to participate in trials, and trial participation increases the risk of financial hardship. Financial barriers (including out of pocket costs, time off work) likely to play an important role in decision-making about participation. In the US, health insurance is an additional key factor. Potential solutions include: better information about costs and resources available to cover them, financial assistance (within ethical limitations). A pilot study of a financial assistance program (e.g. for travel and lodging expenses) was associated with increased accrual. 2) The uncertainties inherent in a clinical trial (e.g. risk-benefit ratio, likelihood of adverse

					events, patient's ability to complete the trial) pose a challenge to recruitment. Clinicians may not offer participation, either because they don't think the patient is likely to be compliant or because they don't wish to jeopardise their existing clinical relationship. Patients may be concerned about adverse effects or question the researchers' motives (mistrust). Quality of communication between care provider and patient is also important. Solutions include better communication, e.g. through patient navigation, question prompt lists, shared decision-making; changing the framing of risk (e.g. as loss-aversion). The Accrual to Clinical Trials Framework shows barriers at multiple levels: community, system, provider, patient. Solutions need to address all of these. Patient Navigators can work across many levels. Limited evaluation so far with respect to PN and clinical trials (as opposed to cancer care), but promising. Adequate funding and additional research on impact needed.
Rivers et al., 2013 [30]	US - African Americans	Systematic review of factors influencing participation in cancer clinical trials	PubMed, PsychInfo	2002-2011	31 articles included. Key barriers include: negative attitudes beliefs about clinical trials ('guinea pigs', risk of harm); low levels of awareness and knowledge about trials; religious beliefs (God determines outcome of disease, fatalism); structural factors (ineligibility due to comorbidities, lack of transportation and childcare, other stressors, access to and cost of health care). Participation more likely if recommended by doctor (trust important), family, friends. Needed: cultural sensitivity of staff, culturally appropriate approaches, multi-media messaging, after-hours appointments, transport/parking, enrolment of minorities an organisational priority, minority staff.
Salman et al., 2016 [31]		Review of barriers to participation - aimed at increasing nurses' competence in recruiting, researching, caring for ethnic minority cancer patients	CINAHL, PubMed, PsychInfo, Medline, Google Scholar	2000-2013	28 articles included. Few from a nursing perspective. Barriers relate to: physician (lack of awareness of trials/protocols, bias, communication deficits, attitude (about trials or about patients), perceptions re: patient cost burden); patient (sociocultural context, language and literacy, perceptions of trials, fear of adverse events, mistrust, cultural beliefs and practices); system (trial design, eligibility criteria, access to care, health insurance). Facilitators: community networking, relationships and programs, improved communication skills, culturally sensitive approaches, appropriate staff (bilingual, bicultural), involving family in decision-making, using the most appropriate media (e.g. ethnic specific). Nurses have a

					critical role to play but need more training. Culturally competent care is needed.
Schmotzer et al., 2012 [47]		Review of barriers and facilitators to participation	PubMed, CINAHL, PsychInfo	1995-2008	22 articles included. Barriers much more commonly reported on than facilitators. Provider barriers: physician triage (failure to consider/discuss trial participation as an option); physician knowledge (not knowing about existing/available trials). Patient barriers: fear (of harm, of randomization, of being a guinea pig), mistrust, burden of participating (time, cost, travel). Facilitators: physician enthusiasm, good communication skills, good relationship between provider and patient (trust); altruism (help others, benefit science), perceived benefit (cure/longer life, better care).
Seifer et al., 2010 [58] and ENACCT & CCPH, 2008 [71]	US underrepresented populations	Description of community-based participatory research principles and approaches in clinical trials partnerships	Not stated	Not stated	Low accrual rate among minorities is a social justice issue. Importance of building trust, increasing access, reducing barriers. Community-based participatory research recommended as a key strategy for increasing participation and improving trials. Opportunities for community involvement at all stages, including design, implementation and dissemination phases. Seifer et al. (2010) is a summary of the process and contents of the "Communities as Partners in Cancer Clinical Trials: Changing Research, Practice and Policy" initiative, funded by AHRQ and NCI to "develop a strategic plan for applying CBPR principles and approaches to multi-site, Phase III CCTs". Full report (ENACCT & CCPH, 2008) indicates why and how to include communities, with 58 recommendations in 7 areas relating to: role of patient advocates and community reps; Institutional Review Board processes; process of informed consent; trial development, design and implementation; recruitment and retention; community support for cancer research; interpretation, dissemination and implementation of results. Action guide also included. Key challenges: lack of trust plus lack of an "organised

					constituency to advocate for change"; system is resistant to change. Paradigm shift needed.
Soc. for Women's Health Research & US FDA Office of Women's Health, 2011 [51]	US – women and minorities	Successful strategies for engaging women and minorities to ensure diversity in clinical trials	presentations and discussions		Key barriers include lack of education about disease, insurance, costs, transport, distance, concern about risk, negative attitudes about research. Note that negative attitudes also present in sponsors about perceived difficulty and higher costs of recruitment. 'Diversity is not a natural priority for industry'. (p.ii) Successful strategies to increase diversity include: recruit minority physicians (as the gateway to minority patients); build trust (transparent communication, cultural sensitivity); education/awareness-raising (about health, health care, clinical trials); involve communities (Community-Based Participatory Research, CBPR). Changes that may transform the landscape include: re-thinking trial design, rethinking ethics (patient information, consent processes that are appropriate - e.g. oral cultural tradition, low literacy, group consent); multi-sector collaboration; using new technologies; adapting to changes in medical science; streamlining regulation/review. Diversity of enrolment is ultimately a social justice issue.
Symonds et al., 2012 [32]	UK - minorities	review and commentary on local experience relating to recruitment of ethnic minorities (focus on South Asians)	Medline, PubMed, CINAHL, PsychInfo, PsycArticle, Social Science Citation Index, Science Citation Index.	not stated	Doctor-patient relationship is critical (mistrust as a key barrier). Western individual informed consent process may not align with decision-making in collectivist cultures. Costs of participation (direct and indirect), beliefs about cancer, stigma, lack of health insurance may play a role. Strict inclusion/exclusion criteria (including comorbidities) may impede participation. Translation may not fix language differences (e.g. there may be no direct translation of some concepts/terms, oral versus written language as preferred). Role of family in decision-making must be appreciated. Perceived status of person inviting participation may be relevant. Suggested methods to improve recruitment of British South Asians include: focus groups to identify issues/barriers; involving community members in the study; relaxation of eligibility criteria; recruiting health professionals from the target ethnic group; cultural competency training for health professionals; identify relevant mass media to promote study.

Trinh-Shevrin et al., 2018 [59]	US - Asian Americans	Review and commentary on barriers to recruitment	Not stated	Not stated	Asian Americans an extremely diverse group; they are also the most under-studied group in the US. Barriers exist at the individual, provider, system and societal levels; multiple approaches required. Partnerships involving researchers, clinicians, community, etc. needed. Community-based participatory research as much as possible; educate health providers about disparities and social and cultural factors; address cultural competency and unconscious bias; ensure health services are culturally and linguistically appropriate; undertake outreach; use community health workers/navigators to facilitate access to care; cater for multiple languages.

Table 1.3.2 Selected references on best practice in Aboriginal and Torres Strait Islander health research.

Author	Title	Key points
NHMRC, 2018a [39]	Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders.	Identifies and describes the six core values of: spirit and integrity; cultural continuity; equity; reciprocity; respect; and responsibility. Explains how these values are demonstrated and how they link to the National Statement on Ethical Conduct in Human Research. Also discusses related principles including: consent, research agreements, cultural and intellectual property, and cultural competency.
NHMRC, 2018b [40]	Keeping research on track II: A companion document to Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders.	Companion document to above Guidelines. Describes how the values and ethics can be implemented during the 8 identified steps along the research journey ('building relationships; developing the research idea; developing the project and seeking agreement; data collection; analysing the data and making sense of the findings; report writing; sharing and translating the results into action; and learning from experience'). Also identifies and discusses a number of rights that Aboriginal and Torres Strait Islander people have in relation to research, including: 'the right to self-determination; the right to say yes; the right to say no upfront; the right for Aboriginal and Torres Strait Islander ways of doing things to be respected; the right to have input into the research agenda; the right to commission research that meets priority needs; the right to negotiate a different focus for the research; the right to request more time to talk about the research proposal; the right to expect respect for culture, values and beliefs; the right to seek advice and support to negotiate a written research agreement; the right to check on the researcher's track record; the right to suspend or withdraw from a research project; the right to make a complaint if something goes wrong; and the right to assert ownership of cultural and intellectual property and shared copyright.
NHMRC, 2018c [41]	Road Map 3: A strategic framework for improving Aboriginal and Torres Strait Islander health through research.	This strategic framework is intended to guide NHMRC's efforts to improve outcomes for Aboriginal and Torres Strait Islander people. Three key areas relate to workforce development; community engagement; and identified research priorities. The highest priorities for research relate to; 1) the social and cultural determinants of health and health services effectiveness; 2) conditions responsible for a high burden of disease and/or a large difference in quality of life; and 3) conditions that are (almost) exclusive to Aboriginal and Torres Strait Islander people, as well as research relating to personalised medicine/health care.

NHMRC, Lowitja Institute and AIATSIS, 2013 [274]	Researching Right Way - Aboriginal and Torres Strait Islander Health Research Ethics: A Domestic and International Review. October 2013.	A review of Australian and international literature on guidelines for ethical practice in research relating to Aboriginal and Torres Strait Islander people. Compares existing Australian guidelines to identify commonalities and differences/inconsistencies, and examines guidelines from the US, Canada and New Zealand to see whether there are items/issues that may provide useful lessons for Australia. Provides a useful and comprehensive summary of what existed at the time of writing.
The Wardliparingga Aboriginal Research Unit, SAHMRI, 2014 [275]	South Australian Aboriginal Health Research Accord: Companion Document 2014.	Provides a guide for researchers and institutions on conducting health research involving Aboriginal communities in South Australia, based on a consultative workshop and a literature review. Reflects community 'expectations of how research with, for and by Aboriginal people should be developed and conducted.' Intended to complement rather than replace existing statements and guidelines (e.g. NHMRC). 9 key principles relate to: priorities; involvement; partnership; respect; communication; reciprocity; ownership; control; and knowledge translation.
Jamieson et al., 2012 [38]	Commentary: Ten 'best practice' principles for Aboriginal health research, proposed by highly experienced Indigenous and non-Indigenous researchers	5 'essential' principles relate to: 1) addressing a priority health issue as determined by the community; 2) conducting research within a mutually respectful partnership framework; 3) capacity building is a key focus of the research partnership, with sufficient budget to support this; 4) flexibility in study implementation while maintaining scientific rigor; 5) respecting communities' past and present experience of research. 5 'desirable' principles: 6) recognizing the diversity of Indigenous Australian populations; 7) ensuring extended timelines do not jeopardize projects; 8) preparing for Indigenous leadership turnover; 9) supporting community ownership; 10) developing systems to facilitate partnership management in multicentre studies
Couzos et al., 2005 [37]	'We are not just participants--we are in charge': the NACCHO ear trial and the process for Aboriginal community-controlled health research.	Describes methodological issues and 22 principles of community-controlled health research - a type of participatory research, that shifts balance of control from researchers to researched. Based on the experience of the NACCHO Ear Trial. Principles relate to: setting the research agenda (n=6); research project planning an approval (n=7); conduct of research (n=5); and analysis, dissemination and application of findings (n=4).

Table 1.3.3 Cochrane Systematic Reviews relating to clinical trial recruitment and retention

Author	Focus	Data sources	Dates	Key findings
Treweek et al., 2018 [276]	Improving recruitment to RCTs	Cochrane Methodology Register; MEDLINE and MEDLINE In Process (OVID); Embase (OVID); Science Citation Index & Social Science Citation Index (ISI); ERIC (EBSCO). Randomised and quasi-randomised trials, including studies recruiting to hypothetical trials. Excluded: studies aiming to increase response rates to questionnaires or trial retention; studies evaluating incentives and disincentives for clinicians to recruit participants.	to Feb. 2015	68 eligible trials, with more than 74,000 participants: 63 studies involving interventions aimed directly at trial participants; 5 evaluating interventions aimed at people recruiting participants. Only 3 comparisons with high level evidence: 1) Open trials better than blinded, placebo trials (10% improvement); 2) Telephone reminders to people who do not respond to a postal invitation (6% improvement) - not clear whether this applies if recruitment is not poor to start with; 3) Using a tailored, user-testing approach to develop participant information leaflets (working with target population on content, format, appearance) - little to no difference (1%; NS). 8 comparisons with only moderate level evidence - mostly results from a single study; 61 comparisons with limited interpretability due to design flaws, reliance on single study, uncertain results, or because they were hypothetical (mock) trials rather than real ones.
Preston et al., 2016 [277]	Strategies to help clinicians recruit patients to trials	Cochrane Methodology Register, CENTRAL, MEDLINE, EMBASE, CINAHL, British Nursing Index, PsycINFO, ASSIA and Web of Science (SSCI, SCI-EXPANDED). Reference lists of included studies and relevant reviews; citation tracking through Web of Science for included studies. Eligible: studies that evaluated a strategy to identify and recruit participants for research via healthcare professionals and provided pre-post comparison data on recruitment rates.	1985 to 5 Jan. 2015	11 studies eligible and included; all judged as having medium to high risk of bias. Several different strategies investigated. 4 studies looked at additional visits or information provision for potential recruiters at the study site - no increases in recruitment. Increases seen in 2 studies that used a dedicated clinical recruiter, and 5 studies that used an automated alert system (either a computer system or a member of staff to check patient records) for identifying eligible participants. Having a dedicated resource other than healthcare providers to identify eligible participants appears promising, but risk of bias is high.
Brueton et al., 2013 [278]	Improving retention in trials	Cochrane Central Register of Controlled Trials, MEDLINE, PreMEDLINE, EMBASE, PsycINFO, DARE, CINAHL, Campbell Collaboration's Social, Psychological, Educational and	up to May 2012	38 eligible retention trials were included. Six broad types of strategies were identified, including: incentives; communication strategies; new questionnaire format; participant case management; behavioural; and methodological interventions. Most trials looked at response to a questionnaire, rather than return to trial site for follow-up, as the outcome

		Criminological Trials Register, and ERIC. Hand search of conference proceedings and publication reference lists. Survey of all UK Clinical Trials Units to identify further studies. Eligible: randomised or quasi-randomised evaluations of strategies to increase retention that were embedded in 'host' randomised trials from all disease areas and healthcare settings.		of interest. Across multiple studies, monetary incentives (including vouchers) were associated with increased return of questionnaires. Unclear evidence regarding reduced questionnaire length and/or Q content. In single studies, recording of Q delivery more effective than telephone reminders; 'package' of postal communication with reminder letters better than 'standard' procedures; open trial design more effective than blind trial. No good evidence of positive or negative impact for: non-monetary incentives, 'enhanced' letters, priority post, additional reminders, or question order, or for telephone survey vs monetary incentive plus questionnaire.
Rendell et al., 2007 [279]	Incentives and disincentives for clinician participation in trials	Cochrane Methodology Register and Cochrane Database of Methodology Reviews searched in May 2006; Cochrane Central Register of Controlled Trials, National Research Register and ClinicalTrials.Gov searched in April 2005; EMBASE, MEDLINE, CINAHL, PsycINFO and AMED searched in April 2005. Reference lists of included studies were checked.	to April 2005	No RCTs identified. 11 observational studies included. 3 measures of recruitment used: invitation to participate; entry into RCT; reported entry to RCT. 5 studies looked at impact of patient characteristics - effect of age and prognosis varied. 6 studies looked at association between clinicians' views and recruitment. Clinicians who agreed to participate because they knew the researchers were less likely to participate than those with other motivation (1 study). Clinicians who had recruited were more likely to report difficulties, e.g. "trials involve extra work" (1 study) and "inviting patients to participate is embarrassing" (1 study). Impact of need to discuss clinical uncertainty was unclear, but concern that doctor-patient relationship would be adversely affected by participation was a deterrent (1 study). Lack of RCTs and variable results across studies limits interpretation. Further research needed.

Table 1.3.4 Patient navigation programs.

Author	Population group	Description	Key findings
CLINICAL TRIALS			
Fouad et al., 2014 [67]	US minorities	Use of community health advisors to promote clinical trial retention and adherence	Community Health Advisor model widely used for recruitment. This study looked at retention and adherence to appointments. 30 volunteer CHAs trained and used as research partners in intervention group of minority and low income women already participating in a study (versus usual care). Intervention group had higher attendance at scheduled visits (80% vs 65%). CHAs not employed, but some monetary and non-monetary incentives/rewards. Most said they did NOT want to be employed - their primary loyalty was to the women, as 'natural helpers'.
Fouad et al., 2016 [68]	African Americans	Evaluation of a clinical trials patient navigator program in one comprehensive cancer centre (University of Alabama Birmingham)	Conducted as part of the IMPaCT program (Improving Minority Participation in Clinical Trials). Two lay people hired and trained as clinical trials navigators to provide education about trials and to provide individual support to patients on trials to overcome barriers. Potentially eligible patients identified through chart review or referrals, and knowledge of available trials. Navigators integrated into the clinical trials team, which helped address system-level barriers. Types of support provided to address individual-level barriers were based on needs assessment and discussion with patient; could include help with transport/accommodation, appointment reminders, referrals to social worker and/or community/social services and resources. 'Ultimately, the goal of the PNs was to help patients navigate the health care system, take advantage of available resources, and follow the clinical trial protocol.' (p.558) In 2007-14, a total of 432 African American patients offered navigation, of whom 272 participated (63%). Most non-participation (about 86% combined) related to trial ineligibility, trial refusal, and not needing assistance. Navigators were employed full-time and handled 33 patients at a time on average. Participation of African Americans in clinical trials increased over the period from 9% to 16%. About 80% of patients referred to the program were enrolled in a trial. Navigated patients were almost 5 times more likely to complete trial. Cost-effectiveness of the model needs to be investigated.

Ghebre et al., 2014 [28]	Under-served groups	Systematic review (PubMed, Medline, CINAHL, articles between 2005 and 2012) examining how patient navigators have been used, types of barriers addressed, and working models of PN in the trial process.	NCI Patient Navigation (PN) Research Program examined effectiveness of PNs in cancer care for underserved groups. PN programs increasingly being explored as a means of addressing barriers to participation in trials in underserved populations. Only 12 eligible studies on PN and trial accrual. 5 reported on curriculum development and PN training; 6 reported on enrolment as an outcome (3 of these were on the Walking Forward program). PN as bridge between cancer centre and community. PN role in increasing awareness, knowledge, access to relevant CTs. Different models relating to where PN sits in the system (e.g. inside or outside the cancer team). A range of competencies addressed in training programs. Majority of people offered a PN accepted. Early evidence of success is promising, but more, larger studies needed. Barriers to cancer care and to cancer trials co-occur. Barriers include financial, psychosocial support needs. Lack of an appropriately matched, available trial remains a large stumbling block (ineligibility). Willingness to participate is not a big issue. Essential characteristics of PN programs include: community engagement, cultural competency and integration with cancer care team. Must address barriers and facilitators at individual patient-level and community-level (e.g. could be distance in one place, mistrust in another).
Petereit et al., 2004; [65] Rogers & Petereit, 2005; [66] *** Guadagnolo et al., 2009 [63] ***	Native Americans	Description and evaluation of the 'Walking Forward' program (Note: Several other articles have been published – these provide a useful overview)	Rapid City Regional Hospital services Lakota (Western Sioux) in western South Dakota. Median patient travel distance is 110 miles. Clinical trials developed (in partnership with larger cancer centres) to shorten radiation treatment from 6-8 weeks to 1-4 weeks to overcome distance barrier. Protocol changes required to reduce risk of radiation toxicities, as there is some evidence of increased susceptibility (this is being investigated). Patient navigator program established to: provide culturally appropriate community education; facilitate trial participation; guide patients in using the health system. Survey to assess potential barriers and solutions - screening, diagnosis, treatment; individual and cultural beliefs and perceptions. ***** 9 out of 94 Native Americans (10%) presenting to the clinic were enrolled in a trial. All trial participants underwent Patient Navigation. Lack of available trials and strict protocol inclusion criteria limited opportunity, but participation was higher than national levels. Very few refused. *****

Petereit et al., 2011 [64]			This paper reports on progress. Nearly 400 patients received patient navigation. Clinical trials accrual rate 10%. Nearly 2,500 AIs participated in research studies. Research infrastructure now in place. Walking Forward located within the Cancer Care Institute of Rapid City Regional Hospital. 100,000square km service area. Tailored Patient Navigation program to reduce disparities, overcome mistrust. PN included both working with cancer patients and community outreach. Phase II trials (breast, prostate), social science research. Close contact with tribal councils, quarterly reporting. Assessment of genetic susceptibility to radiation toxicities. Lack of trial accrual due much more to lack of relevant protocol or restrictive inclusion criteria (73%) than to refusal (only 5%). Program sustainability a major issue. 5 years additional funding from 2009 (but no updates on website since 2016).
OTHER			
McDonald, 2018 [69]	Various sites in the US and UK	Churchill Fellowship report on a study tour to investigate the role of patient navigation in cancer care and determine the feasibility of implementing a volunteer model of patient navigation of cancer care in Australia	Patient-centred care, compassionate health system are required. Four key areas for investment identified through Peter Mac consultations include: information and communication (timely and accessible); navigating your cancer experience (understanding the pathway); building capacity (patients as informed and active partners); support networks (family, friends, carers - but also patient navigation). Importance of defining boundaries and scope of practice for navigators. Navigation needs can fall into different areas, including: care management and coordination; social and psychosocial support; financial support and counselling; nutritional support and education. Fragmentation of care an important issue: navigator and patient are the only constants. Patient navigation less well established in Australia. Usually nurses, but heavy admin load. Confusion around roles and responsibilities. Different types of navigators: community health workers, patient navigators (lay), clinically licensed (nurse, social worker) navigators. Also peer navigators, who are volunteers. Different skill sets, different focus, different models. Peter Mac has implemented a patient navigation model in each tumour stream: first line of response, support patient flow through the system, facilitate access - administrative focused. There is also opportunity for a peer/volunteer model of patient navigation, as well as financial navigation, legal navigation/Health Justice Partnership, end of life care navigation. Aboriginal cancer navigation required (cultural safety, care coordination, system navigation), but workforce

			shortages, and the investment and support needed are more 'than currently available'. Return on investment to improve outcomes 'should be of the highest priority'. No single model can address all needs - need to be clear about what problems you are trying to address. Also need co-design, incorporate as part of multidisciplinary team, be clear about role, scope of practice, evaluate.
Whop et al., 2012 [62]	Indigenous peoples	Systematic review of cancer-related patient navigator programs. Publications up to 2011, identified through PubMed, MEDLINE, CINAHL	8 articles included - two specific programs: Native Sisters Program; Walking Forward Program. Native Sisters focused on breast screening to maximise opportunity for early detection, with support in navigating care for women diagnosed. Walking Forward included community education, care navigation for those diagnosed (including assistance with food, lodging, transport, overcoming other barriers, providing emotional support), encouragement and facilitation to participate in clinical trials. Importance of building trust, cultural competence. Impact of patient navigator programs is unclear due to differences across programs, differences in role/training of PN. Not clear which aspects might be important (Indigenous status, health training vs lay person, practical vs emotional support, etc.). Potentially very useful model, but more work needed to determine what works.

Table 1.3.5 Tele-trials.

Author	Jurisdiction - population group(s)	Description	Key findings
Clinical Oncology Society of Australia, 2016 [14]	Australasia	Australasian Tele-Trial Model	Describes the model and implementation considerations for tele-trials using the established tele-oncology approach. Core principles are to increase accessibility especially, but not exclusively, for rural and remote patients (trials closer to home); develop collaboration and networking to enhance clinical trials activity; and create relationships between sites to establish trial clusters. The additional ethics requirements for special populations (including Aboriginal and Torres Strait Islander people) are noted.
Sabesan & Zalcberg, 2018 [70]	rural and remote cancer patients	Description of COSA tele-trial model	Tele-oncology model has been successful in providing care close to home. This can be extended to enable clinical trials in rural and remote areas to enrol, consent, treat and follow up patients. This increases access for patients and also increases number of patients for trials (e.g. rare cancers). COSA tele-trial model endorsed by COSA Council in August 2015. The model includes primary and satellite sites in a cluster. Issues that need to be addressed include workforce, training in clinical trials, medico-legal issues, ethics and governance, indemnity, pharmacy services and management of toxicities. Internet speed and connectivity required. Documentation and exchange/recording of information is easiest if primary and satellite sites share same electronic medical records, but possible even if not.
Victorian Comprehensive Cancer Centre, n.d. [15]	Victoria	VCCC Tele-trial Program	VCCC Tele-trial Program based on COSA Tele-trials model, taking into account specific of Victorian requirements. 'Regional consumers have been consulted throughout the tele-trial implementation…' - no specific mention about whether this includes Aboriginal people. Initial trial involving a cluster with one metro site and two regional sites (Albury-Wodonga and Bendigo) will be evaluated. 'Tele-trials are a key tool for reducing barriers, such as time, cost and social disruption, for regional patients' access to cancer clinical trials.' Also News item from 12 December 2018 News: implementation under way in Albury Wodonga and Bendigo.

Table 2.0.1 Summary Cancer Control Research Report activities to 2010 (Source: Cancer Australia 2010)[72]

Organisation	Title	Focus
VICTORIA		
Cancer Council Victoria	Tobacco Control Program	Prevention, tobacco control / smoking cessation, treatment, training AHWs
Cancer Council Victoria	Pap Screening Program	Research, prevention, training AHWs
Cancer Council Victoria	Aboriginal Health Worker education	Research, prevention, education AHWs
Department of Health, Victoria	Victorian Aboriginal Palliative Care Program	Palliative care
Quit Victoria	Smoke free workplaces	Tobacco control / smoking cessation
Rumbalara Aboriginal Health Service	No more Dhonga	Tobacco control / smoking cessation
Rumbalara Football Netball Club (RFNC)	Koori Community Smokescreen	
NATIONAL		
AIHW & Department of Health and Ageing	Indigenous Pilot Programs for the National Bowel Cancer Screening Program	Screening
Australian GP Network, Royal College of Nursing Australia, and Batchelor Institute of Indigenous Tertiary Education	E-learning Training Package to Support Medicare Item 10997	Education, AHWs
Department of Health and Ageing	Healthy for Life	Screening

VicHealth Koori Health Research and Community Development Unit (became Onemda VicHealth Koori Health Unit), Centre for Excellence in Indigenous Tobacco Control (CEITC), ABS, Menzies School of Health Research	National Aboriginal and Torres Strait Islander Social Survey, Analysis of Smoking Data	Tobacco control / smoking cessation
Rural Health Education Foundation	Education services	Education
The National Palliative Care Program (Department of Health and Ageing)	Program of Experience in the Palliative Approach (PEPA)	Palliative care education, AHWs
ACOSH; Mary G Enterprises	Mary G Radio Advertising	Tobacco control / smoking cessation
NEW SOUTH WALES		
Aboriginal Medical Service of Western Sydney (AMSWS)	Butt Busters	Tobacco control / smoking cessation
Aboriginal Health College	Cancer Awareness Skills Set	Education, AHWs
BreastScreen NSW	Training on Breast Cancer and Breast Screening for Aboriginal Health Workers on the North Coast – Lismore	Research, screening, access to services, AHW training.
Cancer Council NSW	Aboriginal Health Worker training	AHWs awareness
Cancer Council NSW	Environmental Tobacco Smoke and Children Project	Screening
Cancer Council NSW and Aboriginal Health and Medical Research Council of NSW	Aboriginal Stories of Cancer Journeys Project	Education

Cancer Institute of New South Wales	Aboriginal Cancer Care Coordinator	Research, screening, diagnosis/staging, improve patient journey.
Department of Health and Ageing	No Smokes North Coast – A Comprehensive Koori Quit campaign	Research, Screening, Tobacco control / smoking cessation
Healthy Cities Illawarra, Cancer Council NSW, National Heart Foundation Aust, Illawarra Area Health Service, South Coast Aboriginal Medical Service, Illawarra Aboriginal Medical Service NSW	Smoke Free Zone, Smoke Free Car and Home, Healthy Cities	Tobacco control / smoking cessation
HNE Area Health Service, Awabakal Aboriginal Medical Service and HNE Aboriginal Health Unit	HNE Area Health Service, Awabakal Aboriginal Medical Service and HNE Aboriginal Health Unit Breast Screening Project	Research, screening, access to services, map treatment pathways.
Mid North Coast Division of General Practice, Galambila AHS, UNSW Rural Clinical School	Give Up the Smokes	Screening/prevention, Tobacco control / smoking cessation
National Heart Foundation Australian (NSW Division), Biripi Aboriginal Medical Corporation, SIDS and Kids NSW (Hunter region), and The Cancer Council NSW (Mid-North Coast region)	Environmental Tobacco Smoke, Aboriginal Health Worker Training	Tobacco control / smoking cessation, AHW training
NSW Department of Health	SmokeCheck	Research, screening/prevention, Tobacco control / smoking cessation, AHWs
South Coast Aboriginal Medical Service, Illawara Aboriginal Medical Service, Illawara Health, National Heart Foundation of Australia NSW	Koori Tobacco Cessation Project	Tobacco control / smoking cessation Smoking cessation

South Coast Medical Service Aboriginal Corp, Illawarra Aboriginal Medical Service and Katungal Aboriginal Corporation	Clean Air Dreaming Project	Tobacco control / smoking cessation
SSWAHS Health Promotion Service; Aboriginal Metropolitan Council; Australian Indigenous Doctors' Association; Aboriginal Medical Services Redfern	Environmental Tobacco Smoke (ETS) and Harm of Tobacco Smoke while Breast Feeding	Tobacco control / smoking cessation
The Australian Centre for Health Promotion, Uni of Syd, NSW Health, Cancer Institute NSW	*SmokeCheck*, NSW	Tobacco control / smoking cessation
NORTHERN TERRITORY		
-	Gynaecology Outreach Service (GOS)	Screening/prevention
Aboriginal Resource and Development Service	Audio Education Programs	Research
Aboriginal Resource and Development Service	Community Education Sessions	Research
Cooperative Research Centre for Aboriginal and Tropical Health	Tobacco Action Project	Tobacco control / smoking cessation
Department of Health and Families	Well Women’s Screening Program (WWSP)	Screening/prevention
Department of Health and Families	Northern Territory Tobacco Action Plan, 2010-2013	Tobacco control / smoking cessation
Department of Health and Families	Aboriginal health and families: a five year framework for action	Other

Menzies School of Health Research	Audit and Best Practice for Chronic Diseases (ABCD). Audit and Best Practice for Chronic Diseases Extension (ABCDE)	Research, treatment
School of Public Health, Tropical Medicine and Rehabilitation Sciences, JCU, Cairns	Top End Tobacco Project	Tobacco control / smoking cessation
Wurli Wurlinjang Health Service	Chronic Disease Program	Screening/prevention
Wurli Wurlinjang Health Service	Sexual Health Program	Education, screening/prevention, other.
QUEENSLAND		
Queensland Cervical Screening Program	Healthy Women's Initiative (HWI)	Screening/prevention
Cancer Council Qld	Pilot program – Cancer care course for Aboriginal Health Workers	AHWs (training)
Cancer Council Qld	Speakers Program	Research, screening/prevention, AHWs (training)
Queensland Health	Mobile Women's Health Service (MWHS)	Screening/prevention
Queensland Health (Tropical Public Health Unit Network, Cairns), JCU (School of Public Health and Tropical Medicine, Cairns) and eight participating communities in northern Queensland	Indigenous Tobacco Project: Implementation and Evaluation of Anti-Smoking Interventions	Tobacco control / smoking cessation
Queensland Health, Uni of Queensland, JCU, Tropical Public Health Unit	*SmokeCheck*, QLD	Tobacco control / smoking cessation
SOUTH AUSTRALIA		

Aboriginal Health Council of South Australia (AHCSA)	Aboriginal Health Council of South Australia (AHCSA) Tobacco Control Project	Tobacco control / smoking cessation
Aboriginal Health Council, SA Government, Cancer Council SA, Heart Foundation	Quit SA – Quit skill training program	Research, Screening/prevention, tobacco control / smoking cessation, AHWs (training)
BreastScreen SA	BreastScreen SA	Research, Screening/prevention, access to services
Cancer Council SA, Aboriginal Health Council SA, Aboriginal and Torres Strait Islander Liaison Unit, Royal Adelaide Hospital, Aboriginal Health Division, SA Department of Health	CanSUPPORT - Perko Ngurratti *Healing Messages* Aboriginal and Torres Strait Islander cancer information	Identification of support & information needs
Cancer Voices SA	Pilot study of Cancer Conversations in Aboriginal Communities, South Australia	Research, Screening/prevention, support/survivorship/QoL, stigma.
SA Department of Health	Strategic Health Research Program	Screening/prevention, Tobacco control / smoking cessation, smoking cessation of AHWs
The Second Story; Kumangka Aboriginal Youth Service; AHCSA; South Australian Film Corporation	Nunga Kids don't Need Puiya	Tobacco control / smoking cessation
ACT		
Winnunga Nimmityjah Aboriginal Health Service; QUIT ACT (Cancer Council ACT)	No more Bundah	Tobacco control / smoking cessation
WESTERN AUSTRALIA		
-	Make Smoking History: Fresh start program	Tobacco control / smoking cessation

-	Indigenous Women’s Cancer Support Group, Western Australia	Research, Support/Survivorship/QoL
-	Aboriginal Women’s Cancer Action Group	Support/Survivorship/QoL
Cancer Council WA	Cancer Education for Aboriginal Health Workers	Research, Screening/prevention
Combined Universities Centre for Rural Health	Smoke Free Kids	Tobacco control / smoking cessation
East Metropolitan Population Health Unit	Say No to Smokes,	Tobacco control / smoking cessation
Heart Foundation	Smarter than Smoking	Tobacco control / smoking cessation
Kimberley Aboriginal Medical Services Council (KAMSC) and Aboriginal Health Council of Western Australia (AHCWA)	Beyond the Big Smoke	Tobacco control / smoking cessation
Smoking and Health Program, Health Department of Western Australia	The Western Australian Aboriginal Smoking Project	Tobacco control / smoking cessation
WA Country Health	Community development, health promotion and harm minimisation	Tobacco control / smoking cessation
Women’s Health Care Association	Aboriginal Women’s Project	Tobacco control / smoking cessation

Table 2.0.2 National and Victorian framework, context or policy documents

Institution/Author, Year	Document name	Summary
NATIONAL		
Australian Commission for Safety and Quality in Health Care (ACSQHC), 2018 [89]	Review of the key attributes of high-performing person-centred healthcare organisations	Not focussed on Aboriginal and Torres Strait Islander people, but contains case studies of various services and efforts to improve care for Aboriginal people. Conducted desktop review, site visits to eight high-performing health care organisations (four in Australia). Aimed at complementing the NSQHC Standards and providing practical information to health services to assist in the delivery of person centred care and help meet NSQHS Standards. Advocates striving for equity through partnering with Aboriginal and Torres Strait Islander community representatives, ensure workforce training and resources to provide culturally appropriate care and address barriers in access to care. Cites case study examples. Western Health, Victoria. Improving Care for Aboriginal and Torres Strait Islander Patients Program: development of an Aboriginal Health Roadmap, cultural awareness training for the workforce, partnerships with Aboriginal health services and organisations and Aboriginal employment initiatives. SA Riverland Mallee Coorong Region. Telehealth to deliver multidisciplinary care and person centred care, including lessons learned: patients involved in design and delivery; culture change for clinicians; teamwork and community health connections critical; simple technology; internet connectivity a challenge – SIM cards more reliable than wifi. Strong uptake by Aboriginal patients in cardiology telehealth program.

