Cancer in Aboriginal and Torres Strait Islander peoples: a rapid review of the literature

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An **Evidence Check** review brokered by the Sax Institute for the Cancer Institute NSW

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This rapid review was brokered by the Sax Institute for the Cancer Institute NSW.

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Clarification of cultural terminology

Throughout this report the term 'Aboriginal' refers to Australian Aboriginal and Torres Strait Islander peoples. It is understood that there is no single Australian Aboriginal or Torres Strait Islander culture or group and that there are many diverse communities, language groups and kinships throughout Australia. It is also recognised that Aboriginal and Torres Strait Islander peoples currently live in urban, rural or remote settings, practice urbanised, traditional or other lifestyles, and may frequently move between these ways of living. This report therefore recognises that the established conclusions and recommendations may not be applicable to all Aboriginal and Torres Strait Islanders. The recommendations and views expressed are through the retrieved documents and the attempt to analyse these data with cultural sensitivity, respect and commitment to decrease health disparities.

Abbreviations

ACCHS	Aboriginal Community Controlled Health Service
AHW	Aboriginal Health Worker
AIHW	Australian Institute of Health and Welfare
AMS	Aboriginal Medical Service
CanNET	Cancer Service Networks national program
GP	General practitioner
HPV	Human papillomavirus
ILO	Indigenous liaison officer
NPAPH	National Partnership Agreement on Preventive Health tobacco social marketing campaign
NRT	Nicotine replacement therapy
NSW	New South Wales
NT	Northern Territory
PBS	Pharmaceutical Benefits Scheme
PEPA	Program of Experience in the Palliative Approach
QUMAX	Quality use of medicines maximised for Aboriginal and Torres Strait Islander people
RCT	Randomised control trial
SA	South Australia
WA	Western Australia
WHINURS	The women with human papillomavirus in Indigenous and non-Indigenous, urban and rural populations survey

1 EXECUTIVE SUMMARY

1.1 Background

In Australia, Aboriginal and Torres Strait Islander peoples, hereafter Aboriginal, generally suffer poorer health, and experience substandard cancer outcomes when compared to their non-Aboriginal counterparts. While improved cancer outcomes have been seen in many tumour groups for non-Aboriginal Australian people, the same advancements have not been made within the Aboriginal population.

Overall, incidence rates for all cancers combined are lower for Aboriginal people than non-Aboriginal people. This is a manifestation of death earlier in life from traumatic, non-malignant and infectious diseases. In spite of this, there are a number of cancers where Aboriginal people are over-represented, including cervical, liver, lung and other smoking-related cancers. Despite incidence rates being lower, Aboriginal Australians are over-represented in cancer deaths. This occurs for a number of reasons including: a higher risk factor profile, comorbidity burden, late diagnosis and poor access to treatment. The over representation in aggressive cancers with poor outcomes, such as lung cancer, is of concern particularly as the majority of these are preventable.

Most cancers over-represented in Aboriginal Australians are largely preventable; this is because Aboriginal Australians are more likely to possess one or more cancer risk factors such as smoking, alcohol consumption, poor diet, lack of physical activity and have higher rates of chronic hepatitis virus infections. Much of this risk factor burden is driven by entrenched social and health disparities. Available data suggest that current models of service provision and care delivery do not meet the needs of the Aboriginal Australian population. As a consequence, Aboriginal people are less likely to participate in screening programs, more likely to receive delayed or incomplete treatment and more likely to be reluctant to engage with the health care system. In order to address these factors, future initiatives must address the structural inequalities and institutionalised discrimination.

This report answers the following rapid review questions, identifies gaps in the literature and provides recommendations for future research, programs and policy.

1.2 Rapid review questions

1. What do Aboriginal communities know (including knowledge about what causes cancer) and believe about cancer, its treatment and what the short and long term outcomes are for those diagnosed with cancer?
2. What do Aboriginal communities perceive to be their risk of or susceptibility to cancer?
3. What programs and interventions undertaken in Aboriginal communities have been effective in reducing the risks associated with cancer – including tobacco use, alcohol use, fruit and vegetable consumption, physical inactivity, overweight and obesity, human papillomavirus infection and hepatitis B?
4. What programs and interventions undertaken in Aboriginal communities have been effective at promoting the benefits of early detection of cancer and have resulted in practices which promote awareness of changes to usual condition (such as changes to

skin, breasts, bowel motions, coughing), and greater use of screening and early detection services?

5. What programs or services have been effective in improving the participation of Aboriginal people in cancer treatment (e.g. accepting adjuvant therapy, completing treatment prescribed)?

1.3 Methods

The rapid review of the literature proceeded in two stages. At Stage 1, we identified articles from peer-reviewed journals and at Stage 2, we identified and synthesised the available grey literature. A health librarian was consulted to assist in developing a search strategy and discuss appropriate databases and search terms. Searches used Medical Subject Headings (MeSH) terms or equivalent as well as related keywords. Data bases searched included: Medline, PsychInfo, CINAHL, AMED, Health and Medicine Proquest, Scopus, Aboriginal and Torres Strait Islander Health (ATSIHealth), Australian Family and Society Abstracts Database ATSI subset (Informit)(FAMILY-ATSIS), Australian Indigenous Health InfoNet and the Cochrane Database of Systematic Reviews. CareSearch and Google Scholar were also searched. A deep web trawl search was undertaken using Mednar. Peak professional bodies and relevant government and non-government websites were systematically searched for relevant publications.

1.4 Body of evidence

In order to increase the utility of this review, data has been drawn from a range of policy documents as well as descriptive and comparative studies and selective expert opinion. The majority of the cancer literature in Australia has focused on incidence, mortality and survival rates. However, in the last decade there has been an increase in qualitative work to investigate why cancer outcomes are so poor for Aboriginal people. While the literature describes a number of community-based projects, there has been little evaluation of outcomes or effectiveness. There have been few, if any, evaluation protocols. There has been minimal intervention research and no evidence from randomised controlled trials of cancer-focused interventions in the Aboriginal population. There are significant limitations regarding the data quality and availability of cancer information within Aboriginal populations; this must be taken into consideration when undertaking analysis. Notwithstanding this mainstream stance, it is important to consider research in Aboriginal peoples within the conceptual framework of Indigenous methods. Although not able to be summarised in the traditional metrics of systematic reviews, there is evidence of significant gearing up to address decades of failing to meet the needs of Aboriginal people. This preparatory, largely qualitative work has been critical in laying the ground work for future interventions.

1.5 Findings of the rapid review

Knowledge, attitudes and beliefs

Cancer is not seen as a priority amongst Aboriginal communities. Many see cancer as a foreign concept and lack understanding of its causes, the available treatments and likelihood of survival. The issue of fear was consistently raised throughout the literature; fear was demonstrated across all areas of the cancer journey. The understanding of cancer for Aboriginal people appears to be influenced by a co-existence of western biomedical concepts as well as more traditional and cultural values. The literature review identified that Aboriginal people had only a basic knowledge of the causes of cancer, with considerable variation in understanding. Many blame

the effects of 'white man' for cancer, arguing that this was not an area of concern for Aboriginal people prior to colonisation. Lifestyle factors such as smoking, diet, stress, alcohol and a lack of exercise were also recognised as causes of cancer. Misconceptions were described including cancer being considered contagious and a disease that carries stigma. Those with more traditional beliefs saw cancer as the result of a 'payback' for a wrong doing.

The overwhelming perception emerging from the literature is that Aboriginal people universally saw cancer as a deadly disease, regardless of the type or tumour staging. The few public stories of survivorship and the high mortality rates from cancer and many other causes fuels fatalistic attitudes. The review identified that for many people there is confusion around treatment efficacy and available options. Identified explanations included poor health literacy and a lack of culturally appropriate communication between patients and providers. Willingness to participate in cancer diagnosis and treatment is influenced by stories that circulate in the community in relation to other people's experience. Adherence to cancer treatment is also likely to be affected by the hospital experience, the impact of side effects, family commitments and the cultural relevance and associations of the treatment.