Harrison et al., 2015 [90] Australian Commission on Safety and Quality in Health Care (Sax Institute), 2015	Patients' experiences in Australian hospitals: an Evidence Check Rapid Review brokered by the Sax Institute.	A review of qualitative Australian studies that examined hospital or day-case patient's experiences. Aimed at determining characteristics of positive and negative experiences, identifying system/service related factors and association with patient characteristics. Advised larger multisite studies with qualitative components, focusing on Indigenous patient's (and other groups), to address the failure of structured survey methods to capture nuanced experiences. Summary of findings involving Indigenous people: • Miscommunication and a lack of cultural and spiritual understanding among health professionals • Lack of preparation about what to expect from hospital and challenges of having to leave close communities to give birth • The provision of hospital self-care accommodation valued as a way to feel safe if outside community • Lack of communication and information provision in hospital led to feelings of loneliness • Lack of clear communication with Indigenous women who speak little English threatens safety of care • Those that had a positive experience were proactive in asking questions and seeking information • Cultural competence was highlighted in negative care experiences of Indigenous patients (& others).
Australian Health Ministers' Advisory Council's National Aboriginal and Torres Strait Islander Health Standing Committee, 2016-2026 [86]	Cultural Respect Framework (renewal of 2004-2009)	A National Approach to Building a Culturally Respectful Health System. This framework outlines six domains that underpin culturally respectful health service delivery: 1. Whole-of-organisation approach and commitment 2. Communication 3. Workforce development and training 4. Consumer participation and engagement 5. Stakeholder partnerships and collaboration 6. Data, planning, research and evaluation.

Australian Health Minister's Advisory Council, 2017 [83]	Aboriginal and Torres Strait Islander Health Performance Framework Report	Sixth report against Aboriginal and Torres Strait Islander Health Performance Framework. Acknowledges the clear gap in 'robust evaluation evidence' regarding intervention effectiveness. Released every two years to support efforts across and beyond the health sector to address the factors that contribute to health outcomes experienced by Aboriginal and Torres Strait Islander Australians. High level summary data and policy analysis across 68 performance measures across: health status and outcomes; determinants of health, including socioeconomic and behavioural factors; and health system performance. 'There has been a 21% increase in cancer mortality rates for Indigenous Australians and a 13% decline for non-Indigenous Australians between 1998 and 2015. It will take up to 30 years for the reductions in Indigenous smoking rates to flow through to reduced cancer deaths. Research has found disparities in cancer screening rates, stage at diagnosis, treatment rates (including lower rates of surgery, chemotherapy and radiotherapy) and lower survival rates for Indigenous Australians.'
Australian Institute of Health and Welfare (AIHW) / Closing the Gap (CTG), 2018 [78]	Closing the Gap targets: 2017 Analysis of progress and key drivers of change	Looks at drivers related to COAG targets in Child mortality, early childhood education, school attendance, literacy and numeracy, year 12 attainment, employment, life expectancy. Key themes across the targets: Social determinants are critical; remoteness has a relatively large impact; improved access to services is needed; investment is needed across the life course; interactions between outcomes are important; need more evidence on 'what works'.
Australian Institute of Health and Welfare (AIHW), 2018 [82]	Cancer in Aboriginal and Torres Strait Islander Australians: An overview	Summary statistics on cancer in Aboriginal and Torres Strait Islander people
Willis et al. for Australian Institute of Primary Care (AIPC), Melbourne, 2010 [76]	Improving the Culture of Hospitals Project (ICHP Final report)	Multiple organisations involved in establishing this project. Aimed to contribute to closing the gap by developing a range of resources, tools and guidelines to assist hospitals across Australia to improve their services to Aboriginal and Torres Strait Islander people. Six phases. First three phases: consultation with Aboriginal and mainstream health providers; a review of operating contexts within hospitals; and the development of case studies within hospitals. Last three phases; testing of interventions including culturally sensitive continuous quality improvement (CQI) tools, processes and guidelines on location.

Essential factors from **case studies** include: targets set for increasing the Aboriginal workforce; well-articulated role statements for Aboriginal Health Liaison Workers and all Aboriginal staff; the establishment of Aboriginal teams rather than sole workers; Aboriginal staff employed in mainstream positions not just Aboriginal Hospital Liaison Officer roles; time allocations for Aboriginal workers to maintain relationships with community organisations, visit Aboriginal patients and fulfil their community responsibilities; clearly defined lines of accountability; and supportive senior management staff who are committed to the cultural change program. Most importantly, the hospital must promulgate the explicit understanding that improved outcomes for Aboriginal patients are the responsibility of all hospital staff, not just the Aboriginal workers.

Case study findings: generating strong partnerships with Aboriginal communities was the foundation for any attempt to improve services to Aboriginal people and required commitment, time and resources. All hospitals studied: referred to national Cultural Respect Framework (2004-2009) and undertook a range of activities related to it; had Board members, CEOs and clinical staff who exhibited leadership in relation to improving services to Aboriginal patients; had generated a number of internal strategic policies aimed at improving the health of Aboriginal patients; established a formal Aboriginal Hospital Liaison Officer or an Aboriginal Health Liaison Worker role.

Hospitals had varying approaches to cultural awareness training. Some hospitals had policies that facilitated Aboriginal ceremonies and events, which seemed to be related to the quality and extent of the established relationship rather than the size or location of the hospital.

Recommendations re **CQI toolkit**: 1. Hospital staff need access to support unit for training (initial and ongoing); 2. Health funding agreements fund the Framework and Toolkit, including support for ALO training program and Aboriginal CQI workers. 3. That Australian Council on Healthcare Standards (ACHS) and Evaluation and Quality Improvement Program (EQuiP) include more standards relating to Aboriginal people and reference the Framework and Toolkit. 4. Commonwealth, state and territory health funding for a second phase of this project to generate evidence based case studies and a Train the Trainer component. 5. Conduct evaluation of Aboriginal-specific CQI process and tools in 2 years.

Contains literature review and brief summaries of many articles (prior to 2010) on: cultural safety; quality improvement; evaluation, monitoring and accreditation; and cultural frameworks.

Cancer Australia / Cancer Council South Australia, 2010 [72]	Cancer Control Research Report	Aimed to provide direction for reducing the disparities experienced by Aboriginal people across the cancer continuum, in order to improve their cancer outcomes. Review and gap analysis.
Cancer Australia / Menzies School of Health Research, 2015 [109]	National Aboriginal and Torres Strait Islander Cancer Framework	Widely collaborative effort to set strategic direction to address disparities and improve cancer outcomes for Aboriginal and Torres Strait Islander people. Underpinned by **principles**: Aboriginal and Torres Strait Islander people are engaged and involved throughout the planning, design and delivery of cancer services; Patients, families, carers and communities are informed and empowered; Working together towards a common goal; Policy and practice informed by reliable data and evidence about what works. Seven **priorities**: 1) Improve knowledge, attitudes and understanding of cancer by individuals, families, carers and community members (across the continuum). 2) Focus prevention activities to address specific barriers and enablers to minimise cancer risk for Aboriginal and Torres Strait Islander peoples. 3) Increase access to and participation in cancer screening and immunisation for the prevention and early detection of cancers. 4) Ensure early diagnosis of symptomatic cancers. 5) Ensure Aboriginal and Torres Strait Islander people affected by cancer receive optimal and culturally appropriate treatment, services, and supportive and palliative care. 6) Ensure families and carers of Aboriginal and Torres Strait Islander people with cancer are involved, informed, supported and enabled throughout the cancer experience. 7) Strengthen the capacity of cancer related services and systems to deliver good quality, integrated services that meet the needs of Aboriginal and Torres Strait Islander people.
Cancer Australia, 2016 [85]	National Framework for Gynaecological Cancer Control	Guides future directions in national gynaecological cancer control over the next 5 years to improve outcomes, through consideration of models of care, integration across the cancer continuum, populations with variations in outcomes, research directions. Reports comparatively high burden on Aboriginal and Torres Strait Islander women - calls for quality, integrated services that meet the needs of this population. Priority area two is to improve outcomes for this population. Advocates centralised model of treatment, multidisciplinary care. For Aboriginal women, acknowledges context. Strategies to improve outcomes include: undertake research to identify views and identify barriers to screening, early detection/treatment and access to services; raise awareness of risk factors and symptoms to support prevention and early detection; increase participation in National Cervical Cancer Screening program; improve national recording of Indigenous status in pathology requests and reports; strengthen capacity

		of cancer related services to deliver culturally appropriate, integrated services across the continuum; identify patterns of care.
Cancer Australia, 2018 [84]	Lung cancer framework: principles for best practice lung cancer care in Australia.	Lung cancer framework: principles for best practice lung cancer care in Australia: a national resource for health professionals and service providers who are involved in the care and treatment of people affected by lung cancer across Australia. The Lung Cancer Framework provides evidence-based, best practice information, strategies, tools and resources at consumer level and health service level, to support local adoption of the Principles in the delivery of best practice lung cancer care in Australia, however does not outline specific strategies for Aboriginal people. No specific mention of Aboriginal people other than acknowledgement, glossary, and variations in incidence and outcomes.
Department of Health, 2018 [81] Council of Australian Governments (COAG)	National Palliative Care Strategy 2018	Recognise there may be particular cultural needs or end-of-life rituals for Aboriginal and Torres Strait Islander people receiving palliative care, in the context of person- centred care. ‘Other relevant policies’ include: National Aboriginal and Torres Strait Islander Health Plan (2013-2023) and Cultural Respect Framework for Aboriginal and Torres Strait Islander Health (2016-2026). Acknowledge that Aboriginal and Torres Strait Islander population is currently underserved. Multiple relevant recommendations including overcoming barriers to access (eg culturally safe care environments), providing culturally safe care, collaboration with ACCHOs, partnerships with Aboriginal people, workforce related, improved engagement, and improved identification of Aboriginal and Torres Strait Islander people. An Implementation Plan and a Monitoring and Evaluation Plan will be developed.
Department of Health, 2013 [74]	National Aboriginal and Torres Strait Islander Health Plan 2013–2023	Long term, evidence-based policy framework as part of COAGs' approach to Closing the Gap. Strength based approach. Cancer is included in chronic diseases. A historical summary of the Australian government health related plans, strategies and framework around the health of Aboriginal and Torres Strait Islander people can be found in Appendix A.
Department of Health, 2015 [73]	Implementation Plan for the National Aboriginal and Torres Strait	The Implementation Plan provides the action necessary for government, the ACCHO sector and other stakeholders to enact the National Aboriginal and Torres Strait Islander Health Plan. Contains links to numerous related strategies and frameworks.

	Islander Health Plan 2013–2023	
Indigenous Allied Health Australia, 2015 [88]	Cultural Responsiveness in Action, An IAHA Framework	Places culture at the centre of the model, describes cultural responsiveness as an extension of patient centred care and sets out a framework with six key capabilities and outcomes, guided by 'being, knowing and doing'. Addresses culturally responsive governance.
National Aboriginal Community Controlled Health Organisation (NACCHO), 2018 - 2023 [87]	National Framework for Continuous Quality Improvement (CQI) in Primary Health Care for Aboriginal and Torres Strait Islander People	Provides a framework on which to base plans and improvement priorities, reflecting ACCHO experience. Outlines what is required at health system level to support an effective CQI approach for Aboriginal and Torres Strait Islander people. Implementation needs to be tailored to the local context. CQI part of a range of activities that support and improve quality in health care + governance, accreditation, monitoring and evaluation. The main focus areas of CQI to support improvements in health care and health for Aboriginal and Torres Strait Islander people are outlined in the following four domains: 1. Being culturally respectful in CQI 2. Doing CQI 3. Supporting CQI 4. Informing CQI. The Department of Health is undertaking a multi-level approach to embedding CQI in clinical practices in ACCHOs. This includes developing a National CQI Framework and Implementation Plan, expanding the CQI elements of the Healthy for Life programme, and putting in place the system-level supports required to undertake and embed CQI at the service level. CQI can be defined as making continuous effort to test how well systems are working and the quality of care being given to bring about lasting improvement. It focuses on improving systems. CQI is included in the Purchasing and Performance Framework as a desired organisational characteristic for ACCHOs.

National Aboriginal Community Controlled Health Organisation (NACCHO), 2013-2030 [77]	Healthy Futures 10-point plan	Targets and long-term actions critical to health, communities and services. Outlines 6 steps to success involving feasibility, cost and timing of the targets, service model development, workforce strategy, funding strategy, collaboration agreements and implementation plan to achieve the 10-point plan: 1. Invest in the Aboriginal Community Controlled Health Sector. 2. Deliver Innovative Comprehensive Primary Health Care 3. Aboriginal Health Leadership 4. Partnership 5. Health System Reform 6. Health Finance 7. Health Workforce 8. Health Infrastructure 9. Research and Data 10. Accountability, Reporting, Monitoring and Evaluation
The Wardliparingga Aboriginal Research Unit of the South Australian Health and Medical Research Institute (SAHMRI), 2017 [75] Australian Commission for Safety and Quality in Health Care (ACSQHC)	National Safety and Quality Health Service Standards user guide for Aboriginal and Torres Strait Islander health	For the first time, in 2017 the ACSQHC defined six actions aimed at specifically meeting the needs of Aboriginal and Torres Strait Islander people within the National Safety and Quality Health Service Standards and The Wardliparingga Aboriginal Research Unit developed a user guide to assist health organisations to meet the standards and measure performance. The six actions (each including what the actions mean for the organisation, benefits of taking action, key tasks, strategies, examples of supporting evidence and additional resources) are: a) Partnering with Consumers Standard: The health service organisation works in partnership with Aboriginal and Torres Strait Islander communities to meet their healthcare needs. b) Clinical Governance Standard(b-e): The governing body ensures that the organisation's safety and quality priorities address the specific health needs of Aboriginal and Torres Strait Islander people c) The health service organisation implements and monitors strategies to meet the organisation's safety and quality priorities for Aboriginal and Torres Strait Islander people d) The health service organisation has strategies to improve the cultural awareness and cultural competency of the workforce to meet the needs of its Aboriginal and Torres Strait Islander patients e) The health service organisation demonstrates a welcoming environment that recognises the importance of cultural beliefs and practices of Aboriginal and Torres Strait Islander people f) Comprehensive Care Standard; The health service organisation has processes to routinely ask

		patients if they identify as being of Aboriginal and/or Torres Strait Islander origin, and to record this information in administrative and clinical information systems.
VICTORIA		
Arabena et al (University of Melbourne, Peter MacCallum Cancer Centre), 2015 [95]	Rethinking cancer, Raising Hope - Aboriginal and Torres Strait Islander 'State of Knowledge' on Cancer Roundtable	A Roundtable held in August 2014 brought together participants from cancer services and community controlled, mainstream, government and non-government agencies. The Roundtable aimed to improve collaboration in clinical care and research into cancer in Aboriginal and Torres Strait Islander populations, thereby aiming to improve cancer prevention, control and treatment for Aboriginal communities in Victoria. Priority areas for future action included: Development of Cancer Action Plan for Victoria with a focus on Aboriginal community engagement, coordination and evidence informed strategic initiatives; address barriers to early detection; Demonstrate how Cancer Action Plan can help Close the Gap; support strong, focused workforce in early screening and detection initiatives; Aboriginal capacity building in cancer research and control; pilot innovative transition services; develop understanding of needs of people other than the patient; improve patient pathway to enable accessing of timely, appropriate care and support; promote data linkage and strengthening opportunities; find local explanation for epidemiological disparities; ongoing research and community consultation.
Department of Health and Human Services (DHHS), 2016 [280]	Victoria’s end of life and palliative care framework	A guide for high-quality end of life care for all Victorians. Very limited and general reference to Aboriginal people, other than acknowledging that additional measures and education are needed.

Department of Health and Human Services (DHHS), 2016-2020 [10]	Victorian Cancer Plan: Improving cancer outcomes for all Victorians	First cancer plan developed under the 'Improving Cancer Outcomes Act 2014'. Framework to improve cancer care for all Victorians, to be reviewed every four years. **Long-term goals (2040)** are to: halve the proportion of Victorians diagnosed with preventable cancers; double the improvement in one- and five-year survival of Victorians with cancer; ensure Victorians have the best possible experience of the cancer treatment and care system; achieve equitable outcomes for all Victorians. **For Aboriginal people specifically**: Seeks to embed culturally responsive approaches across the cancer pathway through planning, designing and delivering services with Aboriginal people, building a culturally competent and responsive workforce and increase the number of Aboriginal people in the cancer care workforce, and strengthening data collection and performance monitoring of access and outcomes for Aboriginal people. Cites Working Together for Health (Loddon Mallee Region, Gippsland Region, Ballarat) and Hume region efforts to improve access to cancer care for Aboriginal people. Address barriers, partnerships with ACCHOs, cultural awareness activities. **Priorities** are: Primary prevention: Reduce risk factors related to lifestyle and environment; Prevent cancers related to viral infections. Screening and early detection: Equity in screening participation; Increase access to familial risk assessment for people at risk; Improve cancer awareness and primary care capacity. Treatment: Consistent quality through Optimal Care Pathways; Improve patient's experience of care; Optimise infrastructure, data and system design. Wellbeing and support: Maintain quality of life through strengthening supportive care and self-management, recovery, survivorship, palliative care and end of life care. Research: Improve access to clinical trials; Support researchers to collaborate; Accelerate translation of research into clinical outcomes. The **system supports** to achieve these outcomes include: Integration: working together to deliver optimal care pathways Innovation: supporting and systematic scaling-up of innovative practice Investment: in infrastructure, outcome-focused service models and research platforms Intelligence: better access to and use of data and information to drive continuous improvements Workforce: ensuring a workforce that can meet the future needs of cancer prevention and care **Principles** underpinning the approach: Person-centred care with equitable access; Prevention focused across the care pathway; Quality and safe care; Evidence informed; Sustainable system.

Department of Health and Human Services (DHHS), 2017 [91]	Victorian Cancer Plan Monitoring and Evaluation Framework	Broadly aligns with Cancer Plan 2016-2020 to include indicators and measures of outcomes. Designed to help understand the extent to which avoidable gaps in cancer outcomes are being reduced and provides a mechanism for reporting on inequalities between population groups. Four levels: Outcomes (reduction in inequalities pertaining to the outcomes is implied in each); key result areas; indicators; measures. Data is further defined in Victorian cancer plan monitoring and evaluation framework: data dictionary. Aspects specific to Aboriginal Victorians or of particular relevance to this report are: • Outcome: improve cancer outcomes. Key result areas: 1 decrease incidence of preventable cancers; 2 decrease deaths due to cancer; 3 improve survivorship quality of life. • Outcome: equitable outcomes for all Victorians. Key result areas: 4 equitably reduce cancer incidence (includes measure of the rate ratio of preventable cancer incidence between Aboriginal and non-Aboriginal Victorians); 5 equitably reduce cancer deaths (including measure - rate ratio of premature death between Aboriginal and non-Aboriginal Victorians). • Outcome: prevent cancers; Key result areas: 6 Decrease smoking and harmful alcohol consumption; 7 Increase healthier eating and active living; 8 Decrease obesity; 9 Decrease UV exposure; 10 Decrease HPV and viral hepatitis impact. • Outcome: detect cancers early. Key result area: 11 Increase early-stage diagnosis - (Stages 1 and 2; Breast, CRC, cervix, lung at stages 1 and 2; late stage). • Outcome: optimal diagnostics and treatment. Key result area 12: Increase adherence to optimal care pathways; 13: Increase one- and five-year survival; 14 Improve quality of life. • Outcome: best possible experience of care systems. Key result area 15: Improve patient experience of healthcare; 16: Improve patient experience of screening. • Outcome: integrated research systems. Key result area 17: Innovations and improved evidence of best practice. Availability of data assessed for various categories including Aboriginal and Torres Strait Islander people of Victoria. Measures tabulated (Appendix 2) according to whether they are currently collected and available (Y), not currently collected (N), further work required to develop the measure or data source (TBD) or not applicable to the indicator (N/A).

Department of Health and Human Services (DHHS), 2017 [281]	Koolin Balit 2012-2017	Common themes across the evaluations: Connections to Place and Culture are crucial for health and wellbeing The Aboriginal workforce experiences dangerous levels of racism and vicarious trauma Government should be more active in some specific areas (accountability – effective cultural safety improvement measures; alternative funding models; monitor Aboriginal people's experiences of care; guidelines for delivery and evaluation of cultural safety training. Opportunities for greater coordination and sharing good practice. In some cases, there is a need for more connection within local areas.
Department of Health and Human Services (DHHS), 2017–2027 [94]	Korin Korin Balit-Djak: Aboriginal health, wellbeing and safety strategic plan	Strategic direction 5.2.2: Improve cancer outcomes for Aboriginal Victorians: Over next 3 years: a. Increase access to culturally safe cancer prevention and screening, and improve transition to treatment, support and care. b. Improve community knowledge and awareness about cancer and its effects on Aboriginal people, families and communities. c. Review and respond to the recommendations of Cancer Council Victoria's analysis of barriers to HPV vaccination in Aboriginal young people. d. Develop Aboriginal culturally informed clinical cancer pathways and treatment, which will inform other clinical streams requiring a stronger cultural focus. e. Build a cancer care workforce that is culturally competent and responsive, and increase the number of Aboriginal people in the cancer care workforce.
Social Compass (for Department of Health and Human Services (DHHS)), 2016 [93]	Improving Cultural Responsiveness of Victorian Hospitals (Follows on from Improving the Culture of Hospitals Project (AIPC 2010))	This mainly qualitative evaluation placed the voices of Aboriginal people at the centre (144 of 173 interviews were with Aboriginal people). Conducted January-October 2016 with the following questions: 1. To what extent have Victorian hospitals improved their cultural responsiveness to Aboriginal people? 2. To what extent have people's healthcare experiences in Victorian hospitals (including cultural safety) changed? 3. What strategies have led to the most significant and sustainable improvements in cultural responsiveness and cultural safety of hospitals for Aboriginal people and staff? What are the critical contextual factors which enabled this success, and how could the successful strategies be replicated in other hospitals/settings? Have there been any unintended consequences of the successful strategies?

4. Are there strategies being employed which are relatively ineffective or unsustainable?
5. How can we improve measurement and monitoring of cultural responsiveness and cultural safety, both by individual hospitals and state-wide? How can we incorporate measuring the gaps between Aboriginal and non-Aboriginal people's access to quality care as a key impact?
Phases: >40 consultations (key central and regional department staff and external stakeholders; document and data review of >200 documents (including CQI reports, Quality of care reports, Statement of Priorities analysis, Aboriginal Employment Plans, Victorian Healthcare Experience Survey results, previous evaluations and academic research); 7 hospital case studies and interviews with hospital staff, ACCHO staff, patients, community members; Aboriginal Hospital Liaison Officer (AHLO) Survey: online survey provided to all AHLOs / Koori Mental Health Liaison Officers (KMHLOs) exploring the findings from interviews with AHLOs / KMHLOs at case study sites. The survey was administered through the ICAP Network with VACCHO. There were 15 surveys returned with a response rate of 20 per cent.

Findings: Consistent story of hospitals being sites of trauma for many Aboriginal people, not places of healing. Presents definitions of cultural responsiveness and cultural safety that emerged from community interviews. Found significant gaps in measurement and reporting of cultural responsiveness and cultural safety. Themes (consistent across participants):

- committed leadership (many CEOs and leaders are looking for support to improve cultural responsiveness and cultural safety);
- relationships with ACCHOs;
- AHLOs (most feel undervalued and neglected – subject and object of community trauma – stress leave common) and a stronger Aboriginal health workforce;
- a welcoming environment (flags, plaques, artwork, though tokenistic if the service system does not support them);
- cultural safety training (no evidence available of systematic capturing of performance or outcomes – hospitals looking for support);
- monitoring and reporting) none at hospital or state-wide level for reporting cultural responsiveness or cultural safety – current mechanisms ad hoc, non-mandatory and incomplete – no reliable hospital or state-wide data on Aboriginal patient experience.

	Provided set of indicators and measures to assist with monitoring and reporting cultural responsiveness and cultural safety, and can be used against the new National Safety and Quality Health Service Standards (ACSQHC 2017) ‘Overall the evaluation finds that increasing the support and capacity of the AHLO/KMHLOs will have the biggest impact on cultural responsiveness and cultural safety.’ Contains Loddon Mallee Culturally Responsive Framework: Domain; Description; Actions. Three domains of change influencing a hospital’s ability to provide culturally responsive care and cultural safety: 1. Hospital leadership and organisational culture. 2. Aboriginal and Torres Strait Islander workforce. 3. Aboriginal community relationships – including local ACCHOs, Traditional Owners and Aboriginal patients.

Table 2.1.1 Barriers and enablers to accessing or completing cancer treatment experienced by Aboriginal people with cancer

BA: Barriers accessing. BC: Barriers completing. En: Enablers. 0=no; 1=yes.

Author, year, study type	State or area, Sector	Description	Population	BA	BC	En	Short summary
Adams et al., 2015 [141] Qual	Qld, Tertiary	Prevalence and profile of complementary and alternative medicine (CAM) / traditional Indigenous medicine (TM) users among Indigenous Australians with cancer.	248 Indigenous adults diagnosed with cancer at one of 4 Qld hospitals	0	0	1	"A substantial percentage (18.7%) of Indigenous cancer patients use at least one TM/CAM for support with their care, including traditional Indigenous therapy use (2.8%), visiting a traditional Indigenous practitioner (2.8%), CAM use (10.7%), visiting a CAM practitioner (2.4%), and attending relaxation/meditation classes (4.0%). Having a higher level of educational attainment was positively associated with CAM practitioner consultations (P = .015). Women with breast cancer were more likely to attend relaxation/meditation classes (P = .019). Men with genital organ cancer were more likely to use traditional Indigenous therapies (P = .017) and/or CAM (P = .002). Conclusion. A substantial percentage of Indigenous Australians reported using TM/CAM for their cancer care. Need to expand examination of this area of health care using large-scale studies focusing on in-depth specific cancer(s)."
Arabena et al. (University of Melbourne, Peter MacCallum Cancer	Vic	Rethinking cancer, Raising Hope - Aboriginal and Torres Strait Islander 'State of Knowledge' on Cancer Roundtable (August 2014)	Participants from cancer services and community controlled, mainstream, government and non-	0	0	1	Aimed to improve collaboration in clinical care and research into cancer in Aboriginal and Torres Strait Islander populations, thereby aiming to improve cancer prevention, control and treatment for Aboriginal communities in Victoria. Priority areas for future action: Development of Cancer Action Plan for Vic with a focus on Aboriginal community engagement, coordination and evidence informed strategic initiatives; address barriers to early detection; Demonstrate how Cancer

Centre), 2015 [95]			government agencies				Action Plan can help Close the Gap; support strong, focused workforce in early screening and detection initiatives; Aboriginal capacity building in cancer research and control; pilot innovative transition services; develop understanding of needs of people other than the patient; improve patient pathway to enable accessing of timely, appropriate care and support; promote data linkage and strengthening opportunities; find local explanation for epidemiological disparities; ongoing research and community consultation.
Bernades et al., 2017 [132] Descriptive	Qld, Tertiary	Reflection on experience training Indigenous patient navigator (IPN) in Australia for Indigenous cancer patients. Presents considerations in establishment of the role.	18 Indigenous people. 1 navigator.	1	1	1	Considerations: (1) recognition of the collective bonds within Indigenous community and understanding by IPN of the degree of personal assistance perceived as not intrusive by the patient; (2) conduct ongoing evaluation of the different role of an IPN involved in this intervention care provider vs. researcher. (3) meaningful engagement develops from a trusting/ collaborative relationship between research team and study site staff which may not occur in the study time frame; (4) existing skills as well as training provided may not translate in the IPN understanding and aligning with the study objectives/research values; (5) recruitment of participants requires innovative and highly flexible strategies to be successful.
Caffery et al., 2017 [102] Systematic review	Australia, PHC telehealth	Systematic review: examine reported outcomes of telehealth services delivered to Indigenous Australians.	Indigenous Australians. 14 articles describing 11 telehealth services	1	0	1	Telehealth models of care facilitated through partnerships between Aboriginal community-controlled health services and public hospitals may improve both patient outcomes and access to specialist services for Indigenous people. Interpretation caution as small sizes and descriptive findings.

Caffery et al., 2018 [115] Exploratory - Qual	Qld - remote west, PHC ACCHO	Explore how telehealth facilitates or impedes the provision of culturally appropriate healthcare to Indigenous Australians from the perspective of staff at an ACCHS.	Nine ACCHO staff	1	0	1	Allows specialist consultations to be conducted in the safe environment of an ACCHS instead of mainstream. Improved affordability and convenience (reduced burden of travel and dislocation), reduced stress. Importance of Indigenous health worker to facilitate culturally appropriate healthcare. Supported holistic view of health.
Cancer Australia / Menzies School of Health Research, 2015 [109]	Australia	National Aboriginal and Torres Strait Islander Cancer Framework		0	0	1	Widely collaborative effort to set strategic direction to address disparities and improve cancer outcomes for Aboriginal and Torres Strait Islander people. Underpinned by principles: Aboriginal and Torres Strait Islander people are engaged and involved throughout the planning, design and delivery of cancer services; Patients, families, carers and communities are informed and empowered; Working together towards a common goal; Policy and practice informed by reliable data and evidence about what works. Seven priorities: 1) Improve knowledge, attitudes and understanding of cancer by individuals, families, carers and community members (across the continuum). 2) Focus prevention activities to address specific barriers and enablers to minimise cancer risk for Aboriginal and Torres Strait Islander peoples. 3) Increase access to and participation in cancer screening and immunisation for the prevention and early detection of cancers. 4) Ensure early diagnosis of symptomatic cancers. 5) Ensure Aboriginal and Torres Strait Islander people affected by cancer receive optimal and culturally appropriate treatment, services, and supportive and palliative care. 6) Ensure families and carers of Aboriginal and Torres Strait Islander people with cancer are involved, informed, supported and enabled throughout the cancer experience. 7) Strengthen the capacity of cancer related services and systems to deliver

						good quality, integrated services that meet the needs of Aboriginal and Torres Strait Islander people.
Cancer Australia and Cancer Council 2018 [80]	Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer		0	0	1	Provides guidance to health practitioners and service planners on optimal care for Aboriginal and Torres Strait Islander people with cancer, across the cancer continuum. References relevant tumour-specific Optimal Care Pathway. Acknowledges health and connection to land, culture, community and identity and a whole-of-life view.
Couch, 2018 [120] Loddon Mallee Aboriginal Reference Group (LMR ARG)	Let's Yarn About Cancer Final Report Qualitative research, to investigate understandings and needs regarding cancer, and consider what would be useful to support and inform their practice	Interviews with 18 Aboriginal Health Workers at 6 sites in LMR	1	1	1	Suggestions: establish a peer support network for AHWs; consider if any services can be delivered more locally (i.e. leverage existing telehealth infrastructure); make better use of ‘Integrated Team Care’ teams where they exist within the region; may be opportunity for Cancer Council Victoria to develop further training to support AHWs in their work with cancer clients and survivors; Dissemination of survivorship stories from local communities may help improve community perceptions of cancer and potentially increase screening rates; At a state-wide level, there may be opportunity to commission Ilbijerri to develop a performance that addresses the cancer journey, including cancer survivorship, to change the discourse around cancer diagnosis in Aboriginal communities; There is opportunity for local, regional and state services to consider how culturally appropriate support might be provided for Aboriginal patients and carers; Consider if there is an opportunity for Aboriginal cancer patient navigator(s) in the Loddon Mallee region; There is a continuing need for mainstream services to better support Aboriginal family structures and cultural needs; Future projects could specifically investigate improving linkages between mainstream cancer services and ACCOs, particularly around admission and discharge, as well as how to improve medication management

							at discharge; Review the number and gender of AHLOs employed by Bendigo Health, and compare with other regional health services; cancer services to consider how they can reduce this jargon and to be aware of, and address, power imbalances during interactions, as well as encourage Aboriginal patients to feel safe and confident in asking questions; Re Cancer Healing Messages flipchart and patient flyer to assist health professionals to explain cancer and the cancer journey to Aboriginal cancer patients and families - may be opportunity for a similar tool to be developed for a Victorian context.
Croager et al., 2010 [118] Evaluation	WA, Metro and regional	Deliver and evaluate three 4-day cancer education course for Indigenous HPs. Measure cancer knowledge and confidence at baseline, completion and follow-up (6-8mths)	n=35 Aboriginal HPs	0	0	1	Workforce- Indigenous HPs cancer knowledge. Not sustained after completion.
Cuesta-Briand et al., 2015 [144] Qual from an evaluation study	WA - regional town, Community	Explores different understandings of how a cancer support network should operate and impact of unresolved tensions. Interviews - thematic analysis. See 2016 paper - same author.	Aboriginal women's cancer support network. n=24	0	0	1	Peer support for Indigenous cancer patients. Model needs to address different perspectives.