Perceptions and susceptibility

The issue of Aboriginal people's perceptions of susceptibility needs to be considered against a backdrop of a high morbidity burden – particularly of diabetes, heart disease, end-stage renal disease and chronic obstructive pulmonary disease. The literature suggests that many Aboriginal people are unaware of their risk of and susceptibility to cancer, and factors such as 'shame' and culturally unsafe health services are a negative driver of health seeking behaviours. Many think that cancer is a disease that won't affect them, or that the risk of cancer is beyond their control. Aboriginal people also are unaware of the benefits of screening programs and early detection. Even where there is an awareness regarding the benefits of participating in a screening program, many chose not to as the test is associated with shame and embarrassment. There was also a lack of awareness that cancer progresses without causing symptoms, often until late in the disease, fuelling a belief that only people with symptoms needed to engage in a screening program.

Cancer prevention

Aboriginal communities, government and non-government organisations have a strong commitment to preventing cancer. In all of these initiatives it is impossible to ignore the contribution of social determinants to adverse health and social outcomes. In particular, national tobacco control initiatives have the potential to drive health care improvements. A range of initiatives in improving diet and health care access have been developed to address the high burden of disease for cancer and other chronic conditions. Strategies such as local community activities, yarn ups, Aboriginal media and national media campaigns have been evaluated. Identification of positive role models also has the potential to engage communities. Social marketing strategies should include images, graphics and messages that are appropriate and accessible to communities. Appreciating issues in health literacy is important in developing programs. Increasing the clarity of health messages is likely to leverage benefit.

There are many environmental and lifestyle risk factors that influence cancer risk and are therefore relevant to cancer prevention; culture is closely related with both environment and lifestyle. Notably, the ACE studies of cost effective interventions did not report on prevention of cancer in Aboriginal populations, although universal Hepatitis B vaccination and Hepatitis B Immunoglobulin for carrier mothers were considered to be highly cost-effective.

A recurring theme, across all prevention activities, is the need to engage Aboriginal people and communities in the identification and development of key priorities and actions to improve their

own and their family's health. Talking Circles with Aboriginal women has been one successful approach to this.

Human Papilloma Virus (HPV)

Improved vaccination against HPV for Aboriginal people has been reported to require true collaboration with Aboriginal people and good education, culturally appropriate materials and mentoring. This includes multi-pronged approaches such as vaccinating different age ranges, fully funded vaccine coverage, having community buy-in, staff who believe in the vaccine, and electronic recalls which enable targeted approaches to vaccination.

Tobacco

Tobacco interventions are one of the most widely reported interventions to prevent cancer in Aboriginal people. It seems widely accepted that interventions need to be multi-pronged, with successful approaches involving strategies such as Aboriginal community input and ownership of integrated interventions. These include education, group education, preparing to quit, telephone support, pharmacotherapy, GP management and counselling, and recognising and addressing the role of stress as a cause of smoking and relapse. Evidence is limited for one pharmacotherapy over another, although an individual's preference and context should be considered. The aim is to increase the acceptability and accessibility of good support to quit and there is some limited evidence for group formats being more efficacious. Similarly, higher intensity programs appear to increase quit rates. Access to smoking cessation supports normalisation of quitting smoking as more individuals make quit attempts and diffuse the experience throughout the community. Social marketing and media campaigns increase intentions to quit although evidence of efficacy in smoking cessation is limited.

There was an absence of studies that examined peer/buddy support groups. No trials of varenicline or bupropion in Aboriginal communities were available and the impact of a range of policy and public health interventions still needs to be evaluated. Cost-effectiveness studies which evaluate interventions are not available. A notable difficulty encountered in studies which should inform any future approach was the challenge in following up participants. Similarly, addressing marijuana with tobacco is considered important given that it challenges quit attempts. This underscores the importance of holistic approaches considering the use of tobacco, alcohol and other drugs.

Nutrition

No Aboriginal-specific interventions were identified in peer-reviewed literature that evaluated fruit and vegetable consumption and cancer prevention. Evaluations were weak without randomisation or controls and most omitting important details of interventions, such as attrition rates. There is a need for more rigorous evaluation of interventions and to establish the reliability and validity of measures to quantify their effect. The cost of fresh food in remote communities needs to be considered.