Cuesta-Briand et al., 2016 [145] Exploratory - Qual	WA, Community - regional	Explores roles played by an Aboriginal women's cancer support network in a regional town in WA. Interviews - thematic analysis. See 2015 paper - same author.	n=24. Aboriginal (3) and mainstream health providers (8), network members (6) clients (4). Potential clients (3)	1	0	1	Roles of peer support network. Outlines challenges and strategies for success.
Davidson et al., 2013 [98] Integrative literature r/v	Australia, n/a	Examine experience of lung cancer in Aboriginal pop and identify reasons for poorer outcomes and lower levels of treatment compared with non-Aboriginal pop. Identify opportunities for early intervention.	Articles addressing lung cancer in Australian Aboriginal and Torres Strait Islander people.	1	1	1	Barriers to optimal lung cancer treatment. Proposes collaborative model of care that incorporates building capacity in Aboriginal and non-Aboriginal personnel, recruiting more Aboriginal health professionals, increasing knowledge and skills to develop trusting relationships between mainstream providers and Aboriginal patients, and delivering care that is respectful and culturally competent. For effective and sustainable solutions to be achieved, building relationships with Aboriginal communities must be the centre of any strategy.
Davy et al., 2016 [99] Systematic review	International, PHC	Identify primary health-care or aged-care strategies that have or could support the well-being of older Indigenous peoples. N=21 articles. (USA=9; Australia=5; Canada=4; Alaska=2; Brazil=1)	Older Indigenous people and PHC providers	1	0	1	Three high-level synthesised findings: maintaining Indigenous identity; promoting independence; and delivering culturally safe care; were believed to be important for supporting the well-being of older Indigenous peoples.

Dorrington et al., 2015 [175] Translational res and CQI	ACT, Urban ACCHO	Describes translational research (TR) and CQI processes used to identify barriers / facilitators to Pap smear screening. Aim to increase rates.	survey(n=30) data collection (n=213)	1	0	1	Barriers to Pap smear: forgetting, no time, too busy, discomfort, not liking them, fear, shyness. Significant preferences for provision at ACCHS by female providers known to the client. The use of TR with CQI led to a significant increase in Pap smear screening, which was maintained for 10 months of follow up.
Durey et al., 2017 [119] Evaluation	Australia, HP workforce - rad onc.	Delivery of culturally safe care by radiation oncology HPs to Aboriginal Australians with cancer.	Radiation oncology HPs	1	1	1	Does one workshop improve their (HP) confidence in knowledge, communication and ability to offer culturally safe care. Single cultural safety workshop can be effective in building confidence.....integrate into ongoing prof dev.
Durey et al., 2012 [103] Review	WA, Tertiary	Review to inform a collaborative model of hospital-based organisational change.		1	0	1	Collaborative model of care: “recruiting more Aboriginal HPs, increasing knowledge and skills to establish good relationships between non-Aboriginal care providers and Aboriginal patients/ families, delivering quality care that is respectful of culture, and improving Aboriginal health outcomes.” Key element of model design: “critical reflection on barriers and facilitators to providing respectful and culturally safe quality care at all levels”.
Dwyer et al., 2011 [131]	SA	Managing Two Worlds Together: City Hospital Care for Country Aboriginal People Project Report		1	1	1	The project is based on four separate studies: • Study 1—Report on Admissions and Costs analyses the patterns of admission and length of stay of country Aboriginal patients in city public hospitals • Study 2—Staff Perspectives on Care for Country Aboriginal Patients reports the views of staff who provide care for country Aboriginal patients in city and country hospitals and health services • Study 3—The Experiences of Patients and Their Carers is a first-hand report of rural Aboriginal patients and their carers • Study 4—Complex Country Aboriginal Patient Journeys maps

							four journey case studies, and analyses gaps and breakpoints in those care journeys. Measures outlined for improvement: 1) Complexity principle 2) Need for dedicated coordinator role - Aboriginal Patient Pathway Officers (APPO) or AHLOs in clinical units 3) Assuming coordinating capacity present, attend to: accommodation, transport, financial help; interpreter need; informed consent attention; specialist access in regional centres -ehealth/other IT; improved outpatient coordination systems 4) ensure AHLO/APPO roles were better defined, understood and supported by both city and country staff and organisations 5) incorporate escorts into health care, define roles 6) attention to cultural and spiritual priorities - hospital environment 7) develop skills of non-Aboriginal staff; recognition, then appreciation of cultural values. Existing approaches to cultural awareness training not effective. Focus on cultural safety may be more effective.
Dwyer et al., 2014 [133] Qual i/v	SA, Tertiary	Investigate how policy requiring cultural respect and attention to health equity is implemented in care of rural and remote Aboriginal people in city hospitals. Used cultural competence based framework to identify barriers and enablers in implementation of official policy re care of rural Aboriginal patients.	Public hospital staff interviews n=26.	0	0	1	Interviews with public hospital staff re provision of care to rural Aboriginal people. Advocates for systematic attention to operationalising high policy goals, at hospital and clinical unit level. The framework of cultural competence offers relevant guidance for efforts (at system, organisation and care delivery levels) to improve care, but “requires organisations to address misinterpretation of the principle of equal treatment”.

Effective Change, 2016 [123] (for DHHS)	Vic	Evaluation of Aboriginal Health Case Management and Care Coordination Models in Victoria.	7 projects funded under Koolin Balit investment	1	1	1	Examine approaches to care coordination and case management in Aboriginal health that show promise and potential for replication in other communities through investigating 7 projects. Key findings: Case management is effective and culturally appropriate; The significance of the care coordinator role - critical; (positive) impact of the care coordinator role on clients, colleagues, agencies and local service networks (associated with improvements in client's quality of life, health literacy, engagement with and trust of health services, maintenance of clinical care and health improvements); importance of Supporting and sustaining practitioners; Findings relating to clients' experience of care coordination; practice related findings; organisational or service system findings; evidence base - all 7 projects could improve data collection. See 'approach to replication' (don't transplant) and 'opportunities for replication'. The 7 care coordination projects demonstrate that these culturally-informed, relationship-based models of care are delivering significant benefits for individuals, families and organisations and are also contributing to the more culturally-informed functioning of the broader local service system. The findings are consistent with emerging themes in the literature and add to the growing knowledge about how and why this approach is highly suitable in the field of Aboriginal health.
Gall et al., 2018 [142] Systematic Review	Australia, Canada, New Zealand, and the United States	Systematic Review of traditional indigenous and complementary medicines		0	0	1	Traditional indigenous and complementary medicines (TCM) use alongside conventional medical treatments to both cure and cope with their cancer diagnoses. Findings: importance of TCM use across four countries, with multiple perceived spiritual, emotional and cultural benefits. Patient's perception of health professional's attitudes towards TCM made a difference to disclosure.

Gibberd et al., 2016 [110] Quan - record linkage and POC	NSW, Pop based registry, tertiary	Compare surgical treatment for NSCLC b/w Aboriginal and non-Aboriginal people in NSW. Examine whether patient / disease characteristics assoc with disparities. Describe adjuvant treatment rec by Aboriginal people. Risk of death for Aboriginal and non-Aboriginal people.		1	1	1	Lung cancer - disparities in surgical treatment and mortality - imperative that Aboriginal people are offered active lung cancer treatment, (younger and without comorbidities most likely to benefit), and are provided with assistance to access it if required. Various strategies to improve access - transport, space for family...
Gibson et al., 2015 [104] Systematic review	International, Health	Synthesised international evidence on the factors that enable or inhibit the implementation of interventions aimed at improving chronic disease (CD) care for Indigenous people. Aust (n=18), NZ (n=2), Canada (n=0), USA (n=3). Qualitative findings: meta-aggregative approach. Quantitative data: narrative summary	23 studies (18 qual; 4 quan; 1 mixed.)	1	0	1	Chronic disease: Attitudes, beliefs, expectations, understandings and knowledge of patients, their families, Indigenous communities, providers and policy makers were of interest. Five key factors should be considered: 1) Design attributes: include community engagement, the policy and funding environment, leadership, staff approach to change and sufficient resourcing. 2. CD workforce: workforce issues include difficulties recruiting / retaining staff, unsuitable workforce training and development, lack of dedicated CD positions with clear roles and responsibilities, excluding IHW from decision making, and the need to support staff well-being. 3. Patient /provider partnerships: the role of the provider extends beyond their professional and technical skills. Valued qualities include being understanding, supportive and empowering, being able to communicate sensitively and allowing patients to be partners in their care. 4. Clinical care pathway barriers: poorly performing electronic support systems and vague referral pathways. 5. Access: facilitated by providing consistent services and coordinated care, embedding culturally

							safe work practices (e.g., employing local Indigenous people and providing care in Indigenous spaces, being influenced by patient perspectives related to beliefs and experiences regarding health care and family support.
Green et al., 2018 [124] Qual	Australia,	Indigenous patient's experiences of cancer care. Stakeholders views - what to measure, how to measure it.	Aboriginal people affected by cancer n=17. Health Profs n=28. People in both groups n= 7.	1	1	1	Key themes: feeling safe in the system; importance of Indigenous staff; barriers to care; the role of family and friends; effective communication and education; and coordination of care and transition between services.
Haigh et al., 2018 [97] Review	Australia, Health system	Overview of cancer in Indigenous people in Australia	Indigenous Australians with cancer	1	0	1	Comprehensive synthesis on key information on cancer among Aboriginal and Torres Strait Islander people in Australia to: "(1) inform those involved or interested in Aboriginal and Torres Strait Islander health; and (2) provide the evidence for those involved in policy, strategy and program development and delivery."

Jennings et al., 2018 [135] Systematic qualitative review	Australia, Health	Papers from peer reviewed journals were included if they contained first-person qualitative data identifiably from Australian Aboriginal or Torres Strait Islander respondents discussing the experience of accessing healthcare; this included mixed-methods research papers.	Australian Aboriginal or Torres Strait Islander respondents	1	0	1	"Indigenous clients valued talk within healthcare interactions; it was essential to their experience of care, having the power to foster relationships of trust, strengthen engagement and produce positive outcomes. By mediating the power differentials between health professionals and Indigenous clients, talk could either reinforce powerlessness, through judgmental down-talk, medical jargon or withholding of talk, or empower patients with good talk, delivered on the client's level. Good talk is a critical ingredient to improving Indigenous accessibility and engagement with healthcare services, having the ability to minimise the power differentials between Indigenous clients and the healthcare system."
Le et al., 2013 [125]	NT, Tertiary - AWCCC	Compliance with radiotherapy in NT among Indigenous and non-Indigenous people. Presents model of care that may have increased compliance.	All pts treated with RT at AWCCC. Indigenous courses n=41. non-Indigenous n=224.	1	1	1	Data regarding compliance rates (defined as those who chose and completed the recommended course of treatment), patient, disease and treatment factors were collected. Examined radiotherapy treatment compliance between Aboriginal and non-Aboriginal cancer patients in the NT, where no difference was found in the compliance rates of the two groups, although small numbers were acknowledged. Strategies presented as supporting this outcome included: funded transport, accommodation, meals, transfers for patient and an escort; dedicated Indigenous Liaison Officers; free phone use and laptop access to allow communication between patient and family. This study also found an association between worse toxicity and abandonment of treatment for Aboriginal patients. The impact of other factors which affect toxicity (e.g. site of disease, total dose, concurrent therapy, treatment intent) was not conclusive, however the authors propose that treatment teams may need to focus on those at high risk of toxicity.

Liaw et al., 2011 [105] Literature review	International, Any	Papers included if examined chronic disease intervention for an Aboriginal population and reported on eval/impact/outcomes. 11 of 173 papers met inclusion criteria, 10 of these in Australia, all conducted in rural/remote Aboriginal CCH services.	Aboriginal population - chronic disease	1	0	1	Successful chronic disease care and interventions require adequate Aboriginal community engagement, utilising local knowledge, strong leadership, shared responsibilities, sustainable resources and integrated data and systems (including appropriate identification). Examined outcomes of chronic disease management in Indigenous populations and factors which contributed to their success or failure. Although the interventions and evaluations were diverse, a consistent attribute of programs deemed successful was their connection to the local community through consultation, ownership or partnership. Conceptual framework developed for this study incorporated existing models for Pathway to Care, Access to Care, Chronic Care, Cultural Security; Cultural Competency; Cultural Respect; and Level of Connectedness Model. The four NHMRC principles of cultural competence are: 1. Engaging patients and communities and sustaining reciprocal relationships. 2. Using leadership and accountability for sustained change. 3. Building on strengths – know the community, know what works. 4. Sharing responsibility – creating partnerships and sustainability. Authors added: 5. Integrating data and systems. Outlines success factors and barriers to effective chronic disease management.
Lin et al., 2016 [136] Framework	Australia, General health	‘Yarn with me’: applying clinical yarning to improve clinician–patient communication in Aboriginal health care		0	0	1	Cites numerous barriers to effective communication between health practitioners and Aboriginal patients in the clinical setting. Key elements of clinical yarning: culturally appropriate; patient-centred approach; requires active listening; and develops trusting relationship. Presents an “overarching framework for practitioners to help them reorientate their

						communication with Aboriginal patients using ‘clinical yarning’, which marries Aboriginal cultural communication preferences with biomedical understandings of health and disease. Clinical yarning consists of three interrelated areas: the social yarn, in which the practitioner aims to find common ground and develop the interpersonal relationship; the diagnostic yarn, in which the practitioner facilitates the patient’s health story while interpreting it through a biomedical or scientific lens; and the management yarn, that employs stories and metaphors as tools for patients to help them understand a health issue so a collaborative management approach can be adopted. Cites cultural and research evidence that supports this approach and advocates that clinical yarning has the potential to improve outcomes for patients and practitioners.”
McDonald., 2018 [69] Peter Mac	Vic	Feasibility of a volunteer model of patient navigators in cancer care. Churchill Fellowship Report; travel to USA and UK	0	0	1	Examines the role of patient navigation in cancer care. Report highlighted the need for Australia to consider alternate models of care that better address those experiencing health disparities. Identifying the most challenging part of the continuum of cancer care for the patient, should be the driver for establishing a patient navigation program. “The patient experience movement is increasingly emerging as a credible mechanism for measuring patient navigation success. Research and evidence must underpin the establishment of the patient navigation program ensuring the metrics for measuring success are validated tools that capture what you are trying to address in order to demonstrate return on investment. Every health service or organisation visited was implementing patient navigation models that addressed the particular needs of their patients.” Report proposes to utilise the following principles to support the development of patient navigation: 1. Understand the problem you are endeavouring to address; 2. Ensure the development of a patient navigation

							program is developed utilising principles of co-design with the patient as a partner; 3. Ensure the model is part of the multidisciplinary team. 4. Ensure clear scope of practice and role delineation; 5. Implement a rigorous program evaluation. “The development of patient navigation services that are focussed on particular barriers or cohorts would support the current model of cancer care at Peter Mac. The scoping of these navigation services to ensure they complement and support current service delivery is a priority outcome of this Fellowship”: • Financial Aid Navigation • Health Justice Partnership • End of Life care Navigation • Peer Navigation • Aboriginal and Torres Strait Islander Cancer Navigation.
McGrath, 2010 [163] Qual	NT, Rural/remote	Overview of evidence based model for service delivery to rural and remote Aboriginal people needing palliative care. What is? What works? What is needed? Interviews with 72 people.	Pts (10);carers (19); AHWs(11); health care workers(30); interpreters(2).	1	0	1	Key processes in provision of palliative care: employing AHWs; effective communication (right story to right person); addressing psychosocial and practical problems; building services in communities; encouraging family meetings; educational activities; addressing relocation issues- focus on staying home; understanding / supporting cultural practices; developing culturally appropriate HC facilities; carer support; respite. Attention to beliefs associated with death/dying.
Meiklejohn et al., 2016 [106] Qual	Qld, Tertiary	Health professional’s (HP) perspectives of barriers and enablers to cancer care for Indigenous Australians. Semi-structured interviews.	22 HPs involved in cancer care	1	1	1	HP perspectives of barriers/enablers to cancer care for Indigenous Australians. Barriers: challenges with communication (lack of culturally appropriate information and cultural understanding - limited experience) (constraints: limited appointment times - not developing rapport, no time to ask questions), the health system (ltd screening/diagnostic services in PHC regional/remote. lack appropriate trained staff. high turnover - barrier to continuity of care) (incongruous

		Inductive thematic analysis.					western medicine v traditional medicine) and coordination of care (transport - barrier to attendance and completion treatment. financial issues, accommodation), issues around individual and community priorities and views of cancer treatment and health professional judgement. Enablers: related to the importance of trust and rapport as well as health care system and support factors. Complex approaches could encompass addressing transport and accommodation arrangements, a dedicated patient navigator through pathway, provision of interpreter services, mechanisms for including family and/or community members in supportive roles, specialist outpatient services in regional areas, development of close relationships between tertiary and primary care providers to ensure coordinated outpatient and follow-up care and professional development to improve skills and knowledge of cancer care staff to promote provision of culturally safe health care. In addition, changes should be integrated within all sectors of the health system to improve cultural competency policy and practice at the service level. The findings highlighted the need for recording of Indigenous status in medical records and a coordinated approach to the provision of evidence-based and culturally appropriate cancer care. This could go some way to improving Indigenous patient’s engagement with tertiary cancer care services.
Meiklejohn et al., 2018 [129] Qual.	Qld, PHC centres and tertiary hosp.	Exploration cancer survivorship perspectives of Indigenous cancer survivors. Recommendations for cancer survivorship.	Indigenous cancer survivors n=22 (completed treatment 6m-5yrs), support	1	0	1	Survivorship: establishing a community cancer advocate and peer support program, availability and use of a cancer-specific Indigenous primary healthcare worker and hospital-based Indigenous patient navigator, as well as adoption of question prompt lists and cancer survivorship care plans.

			ppl, healthcare workers.				
Murphy et al., 2015 [122] Collaborative review	NSW, some Vic. Regional health.	Oncology service initiatives and research in regional Australia		1	0	1	Describes development of more effective cancer networks and new models of care to address needs of rural cancer patients. Includes a section on initiatives to address the needs of rural Aboriginal people with cancer. Mostly NSW, but includes Hume RICS, east Hume and border activities.
Newman et al., 2017 [100] Qual - secondary analysis	NSW, Various	Secondary analysis of i/v - Aboriginal men, their carers and clinicians. Experiences of Aboriginal men in responding to cancer diagnosis and treatment in Australia.	Aboriginal men (n=6), their carers (n=12) and clinicians (n=5).	0	0	1	"Aboriginal men could be better engaged with cancer diagnosis and treatment if greater attention was paid to recognising preferred approaches, and supporting connections to family and culture throughout the cancer journey."
Page et al., 2016 [138] Survey	North Qld	Health views that impact on diagnosis/treatment. Rural remote Aboriginal communities	51 comm members, 14 AHWs	1	0	1	Main barriers: communication and follow-up processes. Address: service improvement activities - coordination of care, Indigenous health support services.
Reilly et al., 2018 [126] Qual	SA, Tertiary and primary	CanDAD narratives, relevant to the question of how care coordination, provided by dedicated care coordinators or others, addressed gaps in care or otherwise influenced Aboriginal people's experiences of cancer care.		1	1	1	Cancer care coordination - 4 main areas: "navigating the health system"; "information and communication"; "things to manage at home"; and "cultural safety".

Shahid et al., 2010 [111] Qual	WA, Rural, remote cancer services	From qual study about experience of cancer, (n=37), examined meanings attached and use of bush medicine by Aboriginal people with cancer in WA. What were the key factors for which bush medicine use was chosen and what factors influenced decision not to use it.	n=11	0	0	1	Bush medicine use in Indigenous people with cancer - widespread desire to use it. Culturally safe. Recognition of bush medicine use can boost confidence of Aboriginal people to engage in mainstream services and improve service delivery to Aboriginal people. Reasons for using: preventive means to cope with stress (belief that stress causes cancer), reduces risk of cancer, makes person stronger from the inside. Enabler to maintain connection and beliefs re culture, ancestors - holistic health. Spiritually significant - engaging with bush medicine and associated healing rituals. Link bush medicine with the land and sacredness of relationship with Country and its spirits. Healing not just physical, but mental, emotional and spiritual. Protect bush medicine from western exploitation. Argues for accepting/communicating about use of bush medicine alongside western medicine in cancer treatment plan. May not cure, but will help you. need for health care providers to acknowledge and respect this component of Indigenous beliefs when providing health care. Impact of western treatment (side effects, away from home...) - influences choice of bush med. Also accepting that western medicine cannot do everything - no miracles - some turn to bush medicine when other treatment fails. Many did not use or talk about bush med. Didn't have access to the source, confusion, uncertainty. Most availability in rural/remote areas - restriction availability/access. Needs to be provided by traditional healer - can't just go and get it. Devastating effect of colonisation (missions) - disconnection from land - loss of cultural knowledge. Some expectation of dosage/use etc, like western med. Desire to use traditional medicine widespread. Reconnects with cultural knowledge, which has been lost - reassuring. Incorporate bush medicine when go home for EOL, bringing peace and comfort, empowering patients in health process. Many plants have not

							been studied, so interaction with medication unknown. Health care workers should incorporate an understanding of Indigenous belief systems into their service delivery. family centred approach. important for practitioners to know of bush medicine use in their pts - bioactive.
Shahid et al., 2011 [127] Qual	WA, Various	Describes perspectives on basic infrastructure and logistical problems which impede access to hosp based treatment.	30 Aboriginal ppl affected by cancer. Cancer pts n= 14. Family n= 16.	1	1	1	List of recommendations to address barriers.
Shahid et al., 2013 [139] Qual	WA, Various	Perspective of service providers on communication between service providers and Aboriginal patients/families.	Cancer service providers n=62 (included17 Aboriginal CSP)	1	0	1	Outlines barriers and improvement strategies to care service providers' communication. Thematic analysis of experiences reported, re factors impairing communication. Proactive strategies for promoting effective communication. Analysis - socio-ecological model + whiteness and privilege + cultural security.
Shahid et al., 2016 [121] Qual	WA, Metro Perth, rural/remote (6)	Factors contributing to delayed diag. Open ended i/v. Aboriginal participants asked to describe their or family members' experiences with cancer and cancer services. Specific probes on diagnosis, treatment and follow-up. Service providers' interviews covered questions around their general experience	Aboriginal cancer pts + family n=30. Health service providers=62.	1	1	1	Delayed diagnosis considered in context, health service-related, and patient related areas. Multiple strategies - communication, cultural safety training, patient navigators, telehealth, longer consults, longer term relationships, person centred model of care, address access, enquiry re traditional med. Conclusions: focusing on the primary care sector - key to earlier diagnosis and linkage to cancer service pathways, encouraging GPs to be proactive to suspicion of symptoms with appropriate investigations to facilitate earlier diagnosis (strengthen links b/w PHC physicians, specialists, cancer services) and the need to improve Aboriginal health literacy

	with Aboriginal patients with cancer, specific issues they face and possible solutions to these issues.					regarding cancer (customised health promotion - men 'special' (?different?) focus, Adopting alternative innovative models of cancer care using patient navigators and telehealth services; Building trust and need for cultural safety training. Cultural safety training is often delivered to attune health professionals about the potential adverse effects of the power imbalances between the consumers and healthcare providers on patients accessing the services. Such training also demonstrates that health system works within a political and social context and not just within a scientific, ethical or legal structure. Transparent, respectful and empathetic communication between the HSPs and the patients/families about the diagnostic, treatment and cancer care procedure, longer consultation by the primary care providers, sustainable long-term relationship between the patients and the primary /secondary care staff and development of a person-centred model of care would rebuild the misplaced trust between a lot of Aboriginal patients/ families and the non-Aboriginal HSPs, and ensure culturally safe environment. Access to health services remains a critical problem affecting timely diagnosis. Consideration and respectful enquiry re traditional medicine use necessary - possible interaction with treatment.
Social Compass, 2016 [93] (for Department of Health and Human Services (DHHS))	Improving Cultural Responsiveness of Victorian Hospitals (Follows on from Improving the Culture of Hospitals Project (AIPC 2010))	144 of 173 interviews were with Aboriginal people. Conducted January-October 2016	1	1	1	Placed the voices of Aboriginal people at the centre. Questions: 1. To what extent have Victorian hospitals improved their cultural responsiveness to Aboriginal people? 2. To what extent have people's healthcare experiences in Victorian hospitals (including cultural safety) changed? 3. What strategies have led to the most significant and sustainable improvements in cultural responsiveness and cultural safety of hospitals for Aboriginal people and staff?

Mainly Qual	What are the critical contextual factors which enabled this success, and how could the successful strategies be replicated in other hospitals/settings? Have there been any unintended consequences of the successful strategies? 4. Are there strategies being employed which are relatively ineffective or unsustainable? 5. How can we improve measurement and monitoring of cultural responsiveness and cultural safety, both by individual hospitals and state-wide? How can we incorporate measuring the gaps between Aboriginal and non-Aboriginal people’s access to quality care as a key impact? Phases: >40 consultations (key central and regional department staff and external stakeholders; document and data review of >200 documents (including CQI reports, Quality of care reports, Statement of Priorities analysis, Aboriginal Employment Plans, Victorian Healthcare Experience Survey results, previous evaluations and academic research); 7 hospital case studies and interviews with hospital staff, ACCHO staff, patients, community members; Aboriginal Hospital Liaison Officer (AHLO) Survey: online survey provided to all AHLOs / Koori Mental Health Liaison Officers (KMHLOs) exploring the findings from interviews with AHLOs / KMHLOs at case study sites. The survey was administered through the ICAP Network with VACCHO. There were 15 surveys returned with a response rate of 20 per cent. Findings: Consistent story of hospitals being sites of trauma for many Aboriginal people, not places of healing. Presents definitions of cultural responsiveness and cultural safety that emerged from community interviews. Found significant gaps in measurement and reporting of cultural responsiveness and cultural safety. Themes (consistent across participants):

Committed leadership (many CEOs / leaders looking for support to improve cultural responsiveness / cultural safety);

Relationships with ACCHOs;

AHLOs (most feel undervalued and neglected – subject and object of community trauma – stress leave common) and a stronger Aboriginal health workforce;

A welcoming environment (flags, plaques, artwork, though tokenistic if the service system does not support them);

Cultural safety training (no evidence available of systematic capturing of performance or outcomes – hospitals looking for support);

Monitoring and reporting) none at hospital or state-wide level for reporting cultural responsiveness or cultural safety – current mechanisms ad hoc, non-mandatory and incomplete – no reliable hospital or state-wide data on Aboriginal patient experience.

Report provided set of indicators and measures to assist with monitoring and reporting cultural responsiveness and cultural safety, and can be used against the new National Safety and Quality Health Service Standards (ACSQHC 2017)

“Overall the evaluation finds that increasing the support and capacity of the AHLO/KMHLOs will have the biggest impact on cultural responsiveness and cultural safety.”

Contains Loddon Mallee Culturally Responsive Framework: Domain; Description; Actions.

Three domains of change influencing a hospital’s ability to provide culturally responsive care and cultural safety: 1. Hospital leadership and organisational culture. 2. Aboriginal and Torres Strait Islander workforce. 3. Aboriginal community

							relationships – including local ACCHOs, Traditional Owners and Aboriginal patients.
Tam et al., 2018 [137] Qual	Qld, Tertiary hosp	Sought to elicit enablers to positive cancer care experience.	Adult, Indigenous, cancer. n=12	1	0	1	“Two major categories of enablers were identified: resilience and communication. Individual’s intrinsic strength, their coping strategies, and receipt of support improved participant’s resilience and consequently supported a positive experience. Communication methods and an effective patient-provider relationship facilitated positive experiences for participants. Despite potential barriers to access of care for Indigenous cancer patients, participants demonstrated that it was still possible to focus on the positive aspects of their cancer experiences. Many participants explained how cancer changed their outlook on life, often for the better, with many feeling empowered as they progressed through their cancer diagnosis and treatment processes.” Clear communication enhanced decision making and understanding of disease and treatment.
Taylor et al., 2018 [179] Qual interviews	Australia, cancer services	Telephone interviews used to identify and describe the Indigenous-specific programs and initiatives that are implemented in a subset of the services that participated in a larger national online survey of cancer treatment services	58 of 125 eligible services completed surveys. Range of management, support, and clinical staff	1	1	1	Critical to delivering culturally appropriate treatment and support: having a trained workforce with effective cross-cultural communication skills, providing best practice care, and improving the knowledge, attitudes, and understanding of cancer by Indigenous people. Further research needed.

Thewes et al., 2016 [146] Systematic review	International, Health system	Systematic review of empirical studies of cancer health literacy amongst Indigenous people worldwide	Indigenous people with cancer	0	0	1	“Research is needed to explore the cultural relevance of existing measures of health literacy and to document the prevalence of health literacy amongst Indigenous people with cancer. A better understanding of Indigenous cancer patients’ health literacy is required before health literacy interventions can be designed to improve Indigenous cancer outcomes.”
Thompson et al., 2011 [130] Qual	WA	Community report: A Whispered Sort of Stuff. Interviews with 30 Aboriginal people affected by cancer and health professionals, about beliefs and experiences of cancer care, including bush medicine and communication.	30 Aboriginal people affected by cancer and health professionals	1	0	1	Retained as several publications about this qualitative study were pre-2010 and not included. Recommendations: Aboriginal community education; health system factors (including case conferencing, improved transfer of care, culturally secure hospital environment, treat on-Country, improve coordination, communication assistance included interpreters); professional education (cultural sensitivity, acceptance of traditional medicine); support services (awareness of impact of travel, transport, cancer services in regional areas/outer urban, telehealth etc, outreach, consult with elders about welcoming patients to Country (e.g. DVD), accommodation, Aboriginal support/liaison - more and at higher levels, consider patient navigators, support agencies - help with access.
Tranberg et al., 2016 [101] Systematic review	International	Cancer treatment decision-making by Indigenous people. PRISMA. Peer reviewed journals post 1960. Included qual, quan, mixed method primary res Excluded grey. Narrow search terms.	Indigenous adults, any cancer. Studies included n=5, all Australian	1	0	1	Themes identified: spirituality (fatalism, 'payback', spirituality of body), cultural influences (connection to family/Country, shame and stigma), communication (knowledge transfer, relationships with health workers) and existing healthcare systems and structure (inaccessibility, appropriate support services). Culturally appropriate health care requires health professionals to be well trained in the use of interpersonal skills and to apply these skills to the development of therapeutic relationships in which Indigenous people with cancer are engaged and empowered. This requires accommodating indigenous people’s beliefs within the health system so that Indigenous

							patients and families are supported in a culturally appropriate manner during the cancer treatment journey. “Connection is integral to the indigenous expression and experience of life [29]. It is essential for cancer treatment plans for Indigenous people to recognise this connection because many Indigenous patients will prioritise their connection to family, community and land over any benefits to be gained from successful cancer treatment.” See discussion.
Treloar et al., 2013 [112] Qual	NSW, Various	Examined individual, social and cultural aspects of health literacy relevant to cancer. recruited from Aboriginal Medical Services (AMSs), hospital oncology services, palliative care facilities and personal networks.	Aboriginal people diagnosed with cancer n=22. Carers n=18. HC workers n=16.	1	0	1	Health literacy improvement strategies. Recognising susceptibility to cancer; Recognising opportunities to learn from each other; Opportunities for practical services and programmes for health literacy in relation to cancer - need cancer education / information. Specialty organisations / services could improve their relationship with ACCHOs to raise the profile and understanding of cancer, and to improve the ways that mainstream services engage with Aboriginal people and provide practical advocacy for securing attention to cancer among Aboriginal communities. Such a model has been developed in Western Australia with 20% of Aboriginal health workers in that state having attended a cancer education course conducted by Cancer Council Western Australia (Croager et al. 2010).[118]
Treloar et al., 2014 [107] Qual	NSW, Various	Cancer diagnosis and treatment experiences of Aboriginal people, carers and health workers - building social inclusion (how people at the margins of society engage with service providers).	Aboriginal people with cancer n=22. carers n=18. HC workers n=16.	1	1	1	Three factors were identified as processes of social inclusion that tied these experiences together including socio-economic security, trust (or mistrust arising from historic and current experience of discrimination), and difficulties in knowing the system of cancer treatment. Any innovation in health care to promote inclusion of Aboriginal Australians must work to address deep mistrust in mainstream health systems. Genuine and meaningful partnership work with ACCHOs is a practical way forward to improve the standing of cancer services in

							Aboriginal communities. Patient navigators to address financial, logistical and sociocultural barriers (limited social support and inadequate health literacy). Cancer care and treatment services could develop ways in which to ‘‘welcome’’ Aboriginal people to their ‘‘country’’ of hospital, clinic or specialist protocols, to explain and facilitate its customs and assist the patient to feel accepted and safe in this alien place.
van Schaik & Thompson, 2012 [108] Literature review (doesn't report number articles.)	Australia, Various	Reviews literature re Indigenous Australian's beliefs about cancer treatment, both bush medicine and biomedical, to provide recommendation about accommodating Indigenous beliefs when treating cancer.	Indigenous Australians	1	0	1	Research questions: • What is known about Indigenous Australians’ views of biomedical cancer treatment and • views of bush medicine treatments for cancer? • What success, if any, has there been in combining these two approaches to treat cancer in Indigenous Australian patients? Beliefs about treatment efficacy for cancer - toxicity of treatment, disconnect with physician, fears re absence from home, aetiology beliefs, biomedical model failing to consider holistic health. Principles underlying culturally safe care: Indigenous involvement in design/process of care; peer support; improve PHC links; culturally sensitive person-person contact; fully informed consent; practical aspects addressed; learn about the belief system - accommodate these beliefs.

Whop et al., 2012 [113] Survey - cross-sectional	Qld, Various	Describes availability of cancer support services for Indigenous people and relevant location. Services invited to complete online questionnaire. Mapping of services vs % Indigenous people.	Services classified as Indigenous = only Indigenous people or Indigenous-friendly (>=10 Indigenous people in previous year or staff member available for Indigenous clients).	1	0	1	Mapping revealed services are located where there are relatively low % of Indigenous people c/w the whole population. No 'Indigenous-specific' services were identified; however, 11 services (13%) were classed 'Indigenous-friendly'. The primary support offered by these services was 'information'. Barriers to access for Indigenous clientele: no Indigenous staff, costs involved in accessing the service (unable to address issues due to restricted staff and funding capacity); lack of awareness /knowledge of service; lack of referral; limited culturally appropriate resources; lack of confidence by Indigenous people. Further research into best models of care. Emphasis on: support services where high Indigenous population percentage resides; relationships with Indigenous organisations and mainstream support services; encouraging referral from Indigenous liaison officers. Increasing culturally safe environment in mainstream services. Appropriate support services.
Whop et al., 2012 [62] Review	International, Health system	Review of scientific literature; patient navigator programs in Indigenous people with cancer	Indigenous people with cancer	1	0	1	Review of patient navigator programs yielded eight articles on two programs, both in USA. Although preliminary outcomes are seemingly positive, further rigorous evaluation of quantitative impacts are needed.
Wotherspoon & Williams, 2018 [114] Inpatient experience	Victoria, Tertiary	Measure whether there were any differences in in-patient experiences between Aboriginal and Torres Strait Islander people non-Aboriginal patients.	Hospital Inpatients, Peninsula Health, eligible dates. N=154; 76 Aboriginal (6% of inpatients), 78	1	0	1	There were systemic differences in in-patient experiences. Healthcare services have a responsibility to make systemic changes to improve the health care of all Australians by understanding and reforming how services can be appropriately delivered. Measure patient's experiences and identify gaps.

	non-Aboriginal (<1% of inpatients)	

Table 2.3.1 Service models and cancer treatment for Aboriginal and Torres Strait Islander people

Author, year, study type	Jurisdiction, sector	Description	Population	Short summary
Brown et al., 2016 [150] Qual and quant	SA,	CanDAD - outline of the aims / justifications		Outlines aims and background to CanDAD: - quantitative component involving linking data from the South Australian Cancer Registry (population-based), Clinical Cancer Registry (institution-based), hospital inpatient data, radiotherapy records, breast screening files and Pharmaceutical Benefits insurance data. Although not included in the R&D phase, a longer term aim is to incorporate linked cervical and bowel screening data, Medical Benefits Schedule (MBS) insurance data, and potentially survey and bio-specimen data. - qualitative component to compile and analyse narrative accounts of Aboriginal peoples' self-reported experiences with cancer and the health system, and experiences of service providers, family members and carers. - knowledge translation component will utilise participatory concept mapping methodology to engage service providers, carers and patients in identifying and rating intervention strategies on their perceived importance and feasibility to improve the cancer journey and outcomes.
Bureau of Health Information (BHI), 2016 [155]	NSW	The Insights Series Report – Healthcare in rural, regional and remote NSW.		Key relevant findings; "There were bigger gaps in experiences of hospital care between Aboriginal and non-Aboriginal patients in rural areas compared with urban areas – most notably for questions on communication, respect, patient engagement and patient reported outcomes."

Bureau of Health Information (BHI), 2016 [156]	NSW	Patient Perspectives: Aboriginal people and hospital care report	Mailed survey ~ 3 months after discharge. n=2682. Response rate = 21%.	Ten key findings: “1. Overall, hospital care was highly rated by Aboriginal patients 2. When asked about specific aspects of care Aboriginal patients less positive than non-Aboriginal patients 3. For some aspects of care these differences were large 4. Only one survey question was answered more positively by Aboriginal patients than non-Aboriginal patients (whether patients saw information about their rights during their hospital stay) 5. Most Aboriginal patients said that the hospital care they received definitely helped them, although they were less likely than non-Aboriginal patients to say so. 6. Poor experiences of care were reported by a sizeable minority of Aboriginal patients 7. Results differed across local health districts. 8. Gaps in experiences of care between Aboriginal and non-Aboriginal patients appear bigger in rural and remote areas 9. When comparing Aboriginal patients’ experiences across the state, results varied 10. Variation across question and local health district results suggests that gaps between Aboriginal and non-Aboriginal patients’ experiences are not inevitable”
Caffery et al., 2017 [102] Systematic review	Australia, PHC telehealth	Systematic review to examine reported outcomes of health services delivered by telehealth to Indigenous Australians. 14 articles describing 11 telehealth services, 1 oncology, 1 palliative care.	Indigenous Australians.	“Telehealth models of care facilitated through partnerships between Aboriginal community-controlled health services and public hospitals may improve both patient outcomes and access to specialist services for Indigenous people. Interpretation caution as small sizes and descriptive findings.”

Caffery et al., 2018 [115] Exploratory - Qual	Qld - remote west, PHC ACCHO	Explore how telehealth facilitates or impedes the provision of culturally appropriate healthcare to Indigenous Australians from the perspective of staff at an ACCHS.	Nine ACCHO staff	Allows specialist consultations to be conducted in the safe environment of an ACCHS instead of mainstream. Improved affordability and convenience (reduced burden of travel and dislocation), reduced stress. Importance of Indigenous health worker to facilitate culturally appropriate healthcare. Supported holistic view of health.
Cancer Australia, 2016 [85] Framework	Australia	National Framework for Gynaecological Cancer Control		Guides future directions in national gynaecological cancer control over the next 5 years to improve outcomes, through consideration of models of care, integration across the cancer continuum, populations with variations in outcomes, research directions. Reports comparatively high burden on Aboriginal and Torres Strait Islander women - calls for quality, integrated services that meet the needs of this population. Priority area two is to improve outcomes for this population. Advocates centralised model of treatment, multidisciplinary care. For Aboriginal women, acknowledges context. Strategies to improve outcomes include: undertake research to identify views and identify barriers to screening, early detection/treatment and access to services; raise awareness of risk factors and symptoms to support prevention and early detection; increase participation in National Cervical Cancer Screening program; improve national recording of Indigenous status in pathology requests and reports; strengthen capacity of cancer related services to deliver culturally appropriate, integrated services across the continuum; identify patterns of care.
Cancer Australia, 2018 [84] Framework	Australia	Lung cancer framework: principles for best practice lung cancer care in Australia		Lung cancer framework: principles for best practice lung cancer care in Australia: a national resource for health professionals and service providers who are involved in the care and treatment of people affected by lung cancer across Australia. The Lung Cancer Framework provides evidence-based, best practice information,

				strategies, tools and resources at consumer level and health service level, to support local adoption of the Principles in the delivery of best practice lung cancer care in Australia, however does not outline specific strategies for Aboriginal people. No specific mention of Aboriginal people other than acknowledgement, glossary, and variations in incidence and outcomes.
Chong et al., 2011 [148]	Australia, Tertiary	Outlines Improving the Culture of Hospitals Project (ICHP) Round 1: Maitland Hosp SA, Goulburn Valley Health Vic, Royal Adelaide Hosp, St Vincent's Hosp Vic, Royal Children's Hosp Vic. Round 2: Derby Hospital WA, Royal Brisbane and Women's Hospital Brisbane, Campbelltown Hospital NSW, Mater Hospital Brisbane, Katherine Hospital NT [withdrew].	Round 1: 5 hospitals Round 2: 4 of 5 hospitals completed trial.	State/Territory ACCHOs nominated hospitals to participate, hospitals complete EOI. Five hospitals which demonstrated success in development of services to Aboriginal community were selected. Round one site visits - key themes identified to generate a quality improvement framework toolkit to guide CQI process. Round two – trial of toolkit. Hospitals considered to be successfully addressing issues for Aboriginal patients shared essential characteristics: strong partnerships with Aboriginal communities; enabling state and federal government policy environments; leadership by hospital boards, chief executive officer/general manager and key clinical staff; strategic policies within their hospitals; structural and resource supports; and commitment to supporting the Aboriginal workforce.
Couch, 2018 [120] Loddon Mallee Aboriginal Reference Group (LMR ARG)	Victoria	Let's Yarn About Cancer Final Report Qualitative research, to investigate understandings and needs regarding cancer, and consider what would be useful to support and inform their practice	Interviews with 18 Aboriginal Health Workers at 6 sites in LMR	Suggestions: establish a peer support network for AHWs; consider if any services can be delivered more locally (i.e. leverage existing telehealth infrastructure); make better use of 'Integrated Team Care' teams where they exist within the region; may be opportunity for Cancer Council Victoria to develop further training to support AHWs in their work with cancer clients and survivors; Dissemination of survivorship stories from local communities may help improve community perceptions of cancer and potentially increase screening rates; At a state-wide level, there may be opportunity to commission Ilbijerri to develop a performance that addresses the cancer journey,

				including cancer survivorship, to change the discourse around cancer diagnosis in Aboriginal communities; There is opportunity for local, regional and state services to consider how culturally appropriate support might be provided for Aboriginal patients and carers; Consider if there is an opportunity for Aboriginal cancer patient navigator(s) in the Loddon Mallee region; There is a continuing need for mainstream services to better support Aboriginal family structures and cultural needs; Future projects could specifically investigate improving linkages between mainstream cancer services and ACCOs, particularly around admission and discharge, as well as how to improve medication management at discharge; Review the number and gender of AHLOs employed by Bendigo Health, and compare with other regional health services; cancer services to consider how they can reduce this jargon and to be aware of, and address, power imbalances during interactions, as well as encourage Aboriginal patients to feel safe and confident in asking questions; Re Cancer Healing Messages flipchart and patient flyer to assist health professionals to explain cancer and the cancer journey to Aboriginal cancer patients and families - may be opportunity for a similar tool to be developed for a Victorian context.
Davidson et al., 2013 [98] Integrative literature review	Australia, n/a	Examine experience of lung cancer in Aboriginal pop and identify reasons for poorer outcomes a& lower levels of Rx compared w non-Aboriginal pop. Identify opportunities for early intervention.	Articles addressing lung cancer in Australia Aboriginal and Torres Strait Islander people.	Barriers to optimal lung cancer Rx. Proposes collaborative model of care that incorporates building capacity in Aboriginal and non-Aboriginal personnel, recruiting more Aboriginal health professionals, increasing knowledge and skills to develop trusting relationships between mainstream providers and Aboriginal patients, and delivering care that is respectful and culturally competent. For effective and sustainable solutions to be achieved, building relationships with Aboriginal communities must be the centre of any strategy.

Davy et al., 2016 [154] Framework synthesis	International, PHC	Framework synthesis - access to PHC services for Indigenous people and how Indigenous health services addressed the challenges.		Presents framework for Indigenous people accessing PHC incorporates interrelated features of acceptability, availability, affordability, ability to engage, approachability.
Davy et al., 2016 [99] Systematic review	International, PHC	Identify primary health-care or aged-care strategies that have or could support the well-being of older Indigenous peoples. Older Indigenous people and PHC providers.	N=21 articles. (USA=9; Australia=5; Canada=4; Alaska=2; Brazil=1)	Three high-level synthesised findings: maintaining Indigenous identity; promoting independence; and delivering culturally safe care; were believed to be important for supporting the well-being of older Indigenous peoples.
Department of Health and Human Services (DHHS), 2016 [10]	Victoria	Victorian Cancer Plan: Improving cancer outcomes for all Victorians		First cancer plan developed under the 'Improving Cancer Outcomes Act 2014'. Framework to improve cancer care for all Victorians, to be reviewed every four years. Long-term goals (2040) are to: halve the proportion of Victorians diagnosed with preventable cancers; double the improvement in one- and five-year survival of Victorians with cancer; ensure Victorians have the best possible experience of the cancer treatment and care system; achieve equitable outcomes for all Victorians. For Aboriginal people specifically: Seeks to embed culturally responsive approaches across the cancer pathway through planning, designing and delivering services with Aboriginal people, building a culturally competent and responsive workforce and increase the number of Aboriginal people in the cancer care workforce, and strengthening data collection and performance monitoring of access and outcomes for Aboriginal people. Cites Working Together for Health (Loddon Mallee Region, Gippsland Region, Ballarat) and Hume region efforts to improve access to cancer care for Aboriginal people. Address barriers, partnerships with ACCHOs, cultural awareness activities.

			Priorities are: Primary prevention: Reduce risk factors related to lifestyle and environment; Prevent cancers related to viral infections. Screening and early detection: Equity in screening participation; Increase access to familial risk assessment for people at risk; Improve cancer awareness and primary care capacity. Treatment: Consistent quality through Optimal Care Pathways; Improve patient’s experience of care; Optimise infrastructure, data and system design. Wellbeing and support: Maintain quality of life through strengthening supportive care and self-management, recovery, survivorship, palliative care and end of life care. Research: Improve access to clinical trials; Support researchers to collaborate; Accelerate translation of research into clinical outcomes. The system supports to achieve these outcomes include: Integration: working together to deliver optimal care pathways Innovation: supporting and systematic scaling-up of innovative practice Investment: in infrastructure, outcome-focused service models and research platforms Intelligence: better access to and use of data and information to drive continuous improvements Workforce: ensuring a workforce that can meet the future needs of cancer prevention and care Principles underpinning the approach: Person-centred care with equitable access; Prevention focused across the care pathway; Quality and safe care; Evidence informed; Sustainable system.
Department of Health and Human Services	Victoria, Health	Koolin Balit Evaluation summary	Common themes across the evaluations: – “Connections to Place and Culture are crucial for health and wellbeing

(DHHS), 2017 [92] Evaluation			– The Aboriginal workforce experiences dangerous levels of racism and vicarious trauma – Government should be more active in some specific areas (accountability – effective cultural safety improvement measures; alternative funding models; monitor Aboriginal people's experiences of care; guidelines for delivery and evaluation of cultural safety training. – Opportunities for greater coordination and sharing good practice. In some cases, there is a need for more connection within local areas."
Department of Health and Human Services (DHHS), 2017 [91] Framework	Victoria	Victorian Cancer Plan Monitoring and Evaluation Framework	Broadly aligns with Cancer Plan 2016-2020 to include indicators and measures of outcomes. Designed to help understand the extent to which avoidable gaps in cancer outcomes are being reduced and provides a mechanism for reporting on inequalities between population groups. Four levels: Outcomes (reduction in inequalities pertaining to the outcomes is implied in each); key result areas; indicators; measures. Data is further defined in Victorian cancer plan monitoring and evaluation framework: data dictionary. Aspects specific to Aboriginal Victorians or of particular relevance to this report are: – Outcome: improve cancer outcomes. Key result areas: 1 decrease incidence of preventable cancers; 2 decrease deaths due to cancer; 3 improve survivorship quality of life. – Outcome: equitable outcomes for all Victorians. Key result areas: 4 equitably reduce cancer incidence (includes measure of the rate ratio of preventable cancer incidence between Aboriginal and non-Aboriginal Victorians); 5 equitably reduce cancer deaths (including measure - rate ratio of premature death between Aboriginal and non-Aboriginal Victorians). – Outcome: prevent cancers; Key result areas: 6 Decrease smoking and harmful alcohol consumption; 7 Increase healthier eating and

			active living; 8 Decrease obesity; 9 Decrease UV exposure; 10 Decrease HPV and viral hepatitis impact. – Outcome: detect cancers early. Key result area: 11 Increase early-stage diagnosis - (Stages 1 and 2; Breast, CRC, cervix, lung at stages 1 and 2; late stage). - Outcome: optimal diagnostics and treatment. Key result area 12: Increase adherence to optimal care pathways; 13: Increase one- and five-year survival; 14 Improve quality of life. – Outcome: best possible experience of care systems. Key result area 15: Improve patient experience of healthcare; 16: Improve patient experience of screening. – Outcome: integrated research systems. Key result area 17: Innovations and improved evidence of best practice. Availability of data assessed for various categories including Aboriginal and Torres Strait Islander people of Victoria. Measures tabulated (Appendix 2) according to whether they are currently collected and available (Y), not currently collected (N), further work required to develop the measure or data source (TBD) or not applicable to the indicator (N/A).
Dunn et al., 2017 [149] Qual	Australia, Tertiary	Interviews with multidisciplinary health professionals re views about barriers to lung cancer care, to help build a research and action agenda for improving lung cancer outcomes	“Improving outcomes for this disadvantaged patient group will require government, health agencies, and the community to take an aggressive, integrated approach balancing health policy, treatment priorities, and societal values.”
Durey et al., 2012 [103] Review	WA, Tertiary	Review to inform a collaborative model of hospital-based organisational change.	Collaborative model of care: recruiting more Aboriginal HPs, increasing knowledge and skills to establish good relationships between non-Aboriginal care providers and Aboriginal patients/ families, delivering quality care that is respectful of culture, and

				improving Aboriginal health outcomes. Key element of model design: critical reflection on barriers and facilitators to providing respectful and culturally safe quality care at all levels.
Effective Change, 2016 [123] (for DHHS)	Victoria	Evaluation of Aboriginal Health Case Management and Care Coordination Models in Victoria.	7 projects funded under Koolin Balit investment	Examine approaches to care coordination and case management in Aboriginal health that show promise and potential for replication in other communities through investigating 7 projects. Key findings: Case management is effective and culturally appropriate; The significance of the care coordinator role - critical; (positive) impact of the care coordinator role on clients, colleagues, agencies and local service networks (associated with improvements in client's quality of life, health literacy, engagement with and trust of health services, maintenance of clinical care and health improvements); importance of Supporting and sustaining practitioners; Findings relating to clients' experience of care coordination; practice related findings; organisational or service system findings; evidence base - all 7 projects could improve data collection. See 'approach to replication' (don't transplant) and 'opportunities for replication'. The 7 care coordination projects demonstrate that these culturally-informed, relationship-based models of care are delivering significant benefits for individuals, families and organisations and are also contributing to the more culturally-informed functioning of the broader local service system. The findings are consistent with emerging themes in the literature and add to the growing knowledge about how and why this approach is highly suitable in the field of Aboriginal health.
Garvey et al., 2016 [157] Qual - descriptive	NT, NSW, Victoria, Tertiary, regional oncology	Evaluated clinical implementation of SCNAT-IP in routine care using purpose designed questionnaires and interviews.	Staff and Indigenous cancer patients	"The study provides empirical support for the feasibility and acceptability of the SCNAT-IP in routine cancer care with Indigenous Australians. Routine screening with the SCNAT-IP has the potential to improve cancer care for Indigenous people with cancer."

Gibson et al., 2015 [104] Systematic review	International, Health	This systematic literature review synthesised international evidence on the factors that enable or inhibit the implementation of interventions aimed at improving chronic disease (CD) care for Indigenous people. Australia, NZ, Canada, USA. Qualitative findings: meta-aggregative approach. Quantitative data: narrative summary Attitudes, beliefs, expectations, understandings and knowledge of patients, their families, Indigenous communities, providers and policy makers were of interest.	23 studies (18 qual; 4 quan; 1 mixed.)	Five key factors should be considered: 1). Design attributes: include community engagement, the policy and funding environment, leadership, staff approach to change and sufficient resourcing. 2). CD workforce: workforce issues include difficulties recruiting / retaining staff, unsuitable workforce training and development, lack of dedicated CD positions with clear roles and responsibilities, excluding IHW from decision making, and the need to support staff well-being. 3). Patient /provider partnerships: the role of the provider extends beyond their professional and technical skills. Valued qualities include being understanding, supportive and empowering, being able to communicate sensitively and allowing patients to be partners in their care. 4). Clinical care pathway barriers: poorly performing electronic support systems and vague referral pathways. 5). Access: facilitated by providing consistent services and coordinated care, embedding culturally safe work practices (e.g., employing local Indigenous people and providing care in Indigenous spaces, being influenced by patient perspectives related to beliefs and experiences regarding health care and family support.
Gomersall et al., 2017 [153] Systematic review	Australia, PHC	Systematic review of qualitative evidence re what Indigenous Australians value about PHC. Study period from first ACCHOs. Indigenous Australians accessing ACCHOs.	10 articles on 9 studies reviewed	Small number of articles reporting highly valued ACCHO system of care. Valued: accessibility; culturally safe delivery of care; qualities of staff such as non-judgemental behaviour, trustworthiness, taking time for the patient and sensitivity; a comprehensive, holistic approach; relationships characterised by respect.

Green et al., 2018 [124] Qual	Australia,	Indigenous patient's experiences of cancer care. Stakeholders views - what to measure, how to measure it.	Aboriginal people affected by cancer n=17. Health Profs n=28. People in both groups n= 7.	Key themes: feeling safe in the system; importance of Indigenous staff; barriers to care; the role of family and friends; effective communication and education; and coordination of care and transition between services. Development of new measures warranted.
Harfield et al., 2018 [152] Systematic scoping review	International, Health	Systematic scoping review: characteristics of Indigenous primary health care service delivery models.	Indigenous	Findings used to develop new Indigenous PHC Service Delivery Model containing following characteristics: Accessible health services; flexible approach to care; community participation; self-determination and empowerment; CQI; holistic health care; culturally appropriate and skilled workforce; all underpinned by culture.
Le et al., 2013 [125]	NT, Tertiary - AWCCC	Compliance with radiotherapy in NT among Indigenous and non-Indigenous people. Data regarding compliance rates (defined as those who chose and completed the recommended course of treatment), patient, disease and treatment factors were collected.	All patients rx w RT at AWCCC. Indigenous courses n=41. non-Indigenous n=224.	Radiotherapy - no diff in Rx compliance b/w two patient groups. Model of care that may have increased compliance included funded transport, accommodation, meals, transfers for patient and escort. Dedicated ILOs. Other strategies - free phone use, laptops for patient/family to allow communication. Small numbers.
Liaw et al., 2011 [105] Literature review	International, Any	Papers included if examined chronic disease intervention for an Aboriginal population and reported on evaluation /impact/ outcomes. 11 of 173 papers met inclusion criteria,	Aboriginal population - chronic disease	Successful chronic disease care and interventions require adequate Aboriginal community engagement, utilising local knowledge, strong leadership, shared responsibilities, sustainable resources and integrated data and systems (including appropriate identification).

		all conducted in rural/remote ACCHS.		
McGrath, 2010 [163] Qual	NT, Rural/remote	Overview of evidence based model for service delivery to rural and remote Aboriginal people needing palliative care. What is? What works? What is needed? Interviews w 72 people.	Pts (10);carers (19); AHWs(11); health care workers(30); interpreters(2).	The Living Model. Key processes in provision of pall care: employing AHWs; effective communication (right story to right person); addressing psychosocial and practical problems; building services in communities; encouraging family meetings; educational activities; addressing relocation issues- focus on staying home; understanding / supporting cultural practices; developing culturally appropriate healthcare facilities; carer support; respite. Attention to beliefs associated with death/dying.
Micklem, 2015 [161] Literature review	Australia, Health	Literature review examining HRQL issues, self-reported by Aboriginal and/or Torres Strait Islander people with experience of cancer.	Aboriginal and/or Torres Strait Islander people with experience of cancer	Literature review examining HRQL issues for Aboriginal people with experience of cancer. Areas of concern for this population were identified. Proposes further PROMs work to provide greater insight.
Mooi et al., 2012 [169] Descriptive, semi-struc i/v	Qld, Tertiary - rural	Reports on teleoncology satisfaction and perspectives to Indigenous patients and HWs. Small numbers. 23 Indigenous patients participated in VC b/w 2007-2011. At time of eval, 13 deceased, 1 couldn't be contacted. (Part of Caffery et al 2017 systematic review)	Indigenous patients n=9. HW n=6.	High levels of satisfaction. Issues of patient confidentiality - presence of HW or not. Enhanced partnership with local HWs and specialist teams. Shared care model. The promotion of this shared-care model optimally delivered quality care to Indigenous cancer patients ‘at their doorstep’. Formal skills training and effective communication between specialist and local HWs are essential to maintain safety of practices. Proposes various improvements.

O'Brien et al., 2013 [162] Review	NSW, PHC	Utilises recent literature and lessons derived from Aboriginal consultation. Argues for palliative care models that fit with Aboriginal people's values, beliefs, cultural / spiritual rituals heritage and place.	Aboriginal people needing palliative care	Alternative models to mainstream facilities or palliative care centres: AHW and home visits. HC systems that give control to Aboriginal community have been accepted and improved access. Address staff turnover, training, recruitment, retention and sustainability issues. Address lack of culturally appropriate support for AHWs in all areas. Avoid one-size-fits-all models. Contextualise culturally appropriate models to reflect diversity of local conditions/needs. Models must respect the Aboriginal people's link with land and sense of family and community, acknowledge cultural/spiritual beliefs about illness dying death. Palliative care for the Aboriginal person must focus on the individual as part of a larger family/community and kinship network, providing dignified care, support and education that extends beyond the individual. Preferable that palliative care is delivered under ACCHO auspices, in partnership with mainstream services. Ensure critical mass of Aboriginal clinicians are trained and experienced in end of life / palliation.
Reeve et al., 2015 [151] Cross-sectional retrospective evaluation	WA (NW), Health services	Evaluate the impact of a comprehensive PHC service model on health KPIs in a remote region of Australia. Six year retrospective eval. Involved ACCHO, hospital and community health service.	Service users.	“Demonstrates that strengthening PHC services by addressing key enablers and sustainability requirements can translate into population health gains consistent with the goals underpinning the National Health Care Reform and Closing the Gap policies, and may potentially reduce health inequity for remote-living Aboriginal Australians.” Outcomes included improved occasions of service, health assessment and some quality of care indicators (diabetes related).

Reilly et al., 2016 [147] Systematic review	International - Australia, NZ, Canada, Health	Systematic review of qual and quan studies. Examine the evidence relating to the effectiveness, cost-effectiveness and acceptability of chronic kidney disease management programs designed for Indigenous people, as well as barriers and enablers of implementation of such programs.	Indigenous people Australia, NZ, Canada	Reviewed management programs/models of care designed to manage, slow progression or improve lives of Indigenous people with CKD. Common features of effective and acceptable programs were integration within existing services, nurse-led care, intensive follow-up, provision of culturally-appropriate education, governance structures supporting community ownership, robust clinical systems supporting communication and a central role for Indigenous Health Workers.
Reilly et al., 2018 [126] Qual	SA, Tertiary and primary	Findings from CanDAD narratives regarding how care coordination, provided by dedicated care coordinators or others, addressed gaps in care or otherwise influenced Aboriginal people's experiences of cancer care.		Cancer care coordination - 4 main areas: "navigating the health system"; "information and communication"; "things to manage at home"; and "cultural safety".
Sabesan et al., 2012 [168] Descriptive	Qld, Tertiary - rural	Successful use of telemedicine for rural cancer care. (Part of Caffery et al 2017 systematic review)	18 Indigenous patients + family support. 140 non-Indigenous.	Telemedicine - successful model of care for Indigenous patients. Allows rural and Indigenous cancer patients to rec specialist and chemo treatment closer to home - minimise access difficulties. Lacks data on safety aspects of remote supervision of chemo. Not known whether telemedicine model improves cancer-related clinical outcomes c/w face to face models.
Sabesan et al., 2015 [166] Review / report	Qld, All	Reviewed telehealth models for cancer care - explored ability to deliver specialist cancer care through telehealth.	Reported on program, not people.	Reported outcomes on telehealth models re patient satisfaction, HP perspectives, home supervision safety, cost. New models of telehealth are needed to decrease the disparity of access and survival outcomes between rural and urban patients.

Shahid et al., 2016 [121] Qual	WA, Metro Perth, rural/remote (6)	Factors contributing to delayed diag. Open ended i/v. 'Delayed diagnosis' was identified as a problem from the literature, so possible reasons were explored.	Aboriginal cancer patients + family n=30. Health service providers=62.	Aboriginal participants were asked to describe their or family members' experiences with cancer and cancer services, with specific interview probes on diagnosis, treatment and follow-up. Service providers' interviews covered questions around their general experience with Aboriginal patients with cancer, specific issues they face and possible solutions to these issues. Delayed diagnosis - context, health service-related, patient related. Multiple strategies - communication, cultural safety training, patient navigators, telehealth, longer consults, longer term relationships, person centred model of care, address access, enquiry re trad med.
Shahid et al., 2018 [165] Comprehensive review	International, Multiple	Examine provision of culturally safe palliative care service delivery to Indigenous people in Australia, NZ, Canada and the USA; and to compare Indigenous peoples' preferences, needs, opportunities and barriers to palliative care.	522 articles screened. 39 eligible for inclusion.	"Despite diversity in Indigenous peoples' experiences across countries, some commonalities were noted in the preferences for palliative care of Indigenous people: to die close to or at home; involvement of family; and the integration of cultural practices. Barriers identified included inaccessibility, affordability, lack of awareness of services, perceptions of palliative care, and inappropriate services. Identified models attempted to address these gaps by adopting the following strategies: community engagement and ownership; flexibility in approach; continuing education and training; a whole-of-service approach; and local partnerships among multiple agencies. Better engagement with Indigenous clients, an increase in number of palliative care patients, improved outcomes, and understanding about palliative care by patients and their families were identified as positive achievements. The results provide a comprehensive overview of identified effective practices with regards to palliative care delivered to Indigenous populations to guide future program developments in this field. Further research is required to explore the palliative care needs and experiences of Indigenous people living in urban areas."

Tam et al., 2018 [137] Qual	Qld, Tertiary hosp	Sought to elicit enablers to positive cancer care experience.	Adult, Indigenous, cancer. n=12	“Two major categories of enablers were identified: resilience and communication. Individual’s intrinsic strength, their coping strategies, and receipt of support improved participant’s resilience and consequently supported a positive experience. Communication methods and an effective patient-provider relationship facilitated positive experiences for participants. Despite potential barriers to access of care for Indigenous cancer patients, participants demonstrated that it was still possible to focus on the positive aspects of their cancer experiences. Many participants explained how cancer changed their outlook on life, often for the better, with many feeling empowered as they progressed through their cancer diagnosis and treatment processes.” Clear communication enhanced decision making and understanding of disease and treatment.
Tan et al., 2016 [167] Prospective	Qld - North, Tertiary and PHC	Prospective recruitment of patients to 3 regional hospitals. Times to presentation/treatment of regional/remote head and neck patients. Self-administered questionnaire.	Newly diagnosed head and neck cancer patients	Indigenous patients experience significant delays from diagnosis to first Rx. Some possible strategies to help bridge the rural/regional divide include greater support for regional and remote patients to travel, better managed referral pathways, various specialist outreach models of care such as ‘fly in fly out’ specialists, timely processing of referrals, virtual multidisciplinary teams coordinated by care coordinators and building the capacity of local staff in regional cancer services and telemedicine. Telemedicine may assist with timely diagnosis treatment, and follow-up.
The Wardliparingga Aboriginal Research Unit of the South Australian Health and Medical	Australia	National Safety and Quality Health Service Standards user guide for Aboriginal and Torres Strait Islander health		For the first time, in 2017 the ACSQHC defined six actions aimed at specifically meeting the needs of Aboriginal and Torres Strait Islander people within the National Safety and Quality Health Service Standards and The Wardliparingga Aboriginal Research Unit developed a user guide to assist health organisations to meet the standards and measure performance. The six actions (each including what the actions mean for the organisation, benefits of taking action, key tasks, strategies, examples of supporting evidence and additional

Research Institute (SAHMRI), 2017 [75] Australian Commission for Safety and Quality in Health Care (ACSQHC)				resources) are: a) Partnering with Consumers Standard: The health service organisation works in partnership with Aboriginal and Torres Strait Islander communities to meet their healthcare needs. b) Clinical Governance Standard(b-e): The governing body ensures that the organisation's safety and quality priorities address the specific health needs of Aboriginal and Torres Strait Islander people c) The health service organisation implements and monitors strategies to meet the organisation's safety and quality priorities for Aboriginal and Torres Strait Islander people d) The health service organisation has strategies to improve the cultural awareness and cultural competency of the workforce to meet the needs of its Aboriginal and Torres Strait Islander patients e) The health service organisation demonstrates a welcoming environment that recognises the importance of cultural beliefs and practices of Aboriginal and Torres Strait Islander people f) Comprehensive Care Standard; The health service organisation has processes to routinely ask patients if they identify as being of Aboriginal and/or Torres Strait Islander origin, and to record this information in administrative and clinical information systems.
Thewes et al., 2016 [158] Qual	Australia, Cancer clinics	Semi-structured interview. Attitudes towards feasibility and acceptability of SCNAT-IP in routine care.	n=44 (10 clinical staff; 34 Indigenous people with cancer).	The Supportive Care Needs Assessment Tool - Indigenous People (SCNAT-IP) has the potential to help reduce the inequalities in cancer care experienced by Indigenous Australians by identifying and subsequently addressing their unmet support needs.
Tranberg et al., 2016 [101] Systematic review	International	Cancer treatment decision-making by Indigenous people PRISMA. Peer reviewed, post 1960. qual, quan, mixed	Indigenous adults, any cancer. 5 studies, all Australian.	Themes identified: spirituality (fatalism, 'payback', spirituality of body); cultural influences (connection to family/Country, shame and stigma); communication (knowledge transfer, relationships w health workers); and existing healthcare systems and structure (inaccessibility, appropriate support services).

		method primary res. Excluded grey. Narrow search terms.		Culturally appropriate health care requires health professionals to be well trained in the use of interpersonal skills and to apply these skills to the development of therapeutic relationships in which indigenous people with cancer are engaged and empowered. Need to accommodate Indigenous people's beliefs within the health system so that Indigenous patients and families are supported in a culturally appropriate manner during the cancer treatment journey. E.g., recognising wholeness of the body may override the need for cancer treatment. Essential for cancer treatment plans for Indigenous people to recognise that connection is integral to the indigenous expression and experience of life - many indigenous patients will prioritise their connection to family, community and land over any benefits to be gained from successful cancer treatment. See discussion.
Valery et al., 2017 [159]	Qld, Tertiary	SCNAT-IP - assess overall and specific needs, look at association between risk factors and mod-high unmet needs.	248 Indigenous adults diagnosed with cancer at one of 4 Qld hospitals	54% exp at least 1 mod unmet need at diag. Reduced to 34% at 6mths post diag. The top unmet needs at diagnosis were money worries (27%), concerns about the worries of those close to you (16%) and worry about your illness spreading/getting worse (15%). Having a higher education and having received cancer treatment in the last 30 days were significantly associated with greater needs at diagnosis. Conclusions: While unmet needs decreased over time, some patients continued to experience moderate-high unmet needs. Needs should be monitored throughout the patient's journey. Coordination of support, particularly for those with multiple needs, may be important for this group.
Woods et al., 2018 [164] Cross-sectional, comparative	Australia, PCOC; Pall Care Outcome Collab	Examined timeliness of commencing a palliative care episode of care against the benchmark; Indigenous compared with non-Indigenous	Adults at participating services.	"Although the timeliness benchmark is being met for Indigenous Australians in palliative care, they may experience delayed initiation of care episodes, particularly if younger, and especially at first encounter with a service. Qualitative research is required to explore determinants of delay in initiating palliative care episodes. The

		patients in participating services.		timeliness of initial referral for specialist palliative care in this population remains to be determined.”
Wotherspoon & Williams, 2018 [114] Inpatient experience	Victoria, Tertiary	Measure whether there were any differences in in-patient experiences between Aboriginal and Torres Strait Islander people non-Aboriginal patients. (Peninsula Health hospital)	N=154; 76 Aboriginal (6% of inpatients), 78 non-Aboriginal (<1% of inpatients).	This study found systemic differences in in-patient experiences. “Healthcare services have a responsibility to make systemic changes to improve the health care of all Australians by understanding and reforming how services can be appropriately delivered”. Measure patient's experiences and identify gaps.