Physical activity

No Aboriginal-specific interventions were identified in the peer-reviewed literature on physical activity specific and cancer prevention, however, interventions were evident in initiatives to reduce the risk and burden of other chronic conditions. The available evidence suggests that for programs to be successful, they must have community ownership and direction, and the projects must be ongoing and sustainable, rather than one-off initiatives.

Alcohol

In spite of the highly politicised and contentious space concerning alcohol use in Aboriginal peoples, there are limited evaluations of Indigenous-specific alcohol misuse interventions. The available evidence indicates that for interventions to be effective they should: have the support of and be controlled by local communities; be designed specifically for the needs of a particular community and sub-groups within the community; be culturally sensitive and appropriate; have

adequate resourcing and support; provide after-care; and, cater for complex presentations. A combination of harm minimisation strategies is most effective.

Enhancing the effectiveness of interventions

Ensuring cultural appropriateness and acceptability of interventions recurs as a recommended strategy in indigenous populations. This includes: engaging in community consultation to ensure needs and preferences of the population are met; conducting interventions in culturally-safe, community-based settings; and ensuring community ownership of programs. Programs embedded within the culture's philosophy of health and comprised of elements that reflect and respect the values of culture are likely to foster engagement of community members in interventions. The cultural acceptability of these of interventions needs to be considered. Eliciting feedback, in safe situations, regarding intervention materials and delivery helps ensure acceptability of intervention content and communication style.

It is necessary to consider contextual factors which may impact on participants' ability to engage in interventions. Cultural security can be achieved by not only acknowledging needs or preferences, but taking steps to address these needs in appropriate ways, via provision of instrumental support. Transport to programs and timing of intervention availability need to be considered as do ensuring a comfortable atmosphere, acting with genuine consideration of Aboriginal beliefs and cultures, incorporating holistic approaches and embracing intercultural health systems in which different cultures are valued and incorporated.

Early detection of cancer

A small number of programs and interventions were identified that have been effective in promoting the benefits of early detection of cancer through uptake of prevention and screening services for Aboriginal peoples. These have included marketing campaigns and service re-design interventions for culturally appropriate promotion and provision of screening programs. Outreach models have shown to be important. To date, the majority of initiatives have focused on breast and cervical screening in women. There is minimal data on cancer in men and initiatives to support the early detection of cancer in men focusing on lung, bowel cancer and other smoking related cancers. The use of established structures, such as men's groups may be an early approach. Structured education programs for Aboriginal Health Workers (AHWs), such as those undertaken by the Queensland Cancer Council are a useful model for increasing awareness of cancer screening and early detection.

Early detection of cancer relies upon both screening programs, increasing people's awareness of cancer symptoms, and encouraging them to seek medical attention. A small number of studies aimed at increasing cervical screening rates have been reported. In all, AHWs played a critical role through recruiting, undertaking pap smears and following up with women. A holistic approach, taking time to talk to women, a private and confidential environment and the use of recall systems were seen as important. All studies increased screening rates above those occurring pre-intervention.

Service re-design to improve service coordination and access was reported in a small pilot study as improving service communication and cooperation, and improving health promotion activities, awareness and attitudes in some locations.

Support and education

Indigenous cancer support groups, while primarily focused on care and support, inevitably can have a role in increasing cancer awareness, and participation in cancer screening services. They have been reported as providing instrumental support to women, including through assisting them to attend screening and follow-up.

Aboriginal women participating in education sessions to discuss breast cancer and screening showed an increase in understanding of screening and reported less fear and concern over cultural inappropriateness, with increases in screening rates.

In-reach services and mobile services appear to offer tremendous opportunities to increase cancer screening rates. BreastScreen WA has an Aboriginal project officer who provides a large range of input, including group bookings for screening, and liaising with Aboriginal services and communities. A full-time AHW who oversees the activities resulted in a 30% increase in screening.

A bowel cancer flipchart has been used to facilitate understanding of bowel cancer and the screening program to increase participation rates. Attitudes and intentions to be screened did not change despite the flipchart being well accepted. The nature of the screening test and uncertainly regarding its status may have contributed to this. This also underscores the complexity between knowledge and risk perception.