Table 2.3.2 Optimal Care Pathway and related documents specific to Aboriginal and Torres Strait Islander people

Institution, Year	Document name	Summary
Cancer Australia, 2016 [282]	My Lung Cancer Pathway: a guide for Aboriginal and Torres Strait Islander people and their families	My Lung Cancer Pathway: a guide for Aboriginal and Torres Strait Islander people and their families.
Cancer Australia, 2018 [80]	Optimal Care Pathways for Health Professionals: Quick reference guide	Quick Reference Guide: provides guidance to health practitioners and service planners on optimal care for Aboriginal and Torres Strait Islander people with cancer, across the cancer continuum. Refer to the relevant tumour-specific Optimal Care Pathway at cancerorg.au/OCP.
Cancer Australia, 2018 [283]	What to expect - Optimal Care Pathways for Aboriginal and Torres Strait Islander people	Cancer - what to expect. Information for Aboriginal and Torres Strait Islander People who have cancer. Refers to guides about different cancer types at www.cancerpathways.org.au.
Cancer Australia, 2018 [9]	Optimal Care Pathways for Aboriginal and Torres Strait Islander people with cancer	The Optimal Care Pathway for Aboriginal and Torres Strait Islander people with cancer has been designed to complement the tumour-specific OCPs, focusing on the aspects of the care pathway that need to be responsive to the needs of Aboriginal and Torres Strait Islander people with cancer. Detailed guidance through the cancer continuum and reference guide to other resources.

Table 2.4.1 Cultural safety and cultural competence

Author, year, study type	Jurisdiction, sector	Description	Population	Short summary
Adams et al., 2015 [141] Qual	Qld, Tertiary	Prevalence and profile of CAM / TM users among Indigenous Australians with cancer.	248 Indigenous adults diagnosed with cancer at one of 4 Qld hospitals	"A substantial percentage (18.7%) of Indigenous cancer patients use at least one TM/CAM for support with their care, including traditional Indigenous therapy use (2.8%), visiting a traditional Indigenous practitioner (2.8%), CAM use (10.7%), visiting a CAM practitioner (2.4%), and attending relaxation/meditation classes (4.0%). Having a higher level of educational attainment was positively associated with CAM practitioner consultations (P = .015). Women with breast cancer were more likely to attend relaxation/meditation classes (P = .019). Men with genital organ cancer were more likely to use traditional Indigenous therapies (P = .017) and/or CAM (P = .002). Conclusion. A substantial percentage of Indigenous Australians reported using TM/CAM for their cancer care, and there is a need to expand examination of this area of health care using large-scale studies focusing on in-depth specific cancer(s)."
Bainbridge et al., AIHW / CTGC, Issues paper no. 13, 2015 [173]		Cultural competency in the delivery of health services for Indigenous people		What works, what doesn't. Indicators and measures of cultural competence, in strength of indicator quality. Relationship between cultural competency and healthcare outcomes. Reviewed available international evidence on cultural competence in health care settings, with a view to identifying effective strategies and determining the relationship between cultural competency and health outcomes. This paper presented: • indicators and measures of cultural competence from 14 studies, one of which was from Australia and New Zealand (combined study). Indicators used included: a NZ cultural competence audit tool (mental health nursing); self-reported Healthcare practitioners' knowledge attitudes practice tool regarding cultural sensitivity and others; a validated

			traditional cultural experience tool from USA; case history and discussion from Australian medical students after cultural competence training and interaction with an Indigenous person. • 20 studies which evaluated the effectiveness of interventions designed to improve cultural competence (7 from Australia), though 13 of these were rated as methodologically weak. Of the total 28 of studies, a positive relationship between cultural competency and healthcare outcomes was demonstrated in 15 studies, and at four healthcare levels (Australian examples in brackets): health service (increased antenatal visit frequency in culturally responsive services); practitioner (improved practitioner knowledge and competence to deliver smoking interventions after training); training/education (significant increase in medical students' cultural knowledge, attitudes, skills and competence after cultural competence training); and patient level. There was a consistent message that knowledge alone was insufficient in fostering improvements.
Hunt, AIHW / CTGC, Issues paper no. 5, 2013 [284]	National	Engaging with Indigenous Australia—exploring the conditions for effective relationships with Aboriginal and Torres Strait Islander communities	What works: Engaging successfully with Indigenous communities requires: • an appreciation of—and the cultural competency to respond to—Indigenous history, cultures and contemporary social dynamics and to the diversity of Indigenous communities; valuing the cultural skills and knowledge of community organisations and Indigenous people; • clarity about the purpose and the relevant scale for engagement, which may call for multi-layered processes: engagement needs to relate to Indigenous concepts of wellbeing; • long-term relationships of trust, respect and honesty as well as accessible, ongoing communication and information; • effective governance and capacity within both the Indigenous community and governments themselves; • appropriate time frames (including for deliberation and responsive funding, where applicable).

Hunt, AIHW / CTGC, Resource sheet no. 23, 2013 [172]	National	Engagement with Indigenous communities in key sectors		What works: Engagement occurring through partnerships with Indigenous organisations within a framework of self-determination and Indigenous control.; Strategies explicitly addressing power inequalities, with genuine efforts to share power, including through negotiated agreements.; Staff working with Indigenous people who understand the social and cultural context in each place and contemporary social fluidity; Sharing responsibility for shared, realistic objectives and collaborative formulation of criteria and indicators for annual self-assessments, including assessment of the processes as well as the outcomes; Adequate and sustained resourcing based on the roles and responsibilities of each partner; All parties committing to develop long term relationships based on trust, and to work within appropriate timeframes; Where land and environmental issues are concerned, planning at the scale of each group's 'country'.
Ware, AIHW / CTGC, Resource sheet no. 27, 2013 [285]		Improving the accessibility of health services in urban and regional settings for Indigenous people		What works: Addressing physical and economic barriers through strategies such as: – providing services locally – providing transport to health services – having flexibility in setting appointments – using home visitation as part of a multi-faceted engagement strategy – increasing services that do not require co-payment – improving access to private health insurance and private health services. • Addressing cultural competence, acceptability and appropriateness through strategies such as: – developing services around the holistic model of health and wellbeing – building therapeutic and clinical relationships based on trust and mutual respect – employing Indigenous health professionals and health workers to promote culturally safe service delivery – where feasible, providing a choice between Indigenous-specific and non-Indigenous–specific health professionals and services – adopting strategies that support cultural competency and safety at the systemic, organisational and individual levels, including appropriate communication styles, and working through community Elders and kinship networks – providing services in non-traditional settings.

Stewart et al., AIHW / CTGC, Resource sheet no. 8, 2011 [171]	National	Effective practices for service delivery coordination in Indigenous communities	Evidence from process evaluations and documented practice experience reveal that service delivery coordination initiatives designed with, and for, Indigenous populations must:• focus on outcomes; • be culturally appropriate; • invest time and resources into community consultations; • apply a strengths-based approach; • support Indigenous and non-Indigenous staff. Initiatives work best when they are targeting a specific issue or problem that demands coordination across organisations: that is, they must be 'fit-for-purpose'. Service coordination initiatives are most appropriate for Indigenous Australians when: • the nature of the service suits a collaborative approach (that is, no one agency could feasibly provide the know-how required to produce particular outcomes); • benefits outweigh the time and resources (financial and human) needed for coordination, as opposed to putting the resources into a single agency with sole responsibility for delivery of that service; • current service delivery arrangements can be improved (in terms of equity, efficiency and other policy objectives).
Aitken et al., 2017 [186] Australian Health Ministers' Advisory Council. NT Health, Chief Nursing / Midwifery Office, 2016-2017	National Report	National Stocktake of Organisational Cultural Competence in public Maternity Care for Aboriginal and Torres Strait Islander Women. Prepared on behalf of Maternity Services Inter-Jurisdictional Committee.	Included here as possible future research re cancer services. Aims: 1. Assess the degree to which 14 previously identified characteristics (see below) of effective culturally competent care have been incorporated into the fabric of maternity services nationally. Conclusion: Most action in family engagement and improving communication. Least action in providing information in language and involvement of community members and Elders in governance/formulation of health information. Limited assessment of cultural competency of organisation or individual. Significant correlation between level of Indigenous employment within services and progress towards implementing actions for a range of characteristics. Positive relationship between organisations who cared for more Aboriginal women and staff evaluating maternity outcomes for Aboriginal women as a specific

				cohort. 60% services rated positive progress to improving organisational cultural competency. 2. Raise health service organisational awareness of how to work towards creating a culturally safe environment for Aboriginal and Torres Strait Islander women. 29% response rate, but required depth within each service that responded. Requested organisational level actions. 3. Validate a tool for the cyclic assessment of progress as a driver for implementing positive change. Validated tool and proposed refinement then consideration for use in mandatory reporting requirements in public maternity services to assess progress towards adopting organisational cultural competence. *"Characteristics of effective culturally competent care:* *1. Physical environment and infrastructure. 2. Specific Aboriginal and/or Torres Strait Islander program. 3. Aboriginal and Torres Strait Islander workforce. 4. Continuity of care and carer. 5. Collaborating with Aboriginal Community Controlled Health Organisations and other agencies. 6. Communication, information technology and transfer of care. 7. Staff attitudes and respect. 8. Cultural education programs. 9. Relationships. 10. Informed choice and right of refusal. 11. Tools to measure cultural competence. 12. Culture specific guidelines. 13. Culturally appropriate and effective health promotion / behaviour change activities. 14. Engaging consumers and clinical governance."*
Bertilone et al., 2017 [188] Qual – survey, interviews	WA, PHC	Aboriginal Maternity Group Practice Prog - elements that contributed to provision of culturally competent service.	Clients (16). Staff - partner organisations (22). Staff(15).	Aboriginal Maternity Group Practice Program, NT (one of the programs included in Corocane 2017) - used specific tool to determine elements that contributed to provision of culturally competent service. Many elements contributed.

Bierbaum et al., 2017 [178] Evaluation	SA,	Evaluation of health education cancer resource.	18 HPs	Evaluation survey of health education cancer resource (flipchart and patient flyer) for health professionals, which assist HP in explaining cancer and the journey to Aboriginal patients and families. Whether valuable / culturally appropriate or helpful for explaining aspects of cancer and useful re patient outcomes. Longer term implementation strategy needed.
Breast Cancer Network Australia, 2017 [185]	Website and video	Culture is healing: the making of a possum skin cloak		“Aboriginal Victorian women have made a possum skin cloak to be used by Aboriginal people undergoing cancer treatment at the Peter MacCallum Cancer Centre in Melbourne. Possum skin cloaks are an important cultural item in communities. The aim of the cloak is to enable Aboriginal people to physically wrap themselves in culture during their time in treatment. The video includes interviews with the makers of the cloak, women who are survivors of cancer or, still in treatment.“
Clifford et al., 2015 [180] Systematic review	International, General	Systematic review of interventions to improve cultural competency in health care for Indigenous peoples of Australia, NZ, Canada and USA	Studies focussed on Indigenous people Total n=16. Australia (n=5), NZ (n=0) Canada (n=0) USA (n=11)	Aims and findings: 1) identify published evaluations of interventions designed to improve cultural competence in health care for Indigenous peoples of Aust NZ Canada or the USA. 2) to determine which interventions are effective; main types were education and training of the health workforce, culturally specific health programs and recruitment of an Indigenous health workforce. Main positive outcomes reported were improvements in health professionals’ confidence, and patients’ satisfaction with and access to health care. Although education and/or training of health professionals is an important component of an overall framework for cultural competence, it is generally insufficient to change health professionals’ behaviour, and in turn, patient-related outcomes such as patient satisfaction, adherence and health outcomes. Improving these types of outcomes is likely to require structural changes at the level of the organization, to reinforce and sustain behaviour change in health professionals. Some strategies proposed for achieving this include embedding cultural competency in organizational policy, protocols and related key performance indicators. Although there is some evidence that organizations that have integrated cultural competency standards into

				policies and practices influence health professionals to develop more culturally competent behaviours, more rigorous research is needed in this area. 3) Report methodological quality; variable. Particular problems included weak study designs, low or no reporting of consent rates, confounding and non-validated measurement instruments. Overall, the evidence base for the effectiveness of interventions to improve cultural competency in health care for Indigenous peoples would be strengthened by evaluation studies that employ more rigorous study designs, recruit more representative samples, utilize validated measurement instruments and conduct high-quality economic evaluations.
Coalition of Peaks, NACCHO, 2019 [174]	Fact Sheet	Partnership Agreement on Closing the Gap		"An historic Partnership Agreement on Closing the Gap has been agreed between the Commonwealth Government, State and Territory Governments and a Coalition of Aboriginal and Torres Strait Islander Peak Bodies. The Partnership Agreement means that for the first time Aboriginal and Torres Strait Islander people, through their peak body representatives, will share decision making with governments on Closing the Gap. Under the Partnership Agreement, for the first time, Aboriginal and Torres Strait Islander peoples will have and equal voice and full ownership of the Closing the Gap framework. The Coalition of Peaks believe that shared decision making between governments and Aboriginal and Torres Strait Islander community controlled representative organisations in the design, implementation principles and monitoring of Closing the Gap is essential to closing the gap in life outcomes between Indigenous and non-Indigenous Australians."
Corcoran et al., 2017 [187] Metasynthesis	International studies, General	Synthesis of qual studies of models of care to help guide practice development and innovations re	9 studies (6 Australia; 3 Canada). Indigenous	Synthesis of qual studies of models of care for culturally appropriate midwifery services. Nine studies, 6 Australia; 3 Canada. Main themes; valuing continuity of care, managing structural issues, having negative experiences with mainstream services and recognising success. The most positive experiences for women were found with the services that provided

		culturally appropriate midwifery services.	women and babies	continuity of care, had strong community links and were controlled by Indigenous communities.
Davidson et al., 2013 [98] Integrative literature r/v	Australia, n/a	Examine experience of lung cancer in Aboriginal pop and identify reasons for poorer outcomes and lower levels of treatment compared w non-Aboriginal pop. Identify opportunities for early intervention.	Articles addressing lung cancer in Australian Aboriginal & Torres Strait Islander people.	Barriers to optimal lung cancer Rx. Proposes collaborative model of care that incorporates building capacity in Aboriginal and non-Aboriginal personnel, recruiting more Aboriginal health professionals, increasing knowledge and skills to develop trusting relationships between mainstream providers and Aboriginal patients, and delivering care that is respectful and culturally competent. For effective and sustainable solutions to be achieved, building relationships with Aboriginal communities must be the centre of any strategy.
Davy et al., 2017 [182] Framework development	Australia, PHC	Developed a Framework to support the quality of care and quality of life of, as well as treatment for, Aboriginal and Torres Strait Islander peoples living with chronic disease.	Indigenous Australians	Two core values: upholding peoples' identities in connection to culture, spirituality, families, communities and Country; culturally safe primary healthcare services. Framework, key elements: locally defined, culturally safe services; appropriately skilled and culturally competent staff; responsive, holistic care throughout the lifespan; and best practice care to address local needs. Developed by and for Aboriginal and Torres Strait Islander people. Advocates building relationships so that the patient and provider together determine the type of care the person is seeking. Each of these underpinned by four principles, see Fig 2 in article.
Davy et al., 2016 [154] Framework synthesis	Australia, PHC	Framework synthesis - access to PHC services for Indigenous people and how Indigenous health services addressed the challenges.	Indigenous	Presents framework for Indigenous people accessing PHC incorporates interrelated features of acceptability, availability, affordability, ability to engage, approachability.

Dorrington et al., 2015 [175] Translational res & CQI	ACT, Urban ACCHO	Describes translational research & CQI processes used to identify barriers / facilitators to Pap screening. Aim to increase rates.	survey(n=30) data collection (n=213)	Barriers to Pap smear: forgetting, no time, too busy, discomfort, not liking them, fear, shyness. Significant preferences for provision at ACCHS by female provider known to the client. The use of TR with CQI led to a significant increase in Pap smear screening, which was maintained for 10 months of follow up.
Durey et al., 2017 [119] Eval	WA, workforce - radiation oncology health professionals (HP)	Delivery of culturally safe care by radiation oncology health professionals to Aboriginal Australians with cancer.	59 HPs at workshop. Surveys: 66% pre workshop. 82% post workshop. 64% 2 month survey.	Does one workshop improve their (HP) confidence in knowledge, communication and ability to offer culturally safe care. Exploratory factor analysis identified three dimensions: communication, relationships, awareness. Workshop raised awareness re barriers and enablers to delivering culturally safe care, led to willingness to reflect on pre-existing beliefs & assumptions about Aboriginal Australians - some cases led to improved care. Single workshop can be effective in building confidence, but must be integrated into ongoing professional development.
Durey et al., 2012 [103] Review	WA, Tertiary	Review to inform a collaborative model of hospital-based organisational change.		Collaborative model of care: recruiting more Aboriginal HPs, increasing knowledge and skills to establish good relationships between non-Aboriginal care providers and Aboriginal patients/ families, delivering quality care that is respectful of culture, and improving Aboriginal health outcomes. Key element of model design: critical reflection on barriers and facilitators to providing respectful and culturally safe quality care at all levels.
Dwyer et al., 2014 [133] Qual i/v	SA, Tertiary	Investigate how policy requiring cultural respect and attention to health equity is implemented in care of rural and remote Aboriginal people in city hospitals.	Public hospital staff n=26.	Interviews with public hospital staff using cultural competence based framework to identify barriers and enablers in implementation of official policy re provision of care of rural Aboriginal patients. Systematic attention, at hospital and clinical unit level, to operationalising high policy goals is needed. The framework of cultural competence offers relevant guidance for efforts (at system, organisation and care delivery levels) to improve care, but requires organisations to address misinterpretation of the principle of equal treatment.

Effective Change, 2016 [123] (for DHHS)	Vic	Evaluation of Aboriginal Health Case Management and Care Coordination Models in Victoria.	7 projects funded under Koolin Balit investment	Examine approaches to care coordination and case management in Aboriginal health that show promise and potential for replication in other communities through investigating 7 projects. Key findings: Case management is effective and culturally appropriate; The significance of the care coordinator role - critical; (positive) impact of the care coordinator role on clients, colleagues, agencies and local service networks (associated with improvements in client's quality of life, health literacy, engagement with and trust of health services, maintenance of clinical care and health improvements); importance of Supporting and sustaining practitioners; Findings relating to clients' experience of care coordination; practice related findings; organisational or service system findings; evidence base - all 7 projects could improve data collection. See 'approach to replication' (don't transplant) and 'opportunities for replication'. The projects demonstrate that these culturally-informed, relationship-based models of care are delivering significant benefits for individuals, families and organisations and are also contributing to the more culturally-informed functioning of the broader local service system. The findings are consistent with emerging themes in the literature and add to the growing knowledge about how and why this approach is highly suitable in the field of Aboriginal health.
Garvey et al., 2018 [286] Qual -	Australia,	Part of supportive care needs study. Distress thermometer to assess distress in Aboriginal cancer survivors at ~6 months post diagnosis.	n=155	Need to identify psychological distress and for survivorship care to include culturally sensitive and tailored psychological support for Indigenous cancer survivors.
Gomersall et al., 2017 [153] Systematic review	Australia, PHC	Systematic review of qualitative evidence re what Indigenous Australians value about PHC. Study	Indigenous Australians. Ten articles reporting nine studies.	1. ACCHOs accessibility was highly valued. 2. The way ACCHOs delivered care was highly valued. 3. Particular qualities of ACCHO staff were highly valued. 4. A comprehensive, holistic approach to PHC was highly valued. 5. While relationships were characterised by respect and understanding in ACCHOs, in mainstream services there was often a lack of respect and no

		period from first ACCHOs. (Authors From SA)		shared understanding between providers and clients, or among clients. 6. ACCHO clients identified three unique highly valued characteristics of ACCHOs compared to mainstream PHC services: (1) accessibility, which clients described in terms of welcoming and safe spaces; (2) the way ACCHOs delivered care, in a culturally safe way tailored to need; and (3) comprehensive holistic care. Provider-client relationships characterised by shared understanding of clients' needs, Indigenous staff, and relationships between clients who share the same culture, are central to ACCHO clients' perceptions of ACCHOs' unique value. The client perceptions provide insights about how ACCHOs address socio-economic factors that contribute to high levels of chronic disease in Indigenous communities, why mainstream PHC provider care cannot substitute for ACCHO care, and how to improve accessibility and quality of care in mainstream providers.
Harfield et al., 2018 [152] Systematic scoping review	International, Health	Systematic scoping review: characteristics that contribute to the success of Indigenous primary health care service delivery models.	Indigenous	Findings used to develop new Indigenous PHC Service Delivery Model containing following characteristics: Accessible health services; flexible approach to care; community participation; self-determination and empowerment; CQI; holistic health care; culturally appropriate and skilled workforce; all underpinned by culture. Culture was the most prominent characteristic underpinning all of the other seven characteristics. Interdependence between the characteristics was evident.
Indigenous Allied Health Australia (IAHA), 2015 [88]	Framework	Cultural Responsiveness in Action, An IAHA Framework		Places culture at the centre of the model, describes cultural responsiveness as an extension of patient centred care and sets out a framework with six key capabilities and outcomes, guided by 'being, knowing and doing'. Addresses culturally responsive governance.
Liaw et al., 2019 [184]	Sydney and Melbourne	Cluster randomised controlled trial to examine whether the	28 practices in each control and	Liaw et al. (2019) devised a program 'Ways of Thinking and Ways of Doing' (WoTWoD) to embed the Cultural Respect Framework into routine clinical general practice. WoTWoD comprised a toolkit, one half-day workshop,

		Ways of Thinking and Ways of Doing (WoTWoD) cultural respect program improves clinically appropriate anticipatory care in general practice and the cultural respect of medical practice staff.	intervention group	cultural mentor support for the practice, and a local care partnership of participating Medicare Locals/PHNs and local ACCHOs for guiding the program and facilitating community engagement. The study then conducted a cluster randomised controlled trial to determine improvement in clinically appropriate anticipatory general practice care and cultural respect of practice staff. No changes were determined between the intervention and control groups in the outcome measures assessed: relevant MBS items, documentation of chronic disease risk factors and a questionnaire that measured capacity of staff to deal with four dimensions of cultural diversity. Study design, staff turnover, complex and indirect relationship between the intervention and outcome measures, the timing of the study during a period of PHC restructure and the fact that many PHNs were implementing culturally respectful chronic disease management interventions, reducing potential impact. Qualitative analysis has not yet been reported. Highlighted challenges of measuring impact of a cultural safety intervention and recommended local and regional coordination, and participatory mixed methods research in efforts to conduct robust evaluations.
Couch, 2018 [120]	Victoria, Loddon Mallee Region	Let's Yarn About Cancer Final Report Qualitative research, to investigate understandings and needs regarding cancer, and consider what would be useful to support and inform their practice	Interviews with 18 Aboriginal Health Workers at 6 sites in LMR	Suggestions: establish a peer support network for AHWs; consider if any services can be delivered more locally (i.e. leverage existing telehealth infrastructure); make better use of ‘Integrated Team Care’ teams where they exist within the region; may be opportunity for Cancer Council Victoria to develop further training to support AHWs in their work with cancer clients and survivors; Dissemination of survivorship stories from local communities may help improve community perceptions of cancer and potentially increase screening rates; At a state-wide level, there may be opportunity to commission Ilbijerri to develop a performance that addresses the cancer journey, including cancer survivorship, to change the discourse around cancer diagnosis in Aboriginal communities; There is opportunity for local, regional and state services to consider how culturally appropriate support might be provided for Aboriginal patients and carers; Consider if there is an opportunity for Aboriginal cancer patient navigator(s) in the Loddon Mallee Region; There is a continuing need for mainstream services to better

				support Aboriginal family structures and cultural needs; Future projects could specifically investigate improving linkages between mainstream cancer services and ACCOs, particularly around admission and discharge, as well as how to improve medication management at discharge; Review the number and gender of AHLOs employed by Bendigo Health, and compare with other regional health services; cancer services to consider how they can reduce this jargon and to be aware of, and address, power imbalances during interactions, as well as encourage Aboriginal patients to feel safe and confident in asking questions; Re Cancer Healing Messages flipchart and patient flyer to assist health professionals to explain cancer and the cancer journey to Aboriginal cancer patients and families - may be opportunity for a similar tool to be developed for a Victorian context.
Pilkington et al., 2017 [176] Qual	WA, Multiple	Interviews, yarning and FGDs with Aboriginal women re participation in breast screening. Try to identify potential initiatives to address low rates screening participation.	65 Aboriginal women	Higher participation rates for Aboriginal women in WA. Barriers (lack education re screening/breast Ca, cultural beliefs Ca, competing health/life priorities)/enablers (education by respected Aboriginal women, culturally appropriate promotion, care/support from other women in community) to screening participation identified.
Reilly et al., 2018 [126] Qual	SA, Tertiary and primary	Findings from the CanDAD narratives relevant to the question of how care coordination.		Findings from the CanDAD narratives relevant to the question of how care coordination, provided by dedicated care coordinators or others, addressed gaps in care or otherwise influenced Aboriginal people’s experiences of cancer care. Cancer care coordination - 4 main areas: “navigating the health system”; “information and communication”; “things to manage at home”; and “cultural safety”.

Smith et al., 2017 [181] Qual - exploratory	Qld, PHC	Examined views re whether PHC services are culturally appropriate for Aboriginal people, from staff and community perspective - Mt Isa	n=78. (Healthcare providers, admin staff =24). (Aboriginal community members n=54)	Found significant disparities in whether PHC services provide culturally competent care, between views of Aboriginal community members and PHC staff.
Social Compass, 2016 [93] (for Department of Health and Human Services (DHHS))	Victoria	Improving Cultural Responsiveness of Victorian Hospitals (Follows on from Improving the Culture of Hospitals Project (AIPC 2010)) Mainly qualitative evaluation.	173 interviews, 144 of whom were with Aboriginal people. Conducted January-October 2016	Placed the voices of Aboriginal people at the centre. Questions: 1. To what extent have Victorian hospitals improved their cultural responsiveness to Aboriginal people? 2. To what extent have people's healthcare experiences in Victorian hospitals (including cultural safety) changed? 3. What strategies have led to the most significant and sustainable improvements in cultural responsiveness and cultural safety of hospitals for Aboriginal people and staff? What are the critical contextual factors which enabled this success, and how could the successful strategies be replicated in other hospitals/settings? Have there been any unintended consequences of the successful strategies? 4. Are there strategies being employed which are relatively ineffective or unsustainable? 5. How can we improve measurement and monitoring of cultural responsiveness and cultural safety, both by individual hospitals and state-wide? How can we incorporate measuring the gaps between Aboriginal and non-Aboriginal people's access to quality care as a key impact? Phases: >40 consultations (key central and regional department staff and external stakeholders; document and data review of >200 documents (including CQI reports, Quality of care reports, Statement of Priorities analysis, Aboriginal Employment Plans, Victorian Healthcare Experience Survey results, previous evaluations and academic research); 7 hospital

case studies and interviews with hospital staff, ACCHO staff, patients, community members; Aboriginal Hospital Liaison Officer (AHLO) Survey: online survey provided to all AHLOs / Koori Mental Health Liaison Officers (KMHLOs) exploring the findings from interviews with AHLOs / KMHLOs at case study sites. The survey was administered through the ICAP Network with VACCHO. There were 15 surveys returned with a response rate of 20 per cent.

Findings: Consistent story of hospitals being sites of trauma for many Aboriginal people, not places of healing. Presents definitions of cultural responsiveness and cultural safety that emerged from community interviews. Found significant gaps in measurement and reporting of cultural responsiveness and cultural safety. Themes (consistent across participants):

- committed leadership (many CEOs and leaders are looking for support to improve cultural responsiveness and cultural safety);
- relationships with ACCHOs;
- AHLOs (most feel undervalued and neglected – subject and object of community trauma – stress leave common) and a stronger Aboriginal health workforce;
- a welcoming environment (flags, plaques, artwork, though tokenistic if the service system does not support them);
- cultural safety training (no evidence available of systematic capturing of performance or outcomes – hospitals looking for support);
- monitoring and reporting; none at hospital or state-wide level for reporting cultural responsiveness or cultural safety – current mechanisms ad hoc, non-mandatory and incomplete – no reliable hospital or state-wide data on Aboriginal patient experience.

				Provided set of indicators and measures to assist with monitoring and reporting cultural responsiveness and cultural safety, and can be used against the new National Safety and Quality Health Service Standards.[75] 'Overall the evaluation finds that increasing the support and capacity of the AHLO/KMHLOs will have the biggest impact on cultural responsiveness and cultural safety.' Contains Loddon Mallee Culturally Responsive Framework: Domain; Description; Actions. Three domains of change influencing a hospital's ability to provide culturally responsive care and cultural safety: 1. Hospital leadership and organisational culture. 2. Aboriginal and Torres Strait Islander workforce. 3. Aboriginal community relationships – including local ACCHOs, Traditional Owners and Aboriginal patients.
Taylor et al., 2018 [179] Self-admin online questionnaire	Australia, cancer services	Public cancer treatment centres across Australia; characteristics of centre, incl type service provided, Indigenous patient numbers and policy, implementation of Indigenous-specific initiatives. (see Taylor et al, 2018b)	RN /manager / other, at cancer service	Surveys were completed for 58 of 125 public cancer treatment centres. Almost half (47%) of the services saw more than 10 Indigenous patients per year, although Indigenous patients generally represented a small minority of patients. The most commonly reported initiatives were "having links with Indigenous health organisations in the community" (74% of services), "making a dedicated effort to address the needs of Indigenous patients" (69%) and proactively "creating partnerships with Indigenous communities and health organisations" (69%).

Taylor et al., 2018 [117] Qual interviews	Australia, cancer services	Telephone interviews were used to identify and describe the Indigenous-specific programs and initiatives that are implemented in a subset of the services that participated in a larger national online survey of cancer treatment services (see Taylor et al, 2018a)	range of management, support, and clinical staff	"Participants identified a number of factors that were seen as critical to delivering culturally appropriate treatment and support, including having a trained workforce with effective cross-cultural communication skills, providing best practice care, and improving the knowledge, attitudes, and understanding of cancer by Indigenous people. However, over a third of participants were not sure how their service compared with others, indicating that they were not aware of how other services are doing in this field. There are currently many Indigenous-specific programs and initiatives that are aimed at providing culturally appropriate treatment and supporting Indigenous people affected by cancer across Australia. However, details of these initiatives are not widely known and barriers to information sharing exist. Further research in this area is needed to evaluate programs and initiatives and showcase the effective approaches to Indigenous cancer care."
The Wardliparingga Aboriginal Research Unit of the South Australian Health and Medical Research Institute (SAHMRI), 2017 [75]	National	National Safety and Quality Health Service Standards user guide for Aboriginal and Torres Strait Islander health Australian Commission for Safety and Quality in Health Care (ACSQHC)		For the first time, in 2017 the ACSQHC defined six actions aimed at specifically meeting the needs of Aboriginal and Torres Strait Islander people within the National Safety and Quality Health Service Standards and The Wardliparingga Aboriginal Research Unit developed a user guide to assist health organisations to meet the standards and measure performance. Six actions (each including what the actions mean for the organisation, benefits of taking action, key tasks, strategies, examples of supporting evidence and additional resources) are: a) Partnering with Consumers Standard: The health service organisation works in partnership with Aboriginal and Torres Strait Islander communities to meet their healthcare needs. b) Clinical Governance Standard(b-e): The governing body ensures that the organisation's safety and quality priorities address the specific health needs of Aboriginal and Torres Strait Islander people c) The health service organisation implements and monitors strategies to meet the organisation's safety and quality priorities for Aboriginal and Torres Strait Islander people

				d) The health service organisation has strategies to improve the cultural awareness and cultural competency of the workforce to meet the needs of its Aboriginal and Torres Strait Islander patients e) The health service organisation demonstrates a welcoming environment that recognises the importance of cultural beliefs and practices of Aboriginal and Torres Strait Islander people f) Comprehensive Care Standard; The health service organisation has processes to routinely ask patients if they identify as being of Aboriginal and/or Torres Strait Islander origin, and to record this information in administrative and clinical information systems.
Tully et al., Hunter New England (HNE) Health, 2019 [189] Lowitja Institute Conference Presentation	HNE, NSW	Actioning meaningful cultural governance: organisational governance creating space for Aboriginal sovereignty over public health initiatives.		HNE Public Health (PH) has actioned a Joint Governance model, known as the Joint Governance Group (JGG). This provides a formal process whereby HNEPH Aboriginal staff can collectively provide advice to the Shared Population Health Service Delivery Leadership Group regarding the conduct of the organisations business as it relates to the Aboriginal staff of HNEPH and to the Aboriginal communities in the district. The aim of this model is "to embed cultural considerations into everyday business and shift power imbalances so that the organisation can move towards being culturally safe and respectful".
Tynan et al., 2013 [183] Letter	Victoria, Health services	Aboriginal cultural competence: Assessing health services in regional Victoria: Aspects of partnership and lessons for implementation re development of tool.	n/a	Hume region: and lessons re implementation. Three main issues: the internal dynamics of the working party; a human rights approach being embedded in the framework and audit tool; and implementation issues – in particular whether implementation should be voluntary or compulsory. Working party acknowledged lack of Aboriginal health knowledge & willingness to learn. Multiple stakeholders represented including Aboriginal communities and organisations. Working party accepted higher level statements (e.g. recognising impact of discrimination and colonisation on their health) as challenging them to higher level of cultural competence. References Aboriginal Cultural Competence Action Plans and need for assessment.

Zubrzycki et al., 2017 [177] Qual	NSW Australia, cancer services - rural	Examined how Aboriginal and non-Aboriginal health staff understand and experience cross cultural collaboration in cancer rural services. (in the Working Together project, NSW) FGDs, interviews. Participatory Action Research (focus on collaboration, political engagement and an explicit commitment to social justice)	41 (20 Indigenous. 21 non-Indigenous)	Initiatives which addressed high rates of mortality from cancer, poor access to cancer screening, and engagement with cancer treatment were developed through the formation of close working relationships between Aboriginal and non-Aboriginal health workers. Outlines new ways of knowing, being, and doing that emerged. Learnings: tension and conflict are part of collaboration, reciprocity and respect are important, need whole of organisation investment to sustain collaboration and workers experience collaborative work as personally and professionally transformative. Developing a deeper understanding of cross-cultural collaboration is one way of addressing complex health problems and building the capacity of the health workforce.

Table 2.4.2 Definition of terms related to cultural safety

Term	Reference	Definition
Cultural awareness	Australian Health Ministers' Advisory Council's National Aboriginal and Torres Strait Islander Health Standing Committee, 2015 [86] p19	"Demonstrates a basic understanding of Aboriginal and Torres Strait Islander histories, peoples and cultures. There is no common accepted practice, and the actions taken depend upon the individual and their knowledge of Aboriginal and Torres Strait Islander culture. Generally accepted as a necessary first step and a foundation for further development, but not sufficient for sustained behaviour change."
Cultural competence	Cross et al. 1989 [287] p13	"Cultural competence… is… a set of congruent behaviours, attitudes, and policies that come together in a system, agency, or amongst professionals and enables that system, agency, or those professionals to work effectively in cross-cultural situations. The word culture is used because it implies the integrated pattern of human behaviour that includes thoughts, communications, actions, customs, beliefs, values, and institutions of a racial, ethnic, religious, or social group. The word competence is used because it implies having the capacity to function effectively. A culturally competent system of care acknowledges and incorporates—at all levels—the importance of culture, the assessment of cross-cultural relations, vigilance towards the dynamics that result from cultural differences, the expansion of cultural knowledge, and the adaptation of services to meet culturally-unique needs."
Cultural respect	Australian Health Ministers' Advisory Council's National Aboriginal and Torres Strait Islander Health Standing Committee, 2015 [86] p19	"The recognition, protection and continued advancement of the inherent rights, cultures and traditions of Aboriginal and Torres Strait Islander people. Cultural respect is about shared respect. It is achieved when the health system is a safe environment for Aboriginal and Torres Strait Islander peoples and where cultural differences are respected. It is a commitment to the principle that the construct and provision of services offered by the Australian health care system will not knowingly compromise the legitimate cultural rights, practices, values and expectations of Aboriginal and Torres Strait Islander peoples. The goal of cultural respect is to uphold the rights of Aboriginal and Torres Strait Islander peoples to maintain, protect and develop their culture and achieve equitable health outcomes."

Cultural responsiveness	Australian Health Ministers' Advisory Council's National Aboriginal and Torres Strait Islander Health Standing Committee, 2015 [86] p19	"Refers to health care services that are respectful of, and relevant to, the health beliefs, health practices, cultures and linguistic needs of Aboriginal and Torres Strait Islander consumer/patient populations and communities. Cultural responsiveness describes the capacity to respond to the health care issues of Aboriginal and Torres Strait Islander communities. It is a cyclical and ongoing process, requiring regular self-reflection and proactive responses to the person, family or community interacted with. It thus requires knowledge and capacity at different levels of intervention: systemic, organisational, professional and individual."
Cultural safety	Williams, 1999 [288] p213	"An environment that is spiritually, socially and emotionally safe, as well as physically safe for people; where there is no assault challenge or denial of their identity, of who they are and what they need. It is about shared respect, shared meaning, shared knowledge and experience of learning together"
Cultural security	Australian Health Ministers' Advisory Council's National Aboriginal and Torres Strait Islander Health Standing Committee, 2015 [86] p19	"Commitment to the principle that the construct and provision of services offered by the health system will not compromise the legitimate cultural rights, values and expectations of Aboriginal and Torres Strait Islander people. It is achieved by developing accessible and effective health care systems for Aboriginal and Torres Strait Islander people, based on acknowledgement of these people's right to self-determination, empowerment and health care; and as such, an understanding of, and responsiveness to, their cultural views, beliefs and knowledge systems, which play an integral role in adherence to health care services."

Table 2.5.1 Best practice and survival for Aboriginal and Torres Strait Islander people with cancer

Author, Year, Study type	Jurisdiction, sector	Description	Population	Short summary
Australian Institute of Health and Welfare (AIHW), 2018 [82]	National	Cancer in Aboriginal and Torres Strait Islander Australians: An overview		Summary statistics on cancer in Aboriginal and Torres Strait Islander people
Banham et al., 2018 [192] Matched cohort	SA (sth NT), Tertiary	Examines amount and effect of comorbid conditions (hospital recorded) on cancer death on matched cohort Aboriginal - non-Aboriginal cancer cases. Whether effect of comorbid conditions varied because of Aboriginality.	Retrospective - all cancer cases among Aboriginal SA 1990-2010 (n=777) matched non-Abor random selected Ca's.	Higher levels of comorbidity in Aboriginal cancer cases - encourage earlier detection and management of chronic disease as a cancer risk reduction strategy. Comorbidities at diagnosis increased risk of cancer death (>60%) in addition to risks associated with Aboriginality, remoteness, disease stage at diagnosis. Additional risk if Elixhauser Comorbidity Index (ECI) /subset of ECI conditions recorded up to 5 years before cancer diagnosis. Aboriginal cohort: greater exposure to comorbidities- adds to disparities in outcomes. (Comorbidity effect did not differ b/w cohorts). Aboriginal cohort far more likely to have 4/more comorbid conditions and diagnosed with one of the subset of high risk ECI conditions. Higher levels of comorbidities were observed among Aboriginal cancer cases, and across each age group. Important evidence for encouraging earlier detection and management of chronic disease as a cancer risk reduction strategy. Suggest incorporate tailored chronic disease and wellness checks into cancer screening programs for Aboriginal people. While comorbidities were more concentrated among older non-Aboriginal cases, exposure to comorbidities were observed at higher levels and among each age group for Aboriginal cases. Whether they are operationalised as ECI scores of 4 or more, or as a subset of ECI

			conditions, comorbidities and their distribution are a necessary addition to understanding survival after cancer diagnosis.
Bureau of Health Information (BHI), 2016 [155]	NSW	The Insights Series Report – Healthcare in rural, regional and remote NSW.	Key findings; There were bigger gaps in experiences of hospital care between Aboriginal and non-Aboriginal patients in rural areas compared with urban areas – most notably for questions on communication, respect, patient engagement and patient reported outcomes.
Cancer Australia, 2016 [85] Framework	National	National Framework for Gynaecological Cancer Control	Guides future directions in national gynaecological cancer control over the next 5 years to improve outcomes, through consideration of models of care, integration across the cancer continuum, populations with variations in outcomes, research directions. Reports comparatively high burden on Aboriginal and Torres Strait Islander women - calls for quality, integrated services that meet the needs of this population. Priority area two is to improve outcomes for this population. Advocates centralised model of treatment, multidisciplinary care. For Aboriginal women, acknowledges context. Strategies to improve outcomes include: undertake research to identify views and identify barriers to screening, early detection/treatment and access to services; raise awareness of risk factors and symptoms to support prevention and early detection; increase participation in National Cervical Cancer Screening program; improve national recording of Indigenous status in pathology requests and reports; strengthen capacity of cancer related services to deliver culturally appropriate, integrated services across the continuum; identify patterns of care.

Cancer Australia, 2018 [84] Framework	National	Lung cancer framework: principles for best practice lung cancer care in Australia.		Lung cancer framework: principles for best practice lung cancer care in Australia: a national resource for health professionals and service providers who are involved in the care and treatment of people affected by lung cancer across Australia. The Lung Cancer Framework provides evidence-based, best practice information, strategies, tools and resources at consumer level and health service level, to support local adoption of the Principles in the delivery of best practice lung cancer care in Australia, however does not outline specific strategies for Aboriginal people. No specific mention of Aboriginal people other than acknowledgement, glossary, and variations in incidence and outcomes.
Christou et al., 2010 [207] Review	Australia, All	Characteristics of National Bowel Cancer Screening Prog that may contribute to discrepancies in screening. Analysis of barriers that result in lower participation rates of Indigenous / other groups.		(This is a relatively old article and contains strategies already introduced or being examined). Suggestions to address low CRC screening in Indigenous Aust. Modifications advised: alternative means of distribution (? supply hospitals/AMSs with kits - opportunistic); dedicated health staff for follow-up-support (intensive support necessary for Aboriginal rates to increase); integrate screening into PHC/chronic disease management; improve HP/availability of culturally relevant educational material; comm-based participatory research into Indigenous
Condon et al., 2014 [190] Survival rates	National, Tertiary	Used national cancer registration data - all-cancer and site-specific cancer. analysed time trends and regional variation in all-cancer survival between 1991 and 2005.	Indigenous Australians c/w non-Indigenous Australians	"Cancer survival is lower for Indigenous than other Australians, for all cancers combined and many individual cancer sites, although more accurate recording of Indigenous status by cancer registers is required before the extent of this disadvantage can be known with certainty. Cancer care for Indigenous Australians needs to be considerably improved; cancer diagnosis, treatment, and support services need to be redesigned specifically to be accessible and acceptable to Indigenous people."
Davidson et al. (Sax Inst for Cancer Inst	Australia, General	Best practice in early assessment and diagnosis of	General population	Targeting and tailoring models of screening for high risk populations is warranted, including Aboriginal and Torres Strait Islanders, those living remote from health care services and those from targeted culturally and

NSW), 2012 [204] Rapid review		lung cancer: an Evidence Check rapid review		linguistically diverse populations. Models based on early/rapid assessment need to be seamlessly linked to definitive diagnostic and treatment services.
Diaz et al., 2015 [206] Systematic review and matched retrospective cohort	Qld	Examine association between residential remoteness and stage of cancer at diagnosis, treatment uptake and survival New analyses: Qld Indigenous Cancer Study (QICS) data	Australian Indigenous population. Review: 15 papers from 13 studies. QCIS: n=627 rural/remote. N=329 urban.	Available evidence suggests Indigenous cancer patients are less likely to survive their cancer the further they live from urban centres. New analysis of QICS data indicates that Indigenous cancer patients in rural/remote Queensland were less likely to be diagnosed with localised disease and less likely to receive treatment for their cancer compared to their urban counterparts. Deeper understanding of geographic differentials in cancer outcomes will help identify ways of improving outcomes.
Diaz et al., 2015 [199] Matched cohort	Qld	Factors associated with cancer-specific and overall survival among Indigenous and non-Indigenous gynaecologic cancer patients	Indigenous women n=137. Non-Indigenous women n=120	Improving early diagnosis of cervical cancer in Indigenous women may increase cancer-specific survival in the year after diagnosis.
Diaz et al., 2018 [193] Cohort study	Semi-national, Tertiary	Re cervical cancer in Australian women, does Indigenous women's higher prevalence of comorbidity contribute to their lower survival compared to non-Indigenous women.	Indigenous c/w non-Indigenous women with cervical cancer	“Survival was lowest for women with comorbidity. However, there wasn't a clear comorbidity survival gradient for Indigenous women. Further investigation of potential drivers of the cervical cancer survival differentials is warranted. Comorbidity may form a barrier to participation in cancer screening, which may lead to more advanced disease at diagnosis. The results highlight the need for cancer care guidelines and multidisciplinary care that can meet the needs of complex patients. Also, primary and acute care services may need to pay more attention to Indigenous Australian women who may not obviously need it (i.e. those without comorbidity).” The authors reported the likelihood that comorbidities were not identified and that the comorbidity indices used

				have not been validated for the Indigenous population and it's possible that the most important diseases have been missed, particularly those not requiring hospitalisation.
Dorrington et al., 2015 [175] Translational res and CQI	ACT, Urban ACCHO	Describes translational research (TR) and CQI processes used to identify barriers / facilitators to Pap smear screening. Aim to increase rates.	Survey(n=30) Data collection (n=213)	Barriers to Pap smear: forgetting, no time, too busy, discomfort, not liking them, fear, shyness. Significant preferences for provision at ACCHS by female providers known to the client. The use of TR with CQI led to a significant increase in Pap smear screening, which was maintained for 10 months of follow up.
Garvey et al., 2016 [160] Quan - HRQoL	Qld - 4 hospitals, Tertiary	Assess Health Related Quality of Life (HRQoL) among Indigenous cancer patients.	Indigenous Australians with cancer n=155, 6 months after diagnosis.	Aboriginal patients reported lower HRQoL. Assessing HRQoL important for improving length and quality of cancer survivorship.
Garvey et al., 2016 [157] Qual - descriptive	NT, NSW, Victoria, Tertiary and regional oncology	Evaluated clinical implementation of SCNAT-IP in routine care using purpose designed questionnaires and interviews.	Staff and Indigenous cancer patients	The study provides empirical support for the feasibility and acceptability of the SCNAT-IP in routine cancer care with Indigenous Australians. Routine screening with the SCNAT-IP has the potential to improve cancer care for Indigenous people with cancer.
Gibberd et al., 2015 [198] Cross-sectional	NSW, Tertiary	To determine whether Aboriginal people in New South Wales were diagnosed with more advanced cancer than non-Aboriginal people.	All adults diagnosed with a primary invasive cancer in NSW	"Aboriginal people were more likely than non-Aboriginal people to be diagnosed with more advanced cancer for only a few cancer types, most notably head and neck cancers. Differences in spread of disease at diagnosis are unlikely to explain much of the survival differences observed across a wide range of cancers between Aboriginal and non-Aboriginal people in NSW."

Haigh et al., 2018 [97] Review	Australia, Health system	Overview of cancer in Indigenous people in Australia	Indigenous Australians with cancer	Key information on cancer among Aboriginal and Torres Strait Islander people in Australia to: "(1) inform those involved or interested in Aboriginal and Torres Strait Islander health; and (2) provide the evidence for those involved in policy, strategy and program development and delivery."
Meiklejohn et al., 2018 [129] Qual	Qld, PHC centres and tertiary hosp.	Exploration cancer survivorship perspectives of Indigenous cancer survivors. Recommendations for cancer survivorship.	Indigenous cancer survivors n=22 (completed treatment 6m-5yrs), support people, healthcare workers.	Survivorship: establishing a community cancer advocate and peer support program, availability and use of a cancer-specific Indigenous primary healthcare worker and hospital-based Indigenous patient navigator, as well as adoption of question prompt lists and cancer survivorship care plans.
Moore et al., 2011 [200] Comparative	Qld, Tertiary	Head and neck cancer treatment and survival. Compared clinical characteristics, treatment and survival b/w Indigenous and non-Indigenous people diagnosed in Qld.	67 Indigenous people treated public hospitals. Matched age/location with non-Indigenous.	Indigenous people significantly less likely to receive any cancer treatment. When stage, SES, comorbidities and cancer treatment taken into account, greater risk of death from head and neck cancer and from all other causes. Indigenous Australians receive less cancer treatment. Suggest survival disparity could be reduced if treatment uptake was improved. Need for greater understanding of reasons for such disparities. Plausible that chronic ill-health is associated with less treatment. When those who had treatment were compared, there was no difference in dose, duration or completion rate of radiotherapy between Indigenous and non-Indigenous people with head and neck cancer and overall, time to any treatment and curative treatment was also similar. Although numbers were small, the implication is that once engaged in treatment, the treatment pathway was likely to be similar between Indigenous and non-Indigenous people in the public setting in Queensland. This accords with previous research.

				Although small numbers and lack of statistical precision, disparities in cancer treatment delivery were identified – warrants further investigation.
Moore et al., 2014 [191] Survival analysis, patterns of care	Australia, Health	Survival disparities - analysis of patterns of care and comorbidities among Indigenous and non-Indigenous cancer patients	Indigenous and non-Indigenous diagnosed with cancer	"Indigenous Australians received less cancer treatment, had more comorbidities and had more advanced cancer stage at diagnosis, factors which contribute to poorer cancer survival. Moreover, for patients with a more favourable distribution of such prognostic factors, Indigenous patients received less treatment overall relative to non-Indigenous patients. Personalised cancer care, which addresses the clinical, social and overall health requirements of Indigenous patients, may improve their cancer outcomes."
Moore et al., 2016 [202] Matched cohort	Queensland, Tertiary	Investigate patterns of care and survival between Indigenous and non-Indigenous Australians with CRC.	80 Indigenous and 85 non-Indigenous people diagnosed with CRC, treated in Qld public hospitals	"Similar CRC mortality among Indigenous and other Australians may reflect both the lower incidence and adequate management. Increasing life expectancy and exposures to risk factors suggests that Indigenous people are vulnerable to a growing burden of CRC. Primary prevention and early detection will be of paramount importance to future CRC control among Indigenous Australians. Current CRC management must be maintained and include prevention measures to ensure that predicted increases in CRC burden are minimized."
Roder et al., 2012 [194] Survival	Australia excluding ACT, Tertiary	Survival - breast cancer - Aboriginal and Torres Strait Islander women of Australia	50-69 year old breastscreen participants	Higher risk of death not explained by sociodemographic factors. Previous studies (AIHW 2008) suggest higher levels comorbidity and potentially less complete cancer treatment due to geographic remoteness and cultural factors (differences in perceived value of treatment and obligations of community members to attend to community responsibilities).
Rodger et al., 2015 [195] Quan - POC and survival	NSW, Tertiary	Examine primary treatment for and death from prostate Ca	259 Aboriginal men among 35,214 prostate cancer cases	Aboriginal men had higher 5 year mortality and were 49% more likely to die from prostate cancer (adjusted for demographics, stage, health access and comorbidities). Aboriginal men diagnosed with prostate cancer are less likely to have prostatectomy for localised/regional cancer, and appear less likely to have surgery or radiotherapy than other

				Australian men. Further research on, and ongoing population-based monitoring of, prostate cancer treatment and outcomes are required. Efforts are needed to ensure Aboriginal men with prostate cancer have equitable access to best care.
Supramaniam et al., 2014 [197] Comparative	NSW, Tertiary	Compared surgical treatment of Aboriginal and non-Aboriginal women diagnosed with breast Ca, using logistic regression to compare odds to receiving surgical treatment. Survival: cumulative mortality curves and Cox prop hazards reg models.	1.03% Aboriginal (288)	“The Aboriginal women were younger and more likely to have advanced spread of disease when diagnosed than non-Aboriginal women. Aboriginal women were less likely than non-Aboriginal women to receive surgical treatment. The five-year crude breast cancer-specific mortality was 6.1% higher for Aboriginal women (17.7%, 95% CI 12.9-23.2) compared with non-Aboriginal women. After accounting for differences in age at diagnosis, year of diagnosis, spread of disease and surgical treatment received the risk of death from breast cancer was 39% higher in Aboriginal women. Preventing comorbidities and increasing rates of surgical treatment may increase breast cancer survival for NSW Aboriginal women.”
Whop et al., 2017 [203] Comparison matched dataset - Indigeneity	Australia, Tertiary	Compared 'optimal Rx' vs 'suboptimal Rx' of cervical cancer and Non-Small Cell Lung Cancer (NSCLC) according to clinical guidelines, determine if being Indigenous and other factors associated with treatment.	Indigenous (n=56) adults with cervical cancer and NSCLC, freq matched comparison group non-Indigenous people n=49.	Aboriginal women had more comorbidities, later stage at diagnosis, and were more likely to receive suboptimal treatment. Results highlight critical need for targeted screening programs (that include follow-up after abnormal screening to reduce incidence or late stage presentation) for Indigenous women and better adherence to optimal treatment. “The odds of receiving suboptimal treatment were significantly higher for Indigenous compared to non-Indigenous NSCLC patients (unadjusted OR 1.9; 95% CI, 1.0–3.6) and remained significant after adjusting for stage, comorbidity and age (adjusted OR 2.1; 95% CI, 1.1–4.1). Conclusions: The monitoring of treatment patterns and appraisal against guidelines can provide valuable evidence of inequity in cancer treatment. Study found that Indigenous people with lung cancer or cervical cancer received suboptimal treatment, reinforcing the need for urgent action to reduce the impact of these two cancer types on Indigenous people.”

Table 2.6.1 Recent activities which may warrant follow-up

Institution, year	Document name or activity	Summary
VICTORIA		
Couch, 2018 [120] Loddon Mallee Region Aboriginal Reference Group (ARG), 2018	Let's Yarn About Cancer Final Report	Suggestions: establish a peer support network for AHWs; consider if any services can be delivered more locally (i.e. leverage existing telehealth infrastructure); make better use of 'Integrated Team Care' teams where they exist within the region; may be opportunity for Cancer Council Victoria to develop further training to support AHWs in their work with cancer clients and survivors; Dissemination of survivorship stories from local communities may help improve community perceptions of cancer and potentially increase screening rates; At a state-wide level, there may be opportunity to commission Ilbijerri to develop a performance that addresses the cancer journey, including cancer survivorship, to change the discourse around cancer diagnosis in Aboriginal communities; There is opportunity for local, regional and state services to consider how culturally appropriate support might be provided for Aboriginal patients and carers; Consider if there is an opportunity for Aboriginal cancer patient navigator(s) in the Loddon Mallee region; There is a continuing need for mainstream services to better support Aboriginal family structures and cultural needs; Future projects could specifically investigate improving linkages between mainstream cancer services and ACCOs, particularly around admission and discharge, as well as how to improve medication management at discharge; Review the number and gender of AHLOs employed by Bendigo Health, and compare with other regional health services; cancer services to consider how they can reduce this jargon and to be aware of, and address, power imbalances during interactions, as well as encourage Aboriginal patients to feel safe and confident in asking questions; Re Cancer Healing Messages flipchart and patient flyer to assist health professionals to explain cancer and the cancer journey to Aboriginal cancer patients and families - may be opportunity for a similar tool to be developed for a Victorian context.
Loddon Mallee Region (LMR) Palliative Care	Annual Report 2016-17	Strengthening relationships between Aboriginal and mainstream palliative care partners in Sunraysia Region by conducting a series of joint educational events. Project contracted to La Trobe University and work has commenced.16/17 Annual report.

Consortium, 2017 [289]		
Loddon Mallee Integrated Cancer Services (LMICS) /DHHS, 2019 [290]	Patient Experience of Cancer Care (PECC) survey	In 2018/19, LMICS conducted the DHHS-led Patient Experience of Cancer Care (PECC) survey within most cancer care services in the region. It will be used to create a baseline of consumer experience in Loddon Mallee cancer services, allowing services to measure and identify appropriate local projects as benchmarked against these survey results. Findings will be disseminated through health service reports, written consumer feedback, conference presentations and research papers.
Monash University, for Victorian Department of Health and Human Services [291]	Adapting the patient experiences of cancer care survey for Aboriginal and Torres Strait Islander people in Victoria	Ristevski, E. (Primary Chief Investigator), Nightingale, Claire (Chief Investigator). Department of Rural & Indigenous Health, School of Rural Health. This Project aims to: 1. Adapt the existing patient experiences of care survey to be culturally appropriate to examine the cancer care experiences of Aboriginal people diagnosed with cancer in Victoria. 2. Adapt the accompanying user guide and develop a survey administration protocol which is culturally appropriate to ensure adequate response rates and high quality data collection from Aboriginal people with cancer in Victoria. Reported on website to be finished 10/05/19.
McDonald, Peter Mac, 2018 [69]	Feasibility of a volunteer model of patient navigators in cancer care. Churchill Fellowship Report; travel to USA and UK	Examines the role of patient navigation in cancer care. Report highlighted the need for Australia to consider alternate models of care that better address those experiencing health disparities. “Identifying where in the continuum of cancer care the patient experiences the most challenges, should be the driver for establishing a patient navigation program. The patient experience movement is increasingly emerging as a credible mechanism for measuring patient navigation success. Research and evidence must underpin the establishment of the patient navigation program ensuring the metrics for measuring success are validated tools that capture what you are trying to address in order to demonstrate return on investment. Every health service or organisation visited was implementing patient navigation models that addressed the particular needs of their patients.” Report proposes to utilise the following principles to support the development of patient navigation: 1. Understand the problem you are endeavouring to address; 2. Ensure the development of a patient navigation program is developed utilising principles of co-design with the patient as a partner; 3. Ensure the model is part of the multidisciplinary team. 4. Ensure clear scope of practice and role delineation; 5. Implement a rigorous program evaluation. The development of patient navigation services that are focussed on particular barriers or cohorts would support the current model of cancer care at Peter Mac. The scoping of these navigation

		services to ensure they complement and support current service delivery is a priority outcome of this Fellowship: • Financial Aid Navigation • Health Justice Partnership • End of Life care Navigation • Peer Navigation • Aboriginal and Torres Strait Islander Cancer Navigation.
VACCHO and DHHS, 2019 [292]	Improving the benefits of the renewal of the National Cervical Screening Program for Victorian Aboriginal women. Program of work	Improve the clinical benefits of the national cervical screening program for Aboriginal women. Develop strategies and best practice models that increase the number of Aboriginal women who participate in screening – particularly those women who have never been screened or under screen. Involves VACCHO and Ballarat and District Aboriginal Co-operative, Wathaurong Aboriginal Co-operative, and Mallee District Aboriginal Services, along with other health services with a high number of Aboriginal Clients, such as Co-health.
VACCHO and DHHS, 2019 [293]	Working Together for Health (WTFH). Program of work	Encourage a coordinated approach to deliver culturally safe health promotion, prevention and early detection services across the State, particularly in relation to smoking, oral health, sexual and reproductive health, eye health and cancer prevention and screening. Health Evidence Team, VACCHO; * identifying at risk populations, * identifying client's eligibility for health promotion activities such as Quit Programs, Breast Screen * identifying under screened populations, bowel cancer screening and breast screening in particular.
OTHER		
Aboriginal Health and Medical Research Council (AHMRC), 2018 [294]	NSW Aboriginal State-wide Cancer Forum Report	Sharing stories of success, strengths and need. Purpose: 1) To hear from participants about what works in providing locally led support programs for people with cancer and their families. 2) To learn what resources, training and support are needed to support Aboriginal people living with cancer and to strengthen locally led cancer support networks in NSW. 3) To develop a communications platform moving forward. 4) To facilitate networks and linkages.

CanDAD, South Australia [295]		Multiple published articles, however informal progress report may be worth obtaining.
Tully et al., Hunter New England (HNE) Health, 2019 [189] Lowitja Institute Conference Presentation	Actioning meaningful cultural governance: organisational governance creating space for Aboriginal sovereignty over public health initiatives.	HNE Public Health (PH) has actioned a Joint Governance model, known as the Joint Governance Group (JGG). This provides a formal process whereby HNEPH Aboriginal staff can collectively provide advice to the Shared Population Health Service Delivery Leadership Group regarding the conduct of the organisations business as it relates to the Aboriginal staff of HNEPH and to the Aboriginal communities in the district. The aim of this model is "to embed cultural considerations into everyday business and shift power imbalances so that the organisation can move towards being culturally safe and respectful."
University of Western Australia, Curtin, Fiona Stanley Hosp & Path West, 2018 [296, 297]	Two funded studies; Redfern et al. Defining and defeating Indigenous disadvantage in breast cancer survival. $91k. Meehan et al. Overcoming low Indigenous breast cancer survival. $41k.	The research will look at a large range of factors relating to the breast cancers Indigenous women get and how they are treated, any of which could worsen survival. These will include whether Indigenous women experience differences in: basic types of breast cancers diagnosed eg HER2 positive; how well they activate anti-cancer drugs; the density of tissue and the immune cells around the cancers; the way cancers are treated in early and late stages.
Western Australia Aboriginal Health Policy Directorate, 2018 [221]	Aboriginal patients take own leave: Review and recommendations for improvement	Strategies: cultural competency, consultation, engagement, partnerships, communication and language, hospital environment, Aboriginal workforce, social determinants of health, alcohol and other drugs (reduce stigma/stereotyping), mental health, policies, procedures, practices; use of technology (improve patient journey, contact family...); research. Rural and remote considerations, partnerships ACCHOs, outreach services. Refers to multiple existing programs.
Western Australia Department of Health, 2018 [298]	Aboriginal Patient Experience Review and Recommendation	Recommended actions: Improve existing survey tools (increase data from Aboriginal patients, improve identification, include measures of racism); system wide monitoring of Aboriginal patient experience, culturally appropriate promotion. Develop new survey tools.

Table 3.1.1. Literature relating to the Aboriginal Identification question

Author, year	Jurisdiction	Condition/ sector; Level of care	Description	Data Sources	Dates	Key findings
CANCER SERVICES (n=4)						
Lyford et al., 2018 [209]	Single site (WA)	Radiotherapy; Secondary care	Exploratory study of patient experiences and staff perceptions of Aboriginal patients' service utilisation.	Interviews with service providers (n=21) and Aboriginal people with cancer (n=3); service data	NR	Providers reported low numbers of Aboriginal people attending the service, possibly due to patients not identifying as Aboriginal, or their status not being recorded.
Reilly et al., 2018 [126]	Multiple sites (SA)	Cancer; Various levels	Qualitative study to understand the impact of care coordination on Aboriginal peoples' experiences of cancer treatment (part of CanDAD project).	Interviews with Aboriginal cancer patients or survivors (n=29), carers (n=11), and health service providers (n=22)	2015-16	Aboriginal identification considered a component of cultural safety. It was noted that "identifying Aboriginal patients is the first step toward culturally appropriate care" p.933 Racism and mistrust were considered barriers to accessing services.
Meiklejohn et al., 2016 [106]	Single site (Qld)	Cancer; Tertiary care	Qualitative study to understand health professionals'	Interviews with healthcare	2013	Determining indigenous status was considered challenging due to lack of

			perspectives of factors impacting on cancer care for Aboriginal and Torres Strait Islander people.	providers (n=22)		clear identification by other staff or in medical charts. Providers questioned whether knowing Indigenous status would influence their treatment (i.e. whether it would help with their interactions or whether providing the same care to all was more culturally appropriate).
Thompson et al., 2014 [250]	National perspective	Cancer councils	Environmental scan of Indigenous-related activity within Cancer Councils	Interviews with representatives (n=19) of each state/territory Cancer Council	2010	There was an absence of Indigenous status recording in many jurisdictions. Some providers and services were reluctant to collect Indigenous status which impeded the ability to report on accessibility and extent to which Aboriginal and Torres Strait Islander clients use Cancer Council services.
TERTIARY CARE, not cancer-related (n=8)						
Brown, 2010 [222]	2 sites (NT)	Cardiovascular; Tertiary care	Qualitative component of a mixed methods clinical registry and quality improvement program.	Interviews with Indigenous clients or their family (n=110) regarding experiences of care following acute cardiac event	2001-02	Previous negative experiences (self or others) influenced decisions to engage with services. Poor communication whilst in hospital contributed to patients taking leave from hospital and reluctance to accept invasive investigations.

Chapman et al., 2014 [215]	Single site (Vic)	Emergency departments; Tertiary care	Qualitative research regarding enablers and barriers to accessing care at the emergency department.	Yarning circles (n=3) with 16 Aboriginal community members	NR	Organisational processes, including identification as Aboriginal, was considered a barrier to accessing health care at the emergency department - the majority of patients were not asked their Indigenous status at triage or reception, and often it was assumed based on physical appearance.
Effective Change, 2016 [123]	Multiple regions (Vic)	Various	Evaluation of projects funded under DHHS Victoria's Koolin Balit initiative.	Case studies (n=7)	2016	The Kanyini Qualitative Study* found that reasons for disengagement with health services included experiences of racism, distrust in health services and culturally inappropriate care. The Aboriginal Client Journey Project's Aboriginal Hospital Transition Officer role was perceived by hospital staff to result in Aboriginal patients attending the ED and staying to receive treatment. *Original source not available
McKenna et al., 2015 [213]	Region (Vic)	Mental health (inpatient and emergency department); Tertiary care	Case study of a newly-introduced Aboriginal Mental Health Liaison Officer (AMHLO) role within a mental health service.	Stakeholder interviews (n=11); service data	2014	Stakeholders acknowledged disparities between perceived mental health needs and the number of Aboriginal consumers attending the service, i.e. some need but small numbers. One service manager stated that "sometimes they were not recorded properly".
Stanford et al., 2019 [234]	2 sites (NSW)	Cardiovascular; Tertiary care	Qualitative study to explore health professionals' perspectives on factors	Interviews with health professionals (n=17)	2016	Perceived barriers to health service utilisation included the lack of welcoming environment.

			impacting on, and solutions for, patient-practitioner communication with Aboriginal and Torres Strait Islander patients.			Aboriginal Liaison Officers were seen as important in supporting inpatient service delivery and linking to community-based services.
Wand et al., 2010 [223]	Single site (NSW)	Mental health; Tertiary care	Review of medical records (analysed in consultation with Aboriginal Health Worker), to determine how culture is incorporated into mental health care of Aboriginal and Torres Strait Islander people.	Patient medical records (n=162)	NR	Common use of ‘Aboriginal’ in patient history and/or description of appearance suggested that Indigenous status was assumed, which is often inaccurate as well as invalidating and judgemental. It was suspected that patients may not identify, fearing racism or other negative treatment.
Worral-Carter et al., 2016 [299]	Single site (Vic)	Cardiac care; Tertiary care	Qualitative study of patient experiences of inpatient cardiac care.	Patient interviews (n=10)	2012-13	Patients did not seem to mind being asked their Indigenous status, providing it was asked in the appropriate context.
Wotherspoon & Williams, 2018 [114]	Single site (Vic)	Tertiary care	Qualitative study of patient experiences of inpatient care, including best and least satisfying aspects, how the service could better meet needs of Aboriginal and/or Torres Strait Islander patients and satisfaction with Aboriginal-specific services and admission/discharge.	Patient surveys (n=76)	2010-12	Patients valued being asked their Indigenous status and being identified in their health record, as this enabled interaction with staff from the same cultural background. Others felt that their cultural heritage may result in less service provision.

PRIMARY OR SECONDARY CARE (n=15)						
Anikeeva et al., 2012 [210]	Multiple regions	General Practice; Primary care	Evaluation of activities undertaken by Divisions of General Practice (DGP) under the Commonwealth Government's Closing the Gap initiative.	Qualitative data from DGP annual reports (n=86)	2009-10	Divisions identified barriers to Aboriginal and/or Torres Strait Islander peoples' use of mainstream primary care services, including: – (Lack of) identification of Indigenous patients – Practices unaware of number of Indigenous patients – Lack of staff confidence asking the question – Patients not willing to self-identify.
Artuso et al., 2013 [224]	Region (NT)	Cardiac care; Various levels	Qualitative descriptive study aiming to identify barriers and facilitators to health care utilisation among Aboriginal cardiac patients.	Interviews or focus groups with Aboriginal cardiac patients (n=7), non-cardiac community members (n=15), health care providers and community researchers (n=12)	2006	– Previous negative experiences, clinicians' poor communication and cultural incompetence (contributing to patient uncertainty about illness and treatment options) in some cases caused fear and refusal to use health care services. – Culturally inappropriate services (e.g. gender-appropriate care) enhanced mistrust of the health system. – Perceived or actual racism caused patients to feel they would not receive the same services as non-Aboriginal patients, also reinforcing mistrust in the system. – Aboriginal Liaison Officers were seen to reduce language barriers and alleviate patient fears and concerns.

Aspin et al., 2012 [225]	Various settings	Chronic diseases;	Qualitative study aiming to identify barriers and facilitators to care and support for Aboriginal and/or Torres Strait Islander people with chronic illness.	Interviews with Aboriginal and Torres Strait Islander people (n=16) and carers (n=3)	NR	History of negative treatment and prejudice influenced perceptions of health care and services; this impacted on patient decisions to access services, their level of engagement or their decision to follow up on referrals.
Baba et al., 2014 [226]	2 sites (Qld)	Aboriginal and Torres Strait Islander health services	Qualitative research providing Aboriginal and/or Torres Strait Islander peoples' perspectives on health service access and utilisation.	Focus groups and interviews with Indigenous health service clients from an ACCHS (n=11) and State-government controlled AHS (n=10)	NR	Experiences of discrimination caused hesitation and delays in seeking health care. Lack of culturally appropriate services were considered an ongoing barrier to accessing health care.
Balaratnasingam et al., 2015 [214]	Multiple states (NSW, Qld)	Mental Health, Alcohol, Tobacco and Other Drug Services	Evaluation of cultural information gathering tool.	Clinician responses to surveys	2011	Clinicians recognised that knowing cultural information about their patients can improve access to appropriate services (i.e. Aboriginal mental health worker).
Barclay et al., 2014; Josif et al., 2014 [268, 269]	Region (NT)	Maternity services	Evaluation of **Midwifery Group Practice (MGP) model of care**. MGP	Interviews with MGP staff (n=9),	2009-10	Within the first year, women's engagement with health services (via midwives) had improved.

			staffed by AHWs, Aboriginal midwifery students, and an Aboriginal 'senior woman'. Full-time community-based midwifery positions also introduced.	hospital midwives (n=8), DoH and other agency staff (n=37), Aboriginal consumers (n=12)		There was an apparent reduction in institutionalised racism and improvement in culturally safe and responsive care.
Bertilone et al., 2017 [188]	Multiple health districts (WA)	Aboriginal Maternity services	Evaluation of **Aboriginal Maternity Group Practice program** regarding its contribution to a culturally competent service.	Cultural competence assessment; interviews, surveys with staff (15), service partners (n=22) and clients (n=16)	2014	The model had a positive impact on culturally appropriate care. Clients considered that Aboriginal staff facilitated creation of a welcoming environment and made them feel more comfortable. Aboriginal staff and Grandmothers improved access to care and utilisation of service; accessibility of the service was related to engagement with the program. Continuity of care model considered important in engaging clients long-term.
Canuto et al., 2018 [240]	Multiple states (SA, Qld)	Primary care	Ethnographic study to identify and understand perceived motivators barriers and enablers of primary health care service utilisation by Aboriginal and Torres Strait Islander men.	Interviews with male Aboriginal and Torres Strait Islander health professionals (n=9) and non-health	NR	Health service utilisation was influenced by cultural safety and appropriateness of the health service.

				professionals (n=10)		
DiGiacomo et al., 2010 [211]	Multiple sites (WA)	Cardiac rehabilitation; Secondary care and ACCHOs	Qualitative study to understand practitioners' perspectives on enablers and barriers to implementing NHMRC guidelines *Strengthening Cardiac Rehabilitation and Secondary Prevention for Aboriginal and Torres Strait Islander Peoples*	Interviews with health service staff (n=38)	2007-08	Health professionals and service staff considered a lack of consistent and sufficient data collection processes relating to Indigenous identification was seen as a barrier to service access.
Greenstein et al., 2016 [227]		Physiotherapy and disability care	Qualitative study to understand Indigenous children and their carers' experiences of their community-based physiotherapy service.	Interviews with parents and carers (n=9) of and children/youth (n=5) with physical disabilities	NR	Experiences or perceptions of racism were considered to influence expectations of services, and willingness to access them.
Jobling et al., 2016 [228]	Region (Vic)	Comorbid physical and mental health; Secondary care	Qualitative exploratory study to understand factors influencing health service engagement and experiences among Aboriginal people with comorbid physical and mental health conditions (part of *Bundap Marram Durn Durn* project).	Focus groups and interviews with Aboriginal women (n=19; men were also invited but	NR	Previous negative experiences including being treated disrespectfully, attempted removal of children, and having Aboriginal identity questioned were cited as antecedents and barriers to health service engagement.

				did not participate)		
Kelaher et al., 2010 [212]	Multiple sites	General practice; Primary care	Study undertaken to identify strategies to improve Indigenous identification.	Key informant interviews (n=31)	2009	Practitioners often consider Indigenous patients to make up a small proportion of their clientele, and don't always see the benefit or relevance of ensuring the collection of Indigenous status.
Scotney et al., 2010 [216]	ACT	General practice; Primary care	Qualitative study to determine Aboriginal and Torres Strait Islander people's perspectives on self-reported Indigenous identification in mainstream general practice.	Interviews with Aboriginal and Torres Strait Islander people (n=28)	NR	Several factors influenced individuals' propensity to identify, including previous experiences of racism, relationship with healthcare provider, perceptions that discussing identity would increase consultation time, unclear motives for asking the question, and staff recognition of culture and diversity of Indigenous Australians. All participants stated they would identify if asked, providing they were given information about the rationale for asking and the benefits of identifying.
Vlack, 2019 [233]	Multiple regions (Qld)	General practice; Primary care	Report on **Promoting Indigenous Preventive Care in General Practice (PIPCGP) project** (further detail Table 3.3.1)	In-depth interviews with clinical and non-clinical staff, and community members (n=35); audit findings	2009-2012	One Indigenous participant stated that a lack of respect in a hospital clinic encounter resulted in avoidance of the hospital and the local referring practice. A culturally sensitive routine for Indigenous identification was considered by patients to 'set the tone' for the health service encounter.

						Participants highlighted the importance of explaining the benefits of identifying, which influenced their decision to do so. Previous negative experiences discouraged or prevented patients from identifying as Aboriginal and/or Torres Strait Islander. Overall, patients viewed being asked to identify as positive, in that it recognised their culture and helped to build relationships.
OTHER (n=2)						
Inner North West Primary Care Partnership, 2013 [229]	Region (Vic)	Various	**Inner North West Metropolitan Region Closing the Health Gap project Health Consumer Perspectives Project** Aimed to improve understanding of Aboriginal and Torres Strait Islander peoples' experiences of health care and identify barriers and enablers to health service access.	Interviews with health service consumers (n=26), one focus group	2012-13	Factors influencing consumers' self-identification included: – Not being asked the question – A lack of explanation as to why the question was being asked – Negative reactions from service providers and associated discomfort Regarding service access and utilisation: – Creation of welcoming spaces through artworks, flags, resources – ALOs enabled access to suitable services and encouraged people to return – Previous experiences and level of trust with the health service influenced peoples' decision to return

Jeremy et al., 2010 [241]	Various	Various	Summary of expert opinion based on conference presentations.	Conference presentations	n/a	–	Creation of a culturally safe environment increased health service attendance by Indigenous people (1 site)

ACCHO - Aboriginal Community Controlled Health Organisation; ACCHS - Aboriginal Community Controlled Health Service; AHS - Aboriginal Health Service; DGP - Divisions of General Practice; HPV - Human papillomavirus; NHPVR - National Human Papillomavirus Vaccination Register; NR - not reported;

Table 3.1.2 Other literature not directly answering the research questions.

Author, year Sector; Level of care; Jurisdiction	Description	Summary
Bailie et al., 2017 [300] Primary care	Clinical audit and stakeholder surveys	Describes stakeholder-identified evidence-practice gaps and barriers and enablers and suggestions for improvement to preventive care for Aboriginal and Torres Strait Islander women in the primary care setting.
Bar-Zeev et al., 2014 [301] Maternity services	Health provider interviews	Suggestion that antenatal services would benefit from increased involvement from Aboriginal staff.
Biles & Biles, 2011 [302] Primary care services	Commentary	Mentions cultural discrimination as a factor for under-utilisation of mainstream primary care services by Indigenous people.
Canuto et al., 2018 [303] Primary care services	Systematic review	Discusses primary health service utilisation by Indigenous men; international context which includes 2 Australian papers.
Chenhall & Senior, 2013 [304] Alcohol and Other Drugs; Tertiary	Observational study; staff and board member interviews	Considers cultural factors regarding operation of services.
Coombes et al., 2018 [305] Primary care	Systematic review	Discusses factors impacting access to primary health care for First Nations children; international context with 4 Australian studies.
Davidson et al., 2013 [98] Lung cancer	Integrative review	Reviewed experiences of lung cancer in Aboriginal and Torres Strait Islander peoples, to identify reasons for poorer outcomes and lower levels of treatment, as well as opportunities for improvement. Identification was considered with only one citation pre-2010.

Davy et al., 2016 [154] Primary care	Scoping review	Explores models of service delivery in Indigenous primary care to develop an accessibility framework; includes consideration of health-care seeking in relation to cultural appropriateness of services.
Deek et al., 2013 [306]	Literature review	Considers the role of Aboriginal health professionals in delivering culturally competent health interventions.
Gibson et al., 2015 [307]	Discussion paper	Considers cultural competency from a human rights perspective.
Gilroy et al., 2017 [308] Disability sector	Literature review	Identifies workforce recommendations and strategies, including community-centred approaches, cultural competence training, and development of an Indigenous disability workforce.
Guthrie & Walter, 2013 [309]	Book chapter	Considers Indigenous Australians as recipients of healthcare; includes section on Indigenous identification.
Harfield et al., 2018 [152] Primary care	Systematic scoping review	Describes characteristics of models of service delivery for Indigenous primary care; international perspective with mostly Australian studies.
Hearn et al., 2016 [310] Mental health; Primary care	Descriptive	Describes model of care for an Aboriginal mental health service
Hersh et al., 2015 [311] Speech pathology; Secondary	Survey of practitioners	Explores speech-language pathology practices; considers cultural competence
Isaacs et al., 2010 [312] Mental health	Systematic review	Explores factors influencing access to mental health services; considers cultural factors in deciding to and actually seeking treatment; relevant studies are pre-2008
Jennings et al., 2018 [135]	Systematic review	Explores Indigenous peoples' experiences of healthcare communication
Jennings et al., 2014	Interviews with clinical staff	Identifies factors influencing the undertaking of Indigenous Health Checks; considers cultural factors

Aboriginal Medical Service; Primary care [313]		
Josif et al., 2017 [314] Child health; Primary care	Interviews with clinicians	Explores quality of service provided to Aboriginal infants in remote communities from clinician perspective.
Katzenellenbogen, et al. 2013 [315] Cardiovascular	Cross-sectional analysis	Investigates clinical and demographic factors which predict discharge against medical advice.
Kehoe, 2017[253] General practice	Discussion paper	Summarises other work (included in the main synthesis) regarding changes to software within the general practice setting in order to improve healthcare for Aboriginal and Torres Strait Islander people.
Kilcullen & Day, 2018 [316] Mental health	Case conceptualisation	Describes development of culturally informed case conceptualisation model which may improve culturally competent practice.
Lewis, 2011[317]	Discussion paper	Considers the impact of cultural differences on Indigenous families' access to health care.
Lyle et al., 2017 [318] Primary care	Literature review	Evaluations of primary healthcare services; some specific to the Indigenous setting.
Martin & Reath, 2011 [319]	Commentary	Reviews history of general practice vocational training in Indigenous health; considers cultural competency.
Mbuzi et al., 2017 [320] Cardiac care; Tertiary	Interviews with patients and family members	Explores experiences of hospitalization; considers communication, past experiences, cultural factors.
McCalman et al., 2016 [321]	Review of reviews	Reviews implementation of Indigenous Australian healthcare; maps implementation against conditions required for successful implementation; considers culture and client engagement.

McCalman et al., 2017 [322]	Systematic review	Reviews family-centred primary care interventions for children; considers Indigenous workforce, cultural appropriateness, service utilisation; international context which includes 11 Australian studies.
McCalman et al., 2017 [323]	Systematic scoping review	Reviews approaches to improving cultural competence in healthcare; international context with 4 Australian publications.
Medlin et al., 2014 [324] Outreach service	Evaluation	Describes the development, implementation and evaluation of a specialist outreach service to remote Indigenous communities; considers culturally appropriate design and delivery of services including community involvement and Indigenous workforce.
Molloy & Grootjans, 2014 [325] Mental health	Critical reflection	Argues the importance of cultural safety for nurses in mainstream mental health services.
Molloy et al., 2019 [326] Mental health	Ethnographic study	Explores nurses' perspectives and experiences of mental health nursing practice for Indigenous Australians.
Morgan et al., 2016 [254] General practice	Registrar surveys; patient data	Reports findings of a cross-sectional study of survey and patient encounter data of GP registrars with regard to level of confidence in identifying Aboriginal and/or Torres Strait Islander patients.
Munns & Shields, 2013 [327] Child health; Tertiary	Literature review	Author comment regarding lack of training on culturally appropriate collection of Indigenous status, and that propensity for self-identification may depend on individuals' perceptions about the impact of disclosure on health service delivery received.
Narayanan & Greco, 2016 [328] General practice	Patient survey	Reports on patient experience of General Practices - compares responses of Indigenous and non-Indigenous participants.
Oliver, 2013 [329] Primary care	Literature review	Reviews the role of traditional medicine in primary health care in Aboriginal Australia; considers cultural factors.

Otim et al., 2014 [330]	Surveys and interviews with decision-makers	Explores priority-setting for Indigenous health.
Pilkington et al., 2017 [176] Cancer screening	Interviews with health professionals and Aboriginal consumers	Explores factors influencing participation in breast cancer screening by Aboriginal women.
Shahid et al., 2013 [139] Cancer services	Interviews with service providers	Explores cancer service providers' perceptions regarding barriers to communication with Aboriginal clients and their families; offers practical solutions for effective communication.
Smith et al., 2017 [181] Primary care	Survey questionnaires with healthcare providers, administrative providers, administrative staff and Aboriginal community members	Discusses factors influencing delivery of culturally appropriate primary health care, including staff attitudes, culturally inappropriate physical space, communication, Aboriginal workforce, cultural sensitivity training.
Stewart & Allan, 2013 [331] Mental health	Descriptive	Describes the development of a Cultural Mapping Tool for practitioners working with Indigenous people with mental health problems.
Thomson et al., 2016 [332] General practice	Clinical record audit	Reports on recording of Indigenous status in patient records.
Valery et al., 2016 [333] Child health; Primary care	Program evaluation	Reports carers' feedback on an intervention for childhood asthma delivered by Indigenous health workers; satisfaction with communication and service delivery.
Whop et al., 2012 [113] Cancer support service	Service mapping; questionnaires	Describes the availability of cancer support services, and their cultural appropriateness; considers whether services were 'Indigenous specific', staff participation in cultural awareness training, Indigenous workforce, perceived barriers to access; notes that service utilisation by Indigenous participants is unclear due to lack of reporting of Indigenous status by most services.
Zambas & Wright, 2016 [334]	Discussion paper	Considers the impact of racial discrimination and negative experiences on healthcare utilisation; Australian and New Zealand perspective

Table 3.2.1 Systems in place for data management and self-identification

Author	Jurisdiction	Condition/ sector; Level of care	Description	Data Sources	Dates	Key findings
CANCER SERVICES, and other cancer-related (n=6)						
de Witt et al., 2017 [243]	Multiple sites (Qld)	Cancer; Primary care	Evaluation of services' capacity to identify and provide information on Indigenous cancer patients attending their service (purpose was for recruitment into a study).	Interviews staff at 10 health centres	2014-16	The 10 sites used 6 different PCIS; most sites were able to identify Indigenous cancer patients in this way, while others could only do so via manually searching paper-based records or with a combination of PCIS and staff recall. Authors noted variation in PCIS functions and capabilities, as well as staff knowledge and use of these.
Lyford et al., 2018 [209]	Single site (WA)	Radiotherapy; Secondary care	Exploratory study of patient experiences and staff perceptions of Aboriginal patients' service utilisation.	Interviews with service providers (n=21) and Aboriginal people with cancer (n=3); service data	NR	Measures introduced to increase the number of Aboriginal patients presenting to the service, including creating a welcoming environment and ensuring that Aboriginal status is captured.
Reilly et al., 2018 [126]	Multiple sites (SA)	Cancer; Various levels	Qualitative study to understand the impact of care coordination on Aboriginal peoples' experiences of cancer treatment (part of CanDAD project).	Interviews with Aboriginal cancer patients or survivors (n=29), carers (n=11), and health service providers (n=22)	2015-16	Strategies implemented included education with hospital administration staff about asking the question, and posters displayed within the hospital.

Taylor et al., 2018 [117]	National perspective	Cancer services	Qualitative study to determine the Indigenous-specific programs and initiatives implemented by cancer services, as well as their enablers.	Interviews with service staff, including managers, nurses, project officers and an ALO (n=20 from 14 services)	2015	6/14 services reported having policies or initiatives in place to ensure correct identification of Indigenous patients, including: – encouraging or mandating 'asking the question' of all patients by frontline staff. – provision of "identification training" to frontline staff on how to ask the question respectfully. All services reported improved data quality as a result of these initiatives, and some stated the process was now 'embedded' into practice with no need for ongoing reminders to frontline staff.
Taylor et al., 2018 [179]	National perspective	Cancer services		Surveys of cancer treatment centres (n=58)		Centres predominantly determined Indigenous status from patient medical record as opposed to asking the patient directly. The authors noted that this information would most likely come from previous hospital admission and is likely to be incorrect. It was concluded that cancer services relying solely on Indigenous status from patient medical records likely underestimate the number of Indigenous patients accessing the service.

Thompson et al., 2014 [250]	National perspective	Cancer councils	Environmental scan of Indigenous-related activity within Cancer Councils	Interviews with representatives (n=19) of each state/territory Cancer Council	2010	Reported initiatives which were being implemented to improve Indigenous identification included: – Implementation of standardised identification with GPs, nurses, pathology services and software companies. – Plans to improve database for collecting patient information. – Community-based programs and improvements to cultural appropriateness of offices e.g. display of artwork, acknowledgement statements, Indigenous-specific events.
TERTIARY CARE, not cancer-related (n=3)						
Attwood et al., 2015 [235]	Single site (NSW)	Paediatrics; Tertiary care	Data validation of hospital electronic medical records. Noted any reference to Aboriginal and/or Torres Strait Islander status in admission notes, discharge summaries, and/or referral to or consultation with an Aboriginal health care professional and checked against a separate list of children	Hospital medical records	2010	As a result of data validation showing inaccurate or incomplete recording of Indigenous status, opportunities for improving culturally appropriate health service delivery were recognised. The site introduced a process where the Aboriginal Health Worker has been engaged to notify the ward when seeing an Aboriginal child not recorded as such, provided the family agrees to Indigenous status being amended in the record.

			seen by the Aboriginal health education officer.			
Haswell et al., 2013 [236]	Single site (Qld)	Mental health; Tertiary care	Data validation - Cross-checking Indigenous status recorded in Hospital Based Corporate Information System with that recorded in the Indigenous Mental Health Worker register (considered gold standard) and using IMHW knowledge.	Hospital Based Corporate Information System (separations), Indigenous Mental Health Worker Register, Community Event Service Application	2004-05 and 2005-06	Both datasets missed some Indigenous cases, therefore it was considered that using data from both sources (as well as that from other hospital unit admissions) at the individual level would be optimal. Since 2004/05, communication between the IMHW and provision of monthly lists to HBCIS database managers was proposed to have facilitate accuracy of Indigenous status recording; the IMHW was seen as key in ensuring data quality.
The Royal Women's Hospital, n.d. [246]	State (Vic)	Maternity services; Tertiary care	Aboriginal Newborn Identification Project - part of The Women's Maternity Services Education Program. A range of project resources were developed to complement a guide to improving identification of Aboriginal and Torres Strait Islander babies in Victorian maternity services.	Project information available on RWH website.	Closed 2016	The guide covers how to ask the question, recording the response, reasons for collecting Indigenous status, characteristics of a culturally safe service, and how to embed the resource into practice. Complementary resources include posters, cot cards, pregnancy care booklets for clinicians, training packages and policy and procedure templates. The project closed in 2016.
PRIMARY OR SECONDARY CARE (n=5)						

Anikeeva et al., 2012 [210]	Multiple regions	General Practice; Primary care	Evaluation of activities undertaken by Divisions of General Practice (DGP) under the Commonwealth Government's Closing the Gap initiative.	Qualitative data from DGP annual reports (n=86)	2009-10	Activities undertaken included: – Development of patient resources for general practices, or provision of education and support to Aboriginal and/or Torres Strait Islander people, to encourage self-identification. – Providing reminders and prompts to service providers to ask the Indigenous status question.
DiGiacomo et al., 2010 [211]	Multiple sites (WA)	Cardiac rehabilitation; Secondary care and ACCHOs	Qualitative study to understand practitioners' perspectives on enablers and barriers to implementing NHMRC guidelines *Strengthening Cardiac Rehabilitation and Secondary Prevention for Aboriginal and Torres Strait Islander Peoples*	Interviews with health service staff (n=38)	2007-08	Themes and issues arising from interviews included: – A reliance on information stored in Patient Administration System, or staff knowledge, to determine Indigenous status (one respondent stated if a patient is not identified as Indigenous within the system, they are not identified at all unless the staff member knows the patient or knows their name and suspects they are Aboriginal) – Inconsistent processes within the service to record Aboriginal status (one respondent stated that despite being reasonably certain that there is capacity to record status, i.e. a tick box, it is not used by staff, and that Indigenous status can be determined on physical appearance in some cases, but not in others. – There is a lack of a system to identify Aboriginal status - reliance on assumptions based on referring

						facility or physical appearance. Reasons for not asking patients their status included not appreciating the importance of this information, and oversight by management.
Hamilton et al., 2016 [244]	Multiple sites (WA)	Cardiac rehabilitation; Secondary care	Assessment of cardiac rehabilitation and secondary prevention services, including service provision and culturally appropriate approaches for Aboriginal and Torres Strait Islander patients.	Interviews with service coordinators (n=34)	2015	– 65% of coordinators reported having systems or processes in place to identify Indigenous patients in their service. – A higher proportion of services in remote areas (75%) reported identifying Indigenous clients compared to those in rural (50%) and metropolitan (67%) areas. – No standard system in place for data collection in cardiac rehabilitation services in WA.
Vlack, 2019 [233]	Multiple regions (Qld)	General practice; Primary care	Report on Promoting Indigenous Preventive Care in General Practice (PIPCGP) project (further detail Table 3.3.1)	In-depth interviews with clinical and non-clinical staff, and community members (n=35); audit findings	2009-2012	As part of the project, several practices were noted: – Information materials regarding identification were provided – A field for Indigenous status was included on New Patient Registration forms – Prompts from reception staff in most cases encouraged patients to complete the question if left blank – “Update Your Details” tear off pads were used and considered useful by staff

						Information systems barriers were raised, including ineffective recall systems, challenges with obtaining IT support, or Indigenous status not linking to other screens.
OTHER (n=6)						
Glynn-Robinson, 2014 [251]	Multiple states	HPV vaccination	Consultation with jurisdictional health departments to determine processes and perceived barriers to collection of Indigenous status data within HPV vaccination	Unstructured conversation and semi-structured interviews with health department representatives (n=8) and immunisation coordinator (n=1)	2013, 2014	Consultation revealed a lack of awareness of or adherence to AIHW Best Practice Guidelines to collection of Indigenous status. Following the consultation, several changes were made including: – Updating consent forms to contain a section for Indigenous status in line with the Guidelines; all states except WA using the ABS standard Indigenous question. – Conducting regular review of data. – Updating information systems to prompt for follow-up information. – Education of vaccine providers as to the importance of collecting Indigenous status.
Jeremy et al., 2010 [241]	Various	Various	Summary of expert opinion based on conference presentations	Conference presentations	n/a	Strategies developed to improve health service access for Aboriginal clients at one site included: – Employment of Aboriginal or Torres Strait Islander staff – Creation of a welcoming environment via culturally appropriate resources

						and artworks, and playing Aboriginal radio – Cultural awareness training for all staff – Information provided to the local community about available services; promotion of intersectoral collaboration (1 site). At one district health service, goals developed to improve care after hospital discharge included: – Improved identification of Aboriginal people admitted to health service hospitals – Ensuring culturally appropriate discharge planning and information for Aboriginal people
Knox et al., 2015 [247]	Multiple states	Hepatitis A immunisation	Process evaluation of targeted Hepatitis A immunisation program for Indigenous children	Survey responses (n=15); telephone interviews (n=19)	2014	Promotion of Indigenous identification in general practices was carried out by Medicare Locals via GP education, Indigenous identification stickers on immunisation booklets, asking mothers of Indigenous children their most comfortable approaches to identification.
Massey et al., 2011 [252]	Health Service region (NSW)	Notifiable diseases	Quality improvement project - data validation	Invasive Pneumococcal Disease notifications, Routine hospital admission data	2009-10	Checking disease notifications against hospital admissions data allowed for updating Indigenous status on notifications (complete records prior to checking - 72%; after checking - 99%).

						Providing required access and approvals, the process took approximately 5 minutes and was therefore considered feasible. The project resulted in the region being able to report Aboriginal status for nearly all notified cases, with plans to conduct the exercise annually allowing for service planning and evaluation.
Menzies, 2015; Tashani, 2017 **[**[248](#ref248)**,** [249](#ref249)**]**	Health Service region (NSW)	Immunisation	1.4 Mixed methods evaluation of Aboriginal Immunisation Healthcare Worker program - Pilot program July 2012 for 3 years. 1.5 NSW Ministry of Health provided funding for 13 FTE AIHCWs in Local Health districts, which aimed to improve timeliness of vaccination in Aboriginal children.	Interviews with ALOs, AHWs, AMIHS staff, immunisation providers in AMS, immunisations providers in community health and private practice, PHN staff and Aboriginal community representatives	2016-17	Initially, Aboriginal identification was only listed as a possible strategy to improve immunisation. Activities regarding identification reported to be undertaken by AIHCWs included: – provision of resources to GP and AMS clinics – raising the issue at Local Health District meetings – advocating for improvements; liaising with service providers, ALOs and other stakeholders to ensure access to complete and accurate information – engaging with parents and students, aind in schools, to raise awareness and encourage identification – correcting errors in the register. A successful pilot led to recurrent funding - expanding to include Aboriginal adolescents and adults. Following recommendations from the 2015 process evaluation, a specific KPI

relating to Indigenous identification was included for the program:

- "Implement strategies to improve Aboriginal identification in immunisation service delivery, including for adolescents as part of the NSW School Vaccination Program."

Stage 2 process evaluation reported stakeholders' perceptions of collaborative activities of AIHCWs, which included assistance with recording Indigenous status on the Australian Immunisation Register (41%).

Table 3.3.1 Best practice models for cultural safety and engaging patients in self-identification

Author	Jurisdiction	Condition/ sector; Level of care	Description	Key findings
CANCER-RELATED (n=1)				
Cancer Council Tasmania, 2014 [261]	State (Tas)	Support service	Quit Tasmania (Quitline) is delivered by the Cancer Council Tasmania. Under the Commonwealth Government's Tackling Indigenous Smoking Program, funding is provided to Quitlines to improve their capacity to delivery appropriate and accessible services to Aboriginal and/or Torres Strait Islander people. The TIS also supports employment of Indigenous staff. As at 2014, Quit Tasmania had received funding since 2011 to run a Quitline Enhancement Project which aimed to improve cultural sensitivity and effectiveness of Quitline services for Aboriginal and Torres Strait Islander people. The project had 3 main components: – Engaging with Aboriginal health service providers to identify and address barriers to Quitline access – Promoting Quitline as a culturally appropriate service to the Aboriginal community – Facilitating cultural awareness training for Quitline counsellors	The 2013-14 CCT Annual Report stated that since the implementation of the Enhancement project, there had been a 196% increase in contacts to Quitline Tasmania by Aboriginal clients.

TERTIARY CARE, not cancer-related (n=3)				
Department of Health and Human Services, 2015 [266]	State (Vic)	Tertiary	Program developed which included employment of Aboriginal Hospital Liaison Officers (AHLOs) who worked with hospital admission staff to ensure patient identification on admission. A subsequent program increased the number of AHLOs employed.	Increase in AHLO positions resulted in a significant improvement in Indigenous identification. An increase in Aboriginal births recorded since 2007/08, which was in part attributed to improved identification of Aboriginal babies with non-Aboriginal mothers.
Effective Change, 2016 [123] pp. 20, 24, 57	Region (Vic)	Tertiary	Aboriginal Client Journey Project Project dates back to 2009 following recognition of the need to improve the client journey between hospital and primary care services. Aboriginal Health Transition Officers employed in three hospital emergency departments and one urgent care centre; the role is responsible for 48-hour follow-up care for Aboriginal people who presented at the ED or UCC, and provide support to transition clients to the community sector. The roles are adapted to suit each service. The broader context of the project includes region-wide governance structures, trialling of models of care, staff training to improve processes for Aboriginal identification, community awareness campaigns and resource development for staff and community members.	Health service clients, stakeholders and other staff reported that the AHTO role: – improved the quality of ED and hospital experience for the patient. – provided a strong message that the service was client-focused. – provided links to the wider community and aided in building relationships with the community, and trust and confidence in the service. – facilitated more effective relationships between non-Indigenous healthcare workers and the community. – ensured continuity of care. – improved patient health literacy and health system utilisation by Aboriginal people. – encouraged Aboriginal people to feel safe and identify their Aboriginality within the hospital. The evaluation recognised the time and resources required to implement such a project, as well as the importance of commitment and involvement of the Aboriginal community.

Wilson et al., 2017 [242]	Multi-site (NSW)	Emergency departments	Aboriginal Identification in Hospitals Quality Improvement Program (AIHQIP) Implemented in 8 NSW hospital emergency departments between January 2012 and July 2014, with the aim of improving cultural competence of staff, identification of Aboriginality and reduce the proportion of Aboriginal patients with incomplete ED attendance. The project involved partnership with Aboriginal organisations to implement a CQI project, working with Aboriginal people to identify improvements to hospital services, training of project staff and ongoing support, establishment of a network among ED staff and project newsletters. Program logic developed with processes and structures relating to: Systems re targets for and reporting on Aboriginal identification Orientation, in-service, training and materials for Aboriginal identification Increased number of staff asking the question Increased understanding in Aboriginal people of importance of identifying as such CQI Program objectives (nominated by the sites) relating to Indigenous identification included: "Increase the identification of Indigenous patients (including increasing the consistency of staff asking the Aboriginal identification question)" (8/8 sites)	Observed changes and outcomes included: – Culturally appropriate pamphlet and poster developed to encourage patient identification. – Aboriginal identification training DVD and resources made available to all ED and hospital staff, and nursing and medical students. – Fields for Aboriginal identification made available in PIS. – Aboriginal KPI dashboard developed. Perceived changes and outcomes identified via key informant interviews, meetings and program document review: – New or revised policies and sustainable processes for Aboriginal identification in the ED in 7/8 sites. – New or revised orientation, training and resources regarding Aboriginal identification and cultural awareness in all 8 sites. – Increased number of staff asking the correct Aboriginal identification question in all 8 sites. – Increased understanding of importance of identifying by some Aboriginal people (7/8 sites). – Systems in place to identify targets and report on Aboriginal identification at executive level and in operational plans (7/8 sites). – Quantitatively, there was a significant improvement in reporting of Aboriginality in 2/8 sites (but no significant improvement overall).

			"Improve access to and accuracy of data on Aboriginal identification and improve communication between data systems" (4/8 sites) "Improve identification of Aboriginal patients in the ED (by Aboriginal Liaison Officers (ALOs))" (2/8 sites)	
Primary and Secondary care (n=14)				
Baba et al., 2014 [226]	2 sites (Qld)	Indigenous health services	Interviews and focus groups with Aboriginal and/or Torres Strait Islander people regarding their perspectives on health service access and utilisation.	The successful integration (in one mainstream General Practice) of cultural safety principles (i.e. recognition of practitioners' cultural biases, consciously engaging clients) was reported to increase Aboriginal clientele.
KPMG, 2013; KPMG, 2014; Bailie et al., 2013 [262-264]	National perspective	Primary care	Evaluation of Australian Government's Indigenous Chronic Disease Package Introduced as part of Closing the Gap provided funding providing funding for preventative health, more coordinated and patient-focused primary care, and expanded Indigenous health workforce. Practice Incentives Program Indigenous Health Incentive (PIP-IHI) - required all patients to self-identify to be registered; program guidelines for GPs stated that all patients must be asked their Indigenous status to determine eligibility. Aboriginal and Torres Strait Islander Outreach Workers (ATSIOW) and Indigenous Health Promotion Officers (IHPOs) role which included encouraging Aboriginal and/or Torres Strait	2010/11 Evaluation – Many practices were changing their processes and procedures to consistently ask about Aboriginal and/or Torres Strait Islander status (finding based on analysis of 20 reports and qualitative information from consultations). Sentinel Sites evaluation – Evidence of an increase in Indigenous patients by 10% in 2012 and 14% in 2013. 2014 Final report and patient experiences report – IHPO workforce contributed to increase in number of Aboriginal and/or Torres Strait Islander patients using and self-identifying at GPs (noted as difficult to quantify).

			Islander people to self-identify at primary care services. Activities reported to be undertaken as at 2010/11 included: Working with practices to improve cultural appropriateness which included collecting Indigenous status, updating systems to support identification. Educating community as to why it is important to self-identify, and how the information is used. Specific examples included posters and pamphlets, community forums, and identification training. ** NOTE: These roles now fall under the Australian Government DoH Integrated Team Care Program, with the same roles and responsibilities relating to Indigenous identification. Funds are managed by Primary Health Networks (PHNs, previously termed DGPs and Medicare Locals). Under the ITCP, PHNs have the opportunity to develop flexible approaches which meet local needs in order to improve Aboriginal and Torres Strait Islander peoples' access to care.	– 16/21 (76%) of Medicare locals surveyed said they have encouraged more culturally appropriate ways of identifying patients. – 4/5 Medicare Locals and 9/10 IHPOs agreed/strongly agreed they had improved identification and contributed to self-identification. – Focus groups (n=4) revealed mixed views, that patients are comfortable identifying where reasons for doing so were clear; regional (n=2) felt people were comfortable, urban sites (n=2) more unsure. – Aboriginal and/or Torres Strait Islander patient identification was cited as an ongoing issue which was being addressed by Medicare Locals through GPs and community education and promotion.
Balaratnasingam et al., 2015 [214]	State, multiple (WA, Qld)	Mental Health, Alcohol, Tobacco and Other Drug Services	Cultural Information Gathering Tool Trialled by non-mental health practitioners conducting a mental health assessment.	Clinicians had an improved appreciation for the importance of information about cultural identity and beliefs when conducting mental health assessments and providing access to culturally appropriate care (98% of those surveyed).

Barclay et al., 2014; Josif et al., 2014 [268, 269]	Region (NT)	Maternity services	Midwifery Group Practice (MGP) model of care. Introduced in response to unfavourable findings relating to postnatal outcomes and in Aboriginal women. The MGP was staffed by AHWs, Aboriginal midwifery students, and an Aboriginal 'senior woman'. Full-time community-based midwifery positions were also introduced into remote communities. The program provided continuity of care for women from 2 remote communities.	Within the first year, women's engagement with health services (via midwives) had improved. Apparent reduction in institutionalised racism and improvement in culturally safe and responsive care within the service.
Berger, 2015 [260]	Region (Vic)	Primary care	"Have You Asked the Question?" Project Arose from previous work with community members and services which highlighted self-identification as a key issue to address in order to provide culturally responsive services. The project was based around raising awareness of the importance of asking the question, and included: Resource pack with a mouse-mat and stickers with the text "Are you of Aboriginal or Torres Strait Islander origin?", and guidance for their use and placement in the workplace (resources were launched by the Victorian Aboriginal Health Service CEO) Cultural awareness training delivered by a local Aboriginal trainer and educator	The resources and training were well received and in high demand - requests for resources continued and a waiting list for future training was established. Participants who attended the training and implemented the resources reported increased awareness of and confidence in asking the question. The resources were incorporated into a larger project which is funded by the Victorian DHHS. The project's Mid-point evaluation reported that as at 2016, >400 resource packs had been distributed locally and interstate.
Bertilone et al., 2017 [188]	Multiple health districts (WA)	Aboriginal Maternity services	Aboriginal Maternity Group Practice program. Introduced in response to community-identified need, given than Aboriginal women were	The program had a positive impact on the provision of culturally appropriate care; supportive

			presenting late or not at all for antenatal care. The program was designed by local Aboriginal community members with the aim of improving access to pre-existing maternity services. The program employed Aboriginal Grandmothers; AHOs worked together with midwives to conduct home visits, organise appointments, provide health promotion advice and facilitate engagement with other services. Cultural governance was overseen by the Grandmothers, AHOs and local community members on program steering groups.	management was related to most evidence of improvement. Partnerships between AHOs and non-Aboriginal midwifes facilitated two-way learning. Clients considered that Aboriginal staff facilitated creation of a welcoming environment and made them feel more comfortable (despite some challenges when working with pre-existing infrastructure and policies, e.g. privacy, room sizes not catering to families, limit to number of visitors). Aboriginal staff and Grandmothers improved access to care and utilisation of the maternity service; accessibility of the service was related to engagement with the program. Following the program, a requirement was made for all health service staff to undertake online Aboriginal cultural competency training and a Reconciliation Action Plan was developed.
Freeman, et al. 2014 [265]	2 sites (NT)	Primary care	Case study (including staff interviews and community workshops) to examine service-level strategies to achieve cultural respect, client experiences, and barriers to services being culturally respectful.	Reported strategies in place which enhanced cultural respect (from staff and client perspective) included: – Organisational and staff commitment to social view of health – Employment of Aboriginal health professionals within the service (ideally from the local community) – A welcoming environment, which included familiar faces, the sharing of information, presence of Aboriginal and Torres Strait Islander artwork and flags

				– Accessibility including transport, outreach and walk-in services – Existence of cultural protocols including gender specific services, a cultural advisory board, holding cultural events
Kelaher et al., 2010 [212]	Multiple sites	General practice; Primary care	Examples (with outcomes) relating to the general practice setting, as reported by stakeholders during interviews: New staff training: formal orientation with ‘shadowing’ of more experienced staff. Improvements to and simplification of the patient registration form, from the RACGP form to one provided by the General Practice Network Triage process introduced where patient sees practice nurse, who collects patient information, prior to their GP consultation Actions taken following attendance at cultural awareness training, including display of culturally significant materials, posters encouraging identification and a cultural awareness certificate; staff took on a more culturally appropriate approach to engaging with Aboriginal patients	Reported outcomes included: – Improved staff confidence in asking questions, and responding appropriately to negative reactions – Following changes to patient registration form, increase of 20% in new patients completing the Aboriginal and Torres Strait Islander question – Following introduction of the triage process, patients appeared more willing to discuss Indigenous status in a more private setting – Prior to training, the practice believed there were few Aboriginal people in the area. After putting up posters and stickers, the practice had ~5-6 regular patients self-identify as Aboriginal. The practice reported having 20-30 identified patients through referrals who also brought family members to the practice
Liaw et al., 2015 [239]	Region (South Western Sydney, NSW)	General Practice; Primary care	Ways of Thinking, Ways of Doing Cultural Respect Program Implemented in general practices; comprised a cultural respect workshop, practice support from a cultural mentor, and written materials in a toolkit.	A new patient registration form appeared to be the preferred method of identification. A more sensitive approach to identification at the reception desk was introduced on the suggestion of the cultural mentor. Patients were more comfortable identifying, knowing the practice was interested in serving them better.

				Note: There was a significant increase in proportion of Aboriginal patients across the region, from 0.12% to 0.2% though this could not be directly attributed to changes in identification; numbers were too small to determine changes in the methods used to identify new and existing patients.
Schütze, 2014 [238]	Multiple sites (NSW)	General practice (mainstream); Primary care	Intervention based on social and behavioural theories to influence physician and practice staff behaviour, which included: Provision of practice feedback reports (which included information on asking and recording Indigenous status) Optional RACGP Cultural Awareness Training (researcher-delivered) Practice facilitation based on needs (e.g. redesign of New Patient Registration form; use of practice software to record Indigenous status; process to update status discretely) Support to create welcoming spaces (provision of leaflets, posters, acknowledgement of country statements) Providing information to encourage Indigenous identification (e.g. posters to prompt staff and patients, AIHW resources)	Outcomes of the intervention included: – A shift in attitudes among practitioners and staff regarding barriers to identification (from externalising to the patient, to recognising internal factors such as staff knowledge and awareness, and the physical and structural practice environment) – An increase in the number of Aboriginal and Torres Strait Islander patients identified in 6/7 practices; 5/7 doubled or tripled the number – An increase in completion of Indigenous status (including non-Indigenous patients), i.e. a reduction in missing information by 16% (range - 0.1 - 42.5%) – The intervention was considered feasible to staff, and was acceptable to the local community. The author noted that the effectiveness of the intervention varied by level of understanding and recognition of a problem, the organisational context, and level of engagement of practitioners and other practice staff.
Vlack, 2019 [233]	Multiple sites (Qld)	General practice (mainstream	Promoting Indigenous Preventive Care in General Practice (PIPCGP) Project Intervention based on social and behaviour theories to influence professional practice;	Following the workshop: – Participants reported higher confidence in asking the question.

		); Primary care	outcomes included improved Indigenous identification and child immunisation. Support provided by the Divisions of General Practice (DGP) and Public Health Unit (PHU) over 12mo, including: Supporting materials (AIHW education resources, patient details forms, DGP resources for using practice software) 3-hour workshop (cultural orientation, knowledge of health issues, logistical info; one session on Indigenous identification and patient communication) Quarterly audit and feedback Provision of Indigenous-identified information by the PHU (with approval from the local Indigenous immunisation reference group) to enable targeted follow-up	– Positive response to the notion that identification could help their patients. – Following the intervention overall: – Reduction in under-identification; 14/15 practices improved their processes and increased the number of identified patients, both new and existing. – All practices promoted identification through posters/brochures and included the field on their new patient registration form (<50% pre-intervention). – Improved completeness of child immunisation records. – The provision of Indigenous-identified information resulted in a guideline being produced, which was further developed to apply to the state as a whole, and elevated and approved by the National Indigenous Immunisation Advisory Group in 2010, to be used in a state-wide project to follow-up overdue immunisations in Indigenous children. – Author concluded that Indigenous identification in mainstream urban general practice is implementable and can benefit provider-patient relationships.
OTHER (n=1)				
The Wardliparingga Aboriginal Research Unit of the South	State (SA)	Review of Health Plan; examples within tertiary and	Examples of good practice within the hospital setting and drug and alcohol services, including:	Reported outcomes included: – Increase in number of Aboriginal and Torres Strait Islander patients – Provision of culturally appropriate services

Australian Health and Medical Research Institute, 2017 [75]	AOD services	Development of district-wide reporting platform and setting organisational targets for unknown Aboriginal and/or Torres Strait Islander status Targeted training for staff on how to ask the question and the importance of doing so Employment of ALO Cultural events held at the service to improve patient support and create community links Procedures in place within SA Drug and Alcohol Services to collect and record Indigenous status in information systems and on referral forms Mandatory ‘Asking the Question’ training Display of posters within the service promoting identification Integrated identification as a key component of clinical pathway Aboriginal and/or Torres Strait Islander flags/markers on patient records Specific Aboriginal and Torres Strait Islander admission forms

Table 3.3.2 Existing documents, resources and initiatives of relevance to Indigenous identification

Organisation/Institution	Document/Resource	Summary
LEGISLATIVE AND POLICY		
NSW Ministry of Health, 2012 [335]	Aboriginal and Torres Strait Islander Origin - Recording of Information of Patients and Clients Policy Directive	Policy directive outlines: – Mandatory requirements for NSW Health Services "to collect consistent and comprehensive data on Aboriginal and Torres Strait Islander health", including use of the standard question-response, how to ask/collect the information and record it, roles and responsibilities for implementation. Procedures: – Details legislative framework, standard response options, asking the question, recording responses, mandatory completion, identifying records for follow-up, specific situations (e.g. births, under 15 years, client wishes to know why information being collected, client declines to answer), staff training, quality assurance and monitoring
Australian Commission on Safety and Quality in Health Care, 2018 [336]	Advice on the applicability of Aboriginal and Torres Strait Islander specific actions	Advisory issued by ACSQHC in 2018, for review in Dec 2020. Compliance stated to be "mandatory for approved accrediting agencies to implement this Advisory." Information in the Advisory applies to all approved accrediting agencies and all health service organisations. Specific Actions of relevance: – 5.8 – "the health service organisation has processes to routinely ask patients if they identify as being of Aboriginal and/or Torres Strait Islander origin, and to record this information in administrative and clinical information systems." No exemption is available for this action.

Bendigo and District Aboriginal Cooperative, 2018 [337]	Medical Policy	"Our Health Service identifies the cultural background of our patients to assist with disease prevention and delivering culturally appropriate care. To do this, our Health Service does the following activities: – encourage and record self-identification of whether a patient is Aboriginal, Torres Strait Islander or of another cultural background. A patient registration form is useful in assisting with 'self-identification' of cultural background."
STRATEGIES AND PLANS		
Cancer Australia and Menzies School of Health Research, 2015 [109]	National Aboriginal and Torres Strait Islander Cancer Framework	The document considers seven priorities for cancer control efforts at the national, jurisdictional, regional and local levels. Priority 7 specifically refers to Indigenous identification: – "Strengthen the capacity of cancer related services and systems to deliver good quality, integrated services that meet the needs of Aboriginal and Torres Strait Islander people." 7a. Enhance data systems to inform better outcomes – Enablers: Improve the identification and recording of Indigenous status, including on pathology requests and reports.
Cancer Australia, 2018 [80]	Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer	Key points: – All Aboriginal and/or Torres Strait Islander patients should be asked whether they identify as such and this information should be clearly recorded if they wish to be identified. – Partnerships between health services and Aboriginal and Torres Strait Islander people are encouraged, to determine the use of data for evaluation of experiences of care, programs and service models. – Increasing Aboriginal and Torres Strait Islander peoples' involvement in screening programs may be facilitated by encouraging patients to record their Indigenous status on forms. – Peoples' decision not to identify as Aboriginal and/or Torres Strait Islander must be respected.

AIHW, 2011 [338]	NAGATSIHID Strategic Plan 2010-2015	Established in 2000 to improve reporting on the status of health of Indigenous Australians; main role to provide strategic advice in Indigenous health data issues.
Victorian Government Department of Health, 2012 [281]	Koolin Balit: Aboriginal health strategy (2012-2022)	Key points: – 3 enablers for action, including “Improving data and evidence”. – Accurate identification of Aboriginal people attending hospital or other health services is required to enable provision of appropriate care as well as provide baseline health-related data. – Working with partners to improve Aboriginal identification. Notes strategies implemented since ICAP review: – identification of Aboriginal babies (not just those with Aboriginal mothers). – working with Medicare Locals to assist GPs with identification practices. – AIHW hospital data quality audit 2011.
Department of Health and Human Services Victoria, 2017 [94]	Korin Korin Balit-Djak: Aboriginal health, wellbeing and safety strategic plan 2017–2027	Strategic directions: – 3.3.2: Increase Aboriginal community ownership of data and access to data - (g) Review practices and quality of data collection on Aboriginal identification across the health and human services sector (Department action - 3 years) – Invest in primary prevention, early detection and early intervention to reduce chronic disease and its impacts - Aboriginal status will be correctly identified across all datasets (Indication of success - 10 years) – Manage illness better through culturally responsive, connected supports and care - (m) Improve data collection across all risk factors to ensure Aboriginal identification (Department action - 3 years)
NSW Ministry of Health, 2012 [339]	NSW Aboriginal Health Plan 2013-2023	Strategic Direction 2 - Implementing what works and building the evidence: – Strategic Action “Implement quality improvement strategies in data collection (particularly identification of Aboriginal clients) and reporting related to Aboriginal people in all health system settings”

		2019 mid-term evaluation noted strategies being implemented under the plan to improve recording of Indigenous status (i.e. relevant to SD 2): – “Aboriginal and Torres Strait Islander Origin: Recording of Information of Patients and Clients policy & procedure” – “Asking the question: Improving identification of Aboriginal people training” - Available via online training platform for all NSW health employees – Enhanced reporting of Aboriginality – Aboriginal maternal and infant health service data collection.[259]
Commonwealth Department of Health, 2015 [73]	Implementation Plan for the National Aboriginal and Torres Strait Islander Health Plan 2013–2023	Strategy 1F - Quality and completeness of data to support continued policy development and improved service design, planning and evaluation – Action - improved identification as Aboriginal and Torres Strait Islanders peoples in data collection sets – Deliverable by 2018 - implementation of AIHW and ABS Data Acquisition and Collection Program reported to NAGATSIHID – Deliverable by 2023 - AIHW and ABS data collection program reviewed and recommendations actioned
Australian Health Ministers’ Advisory Council’s National Aboriginal and Torres Strait Islander Health Standing Committee, 2016 [86]	Cultural Respect Framework 2016-2026 for Aboriginal and Torres Strait Islander Health	Aboriginal and Torres Strait Islander identification is an important factor relating to mainstream health system access. Health professionals should provide Aboriginal and Torres Strait Islander people the opportunity to respond to the identification question. Disclosing Indigenous status is voluntary. Health services must support the decision to identify by providing information about the availability of Indigenous-specific health services.
GUIDELINES AND STANDARDS		
AIHW, 2010 [255]	National best practice guidelines for collecting	Provides guidance on: – How to ask the question

	Indigenous status in health data sets	– Advice for different scenarios (<15years, literacy, staff reluctance, explaining reasons for collection etc) – Recording responses (should be mandatory in data entry systems; follow-up) Note: The National Indigenous Data Improvement Support Centre provides information and support on using and implementing the Best Practice Guidelines
AIHW, 2015 [340]	General practice software model to support best practice in Indigenous health care	Model of software attributes and recording practices for General Practice. Intended to raise awareness and change general practice software to improve healthcare for Aboriginal and Torres Strait Islander people. 2/5 of the model's components relate to Indigenous status (collection, recording and transmission). Provides aspects of best-practice and suggested software features and rationale for each.
Inner North West Primary Care Partnership and Victorian Government, 2015 [341]	A Guide to Culturally Aware and Responsive Communication	Developed for the North West Metropolitan Region PCP management and staff regarding appropriate communication and use of terminology when working with Aboriginal and/or Torres Strait Islander people and within written information. Notes that a person's Aboriginality should not be questions, and be accepted based solely on self-identification.
Royal Australian College of General Practitioners, 2017 [342]	Standards for general practices (5th edition)	Criterion C7.1 - Content of patient health records – "Our practice routinely records the Aboriginal and/or Torres Strait Islander status of our patients in their patient health record. ○ You must: document the patient's Aboriginal and/or Torres Strait Islander status in patient health records. ○ You could: maintain a policy addressing the management of patient health information." – Includes detail and explanation about reasons for collecting this information, importance of following up if missed, not assuming. Core Standard 4 - Health promotion and preventive activities.

		– Refers to an holistic approach, where practices are encouraged to “consider and respond to each patient’s individual circumstances…for example, heritage (e.g. does the patient identify as being of Aboriginal or Torres Strait Islander origin?)”
National Cervical Screening Program Quality and Safety Monitoring Committee, 2017 [343]	NCSP Quality Framework	Sets out principles of quality, their application and who is responsible. Under Principle 9 “The performance and outcomes of the NCSP are monitored and evaluated on a regular basis”, two points relate to Indigenous status: – “The healthcare provider ascertains the woman’s Indigenous status…data are recorded on the pathology request form where possible.” - responsibility of healthcare providers. – “Pathology laboratories provide all cervical test reports to the NCSR…includes…a woman’s Indigenous status…where provided on the pathology request form.” - responsibility of pathology laboratories.
The Wardliparingga Aboriginal Research Unit of the South Australian Health and Medical Research Institute, 2017 [75]	National Safety and Quality Health Service Standards: User Guide for Aboriginal and Torres Strait Islander Health	Identifies standards within the NSQHS which specifically relate to Aboriginal and Torres Strait Islander people, including Action 5.8: Identifying people of Aboriginal and/or Torres Strait Islander origin - a web-based summary is available. An Advisory to these specific actions was released in October 2018, mandating accrediting agencies to require compliance from healthcare organisations. Sets out the actions, implications for health services, benefits of taking action, key tasks, and suggested strategies as well as related actions within the NSQHS. Strategies (with suggested approaches) include the development of policies, business rules, procedures and protocols; review of systems (consistent wording and coding of SIQ, mandatory field, prompts to follow-up missing/incomplete information), enabling client review of own information, workforce training, development of resources to inform clients and encourage self-identification. Provides examples of good practice from health services and health districts.
NACCHO and RACGP, 2018 [344]	National guide to a preventive health assessment for Aboriginal and Torres Strait Islander	The guide is intended to be a practical resource for all health professionals who deliver primary healthcare to Aboriginal and/or Torres Strait Islander peoples. The importance of identifying Aboriginal and Torres Strait Islander clients is included as a subsection of the introduction, with reference to Closing the Gap, specific

	people: Evidence base. Third edition	government measures (i.e. PIP-IHI, PBS co-payment and Medicare rebates), cultural safety, and additional educational resources.
Victorian Government Department of Health, 2013 [345]	Continuous quality improvement tool: Aboriginal health in acute health services and area mental health services	Developed in response to several Vic Health strategies/plans (Vic Health Priorities Framework, Koolin Balit, ICAP review, Koori Mental Health Liaison Officer program). The CQI tool is stated to provide health services with processes around practice, cultural responsiveness, prioritisation, systemic effort and accountability; can be used as evidence within accreditation processes, and learnings, opportunities and challenges can help inform state-wide priorities. The CQI Tool is a checklist which includes a self-rating, evidence and strategies for maintaining or making progress Under Key Result Area 4: Systems of Care “Culturally appropriate strategies exist for collecting patient identification data on Aboriginality”
Department of Health and Human Services, 2017 [346]	Koori Maternity Service guidelines - delivering culturally responsive and high-quality care	Highlights that the delivery of culturally safe and responsive care relies on consistent and early identification of Aboriginal women, families and babies and emphasises the role of ACCOs and health services (and individual staff members) in collecting this information. States that improving clinical data systems is a component of efforts to improve collection of Indigenous status. Program requirement for Koori Maternity Services: – KMS are sensitive and responsive to local Aboriginal culture and the unique cultural needs of Aboriginal women and families. – Aboriginal women and non-Aboriginal women having an Aboriginal baby are routinely identified and offered referrals to appropriate services and support. – Client reception, waiting and treatment spaces are welcoming and accessible for local Aboriginal people.

Victorian Equal Opportunity & Human Rights Commission, 2014 [347]	Guideline for General Practices - Complying with the Equal Opportunity Act 2010 when providing services	Includes example and rationale for encouraging identification under Section 3 Review practices, 3.1 Prevent discriminatory questioning – Practice asks all new patients via form to respect privacy, and GP offers appropriate referral – highlights importance of identification, recognises barriers and need to explain reasons for collecting the information, accept the person's response; display information re benefits, reasons, patient rights and confidentiality
ACT Health, n.d. [348]	Asking patients "Are you of Aboriginal and/or Torres Strait Islander origin?"	Guideline published on ACT Health Website under Aboriginal and Torres Strait Islander Health, Resources, Forms and Policies section. Outlines issues surrounding identification, how to ask the question, who should be asked, when and where to collect data, why doing so is important, and how the data is used. Also provides suggestions for responding to common questions that may be asked.
POSITION STATEMENTS		
Australian Medical Association, 2008 [349]	Report Card Series - Ending the Cycle of Vulnerability - the health of Indigenous children	Recognises issue of under-identification. Recommends that the Federal Government coordinates national improvements in data management to ensure that comprehensive Indigenous status is recorded and made available for every jurisdiction. Proposed that Australian Governments should set and achieve targets including specified levels of completeness in health records and recording of Indigenous status in every jurisdiction to achieve 80% accuracy within 5 years.
AIHW, 2013 [350]	Towards better Indigenous health data Cat. no. AIHW 93	Phase 1 Evaluation of National Best Practice Guidelines for collecting Indigenous status in health data sets
AIHW, 2013 [351]	Taking the next steps: identification of Aboriginal	Arose as priority area during evaluation of National Best Practice Guidelines Identified the need for practice software changes and consistency and lack of knowledge re need to identify Indigenous patients

	and Torres Strait Islander status in general practice	
AIHW, 2013 [352]	The inclusion of Indigenous status on pathology request forms	Details previous and current studies to investigate ways to improve Indigenous identification in health registries Explains data collection and recording processes in cancer screening and other registries Sets out recommendations for inclusion of Indigenous status on pathology request forms
Australian Indigenous Doctors' Association, 2019 [353]	Position Statement - Aboriginal and Torres Strait Islander Patient Identification	The Position Statement recognises the challenges surrounding Indigenous identification, the importance of cultural safety training, community education, and advocates for best practice and evaluation to underpin all initiatives. Makes nine recommendations to improve identification of Aboriginal and/or Torres Strait Islander peoples in the healthcare system: – Increase efforts to improve access to appropriate healthcare based on the best available evidence – Use of the standard question and answers as developed by the ABS and AIHW – Adhere to best practice in collecting identification data, including cultural safety training for all staff and targeted community education strategies, as supported by the Lowitja Institute – The specific inclusion of Indigenous status as a mandated question on pathology collection forms – Continued advocacy of the National Anti-Racism Strategy – Create culturally safe spaces for Aboriginal and Torres Strait Islander Peoples – A national approach that includes practice and patient level initiatives, such as sign-on incentives and access to improved healthcare programs – Ability to use collected data in public policy development work

EXISTING TRAINING AND RESOURCES		
The RACGP National Faculty of Aboriginal and Torres Strait Islander Health, 2011 [258]	Cultural awareness education and cultural safety training	Listed under Mandatory Content – "Cultural awareness education should identify good practices for cultural safety (eg. …identification of Aboriginal and Torres Strait Islander patients…) – "…the cultural safety training program should include the following key elements… current national Aboriginal and Torres Strait Islander Health initiatives, including identification…"
DHHS Victoria n.d. [354]	Indigenous Identification pamphlet for midwives	Electronic copy of a presentation, available on DHHS website, which provides information on reasons for asking the question, how the information is used and by whom, how to ask the question and respond to difficult situations.
Inner North West Primary Care Partnership, Victoria, 2014 [355]	Asking the Question Training Package	Electronic training manual and video available online. Other resources are available for order.
North East Heathy Communities and Victorian Aboriginal Health Service, n.d. [356]	Self-Identification of Aboriginal and Torres Strait Islander Consumers	Project resources available online (detail from project evaluation by Berger, 2015 [260] included in **Table 3.3.1**)
Queensland Health Aboriginal and Torres Strait Islander Cultural Capability Team, 2017 [357]	Aboriginal and Torres Strait Islander Identification - webpage	Outlines reasons for identification of Aboriginal and Torres Strait Islander people within healthcare and how to ask the question. Provides links to an online training module, developed by the Aboriginal and Torres Strait Islander Cultural Capability team, targeting frontline and clinical staff. Learning outcomes related to reasons for and approach to asking the Indigenous identification question.

		Also links to a Qld Health video “Are you of Aboriginal of Torres Strait Islander origin?”, printable brochures and posters, and a Guide to improving identification of Aboriginal and Torres Strait Islander people in healthcare in Queensland.
NSW Government Health Education and Training, 2016 [257]	“Asking the question: Improving identification of Aboriginal people” training	Available via online training platform for all NSW health employees. Module aims to improve awareness and understanding of the importance of asking the question; provides information on how to ask the question and address various responses. May qualify for up to 0.4 hours of CPD.
VACCHO in collaboration with Mungabareena Aboriginal Cooperative and Rumbalara Aboriginal Cooperative [358]	Recording of Aboriginal and Torres Strait Islander Status	Series of three videos available on YouTube and the Vic Health website.
Aboriginal Health Council of Western Australia, n.d. [256]	Cultural Safety Training	Contains 6 modules, with Module 2 - Better Consultation relating to improving communication during patient consultation and including activities around methods for identification. Completion of Modules 1 and 2 are were approved as an Active Learning Module under the RACGP QI & CDP program (2014-16), with the program due to be reassessed in December 2019.
INITIATIVES		
Department of Health Victoria, 2009 [359]	Improving Care for Aboriginal and Torres Strait Islander Patients (ICAP) program	– Established in 2004/05, building upon Aboriginal Hospital Liaison Officer program – Recognises under-identification as a barrier to “policy and service development based on service access and health needs”. – ICAP reform outcomes includes “Improved identification and health care for Aboriginal patients” (p. xi) – ICAP Resource Kit developed in 2009 - includes orientation guides, practice examples, list of resources all with relevance to Indigenous identification.

NSW Ministry of Health [248, 249]	Aboriginal Immunisation Healthcare Worker program	Pilot program July 2012 for 3 years - NSW Ministry of Health provided funding for 13 FTE AIHCWs in Local Health districts, which aimed to improve timeliness of vaccination in Aboriginal children. Initially, Aboriginal identification was only listed as a possible strategy to improve immunisation: – "Submit a 12-month project workplan… that must include innovative strategies to increase timely Aboriginal immunisation and could also include strategies to improve Aboriginal identification." – Activities reported to be undertaken included provision of resources to GP clinics, raising the issue at meetings, advocating with providers, parents and students, correcting errors in the register and liaising with other stakeholders.[248] Successful pilot led to recurrent funding - expanding to include Aboriginal adolescents and adults. Following recommendations from the 2015 process evaluation, a specific KPI relating to Indigenous identification was included for the program: – "Implement strategies to improve Aboriginal identification in immunisation service delivery, including for adolescents as part of the NSW School Vaccination Program. Stage 2 process evaluation reported stakeholders' perceptions of collaborative activities of AIHCWS, which included assistance with recording Indigenous status on the AIR (41%).[249]
Metro North Hospital and Health Service, 2016 [360, 361]	Accurate Indigenous Identification Campaign	Launched during NAIDOC week July 2016, with the slogan "Identification: It's your right to a healthier life" to highlight the importance of identification of Aboriginal and Torres Strait Islander patients. Press release provides statements from the MNHHS Aboriginal and Torres Strait Islander Health Unit Director, and the Cultural Capability Officer. The Campaign was envisaged to support measurement of Indigenous health status and effectiveness of intervention programs.

		The May/June 2016 Newsletter contains articles highlighting the importance of identification, and provides examples of materials including t-shirts to promote the issue.
Australian Healthcare and Hospitals Association and the Heart Foundation, 2016 [362]	The Lighthouse Hospital Project	**Phase 1 (2012-2013)** Literature review and documentation of case studies (n=10 sites) highlighting best practice in care showed that better identification of Aboriginal and Torres Strait Islander patients was one of the factors impacting on care for acute coronary symptoms. **Phase 2 (2013-2015)** Development and pilot of a toolkit for quality improvement for hospitals (n=8) to undertake quality improvement in governance and accountability, clinical care pathways, cultural competence and workforce – Under Domain 4 - Care pathways “Key performance area 4.1.1 – Improve identification of Aboriginal and Torres Strait Islander peoples” Examples of activities included developing culturally appropriate resources, creating culturally safe and welcoming spaces, cultural awareness training for staff, changes to forms to improve communication with AMSs – Case study - development of an image by local artist for Aboriginal and Torres Strait Islander people to identify with and feel comfortable. Symbol placed at key points, and became recognised at the official hospital site symbol. Increase in self-identification was reported. Improvements to Indigenous identification was one of the key outcomes of the project. **Phase 3 (2017-2019)** Goal to “improve the integration of health services and care coordination by strengthening relationships between hospitals, local ACCOs and PHNs.” Training and support to 18 sites re identifying and implementing quality improvement activities; development of networks in local communities.

	National Forums held in 2018, centred around project priorities, including “Building service capacity to provide culturally safe and clinically competent care”, under which improving patient identification rates is listed. Second National Forum held in 2019 to share information, discuss sustainability and celebrate achievements.