Cancer services and treatment

This rapid review identified that the majority of the efforts to date have been invested in prevention and screening initiatives. It is true that many projects have focused on relationship building and community engagement. The literature highlights that initiatives for Aboriginal people are most likely to be effective when planned and implemented in an Aboriginal controlled setting. This must go beyond tokenistic representation to effective engagement with Aboriginal people who are consulted at all levels of service design, implementation and evaluation. Available data highlights the importance of outreach health services, and where possible, assistance with transport and accommodation should be provided. Key areas of improved service delivery emphasise communication and relationship-based care, consultation, decreasing barriers, improving the cultural competence of staff and services and ensuring a continuation of care. Trust, safety, respect and recognition are critical factors for driving health care system reform. Structural changes need to be made to address the racism and discrimination that continue to permeate the Australian health care system. Case management and coordination are likely to be critical in ensuring adherence to treatment. Achieving trust and reciprocity in relationships are critical and these are most effectively forged through the engagement of AHWs. Research in other countries has identified the success of navigator models; no published research has yet to be done in Australia on investigating the effectiveness of such a model with the Aboriginal population. Achieving representation of Aboriginal people in the health workforces is also a critical factor in driving systemic and cultural change.

The burden of cancer in Aboriginal people is a clear signal of health disparities and the adverse outcomes of entrenched social and health disparities. This review has determined that a 'one size fits all' approach to Aboriginal cancer control is not appropriate. Although key elements of interventions are non-negotiable: cultural competence, coordination, instrumental support and the engagement of communities, elements such as sex-specific programs, site and delivery of programs need to be considered at an individual level. Accessing therapeutic, curative, adjuvant and palliative therapies require interaction with mainstream services. Ensuring that these environments are welcoming to Aboriginal people and they are treated with respect is critical in developing trusting relationships which are a trigger for Aboriginal engagement. Overcoming barriers such as transportation, cost, absence of support and separation from country need to be addressed. This review has identified that many attempts are being made, nationally and internationally, but currently there is a lack of co-ordinated, sustainable and ongoing efforts, particularly across jurisdictions. Cross-sector and cross-jurisdiction issues challenge coordination and seamless care for Aboriginal individuals. The importance of the Aboriginal Community Controlled Sector in driving health care reform is underscored and these communities need to be engaged beyond tokenistic representation.

Despite the need for improvements in data quality and availability, the burden of cancer in Indigenous Australians is profound. The patterns of incidence and mortality are largely explained by the higher prevalence of risk factors and entrenched health and social disparities. As a priority, there is a need to address tobacco smoking to ensure that effective programming involves addressing the social and cultural role of smoking in Indigenous people. Although this is part of a broader national strategy, elements of tobacco control interventions need to pervade all health interactions. The later diagnosis of cancer in Indigenous people compared with non-Indigenous people, differences in treatment outcomes after adjustment for cancer stage at diagnosis underscore the need to address these issues. As mentioned above, there are limited intervention studies in cancer. In spite of this, there is clear documentation of the barriers and enabling solutions. Collaboration between mainstream health and social services and Aboriginal organisations; cross-discipline, cross-jurisdiction are required to develop innovative and collaborative solutions. Emerging literature to address health disparities underscores the importance of a life course approach. Addressing preventive strategies early in school is likely to leverage some benefit.

1.6 Key findings

- It must be recognised that Aboriginal Australians are not a homogenous population and that specific attention must be given to the different needs and experiences of Aboriginal people living in urban areas versus rural/remote areas. Further, gender specific needs are not generalisable and are individual and community specific
- Increasing representation of Aboriginal people in all levels of the workforce and all health professions is important in driving cultural change
- Aboriginal health workers are in an ideal position to play a vital role in cancer control programs with the Aboriginal population. They must be trained and supported to provide education to Aboriginal people on the risks, causes, treatment and likely outcomes of cancer
- Aboriginal Health Workers need to be actively engaged in any community intervention to ensure that the project is culturally appropriate and the community is effectively engaged. Aboriginal Health Workers and Aboriginal Liaison Officers are also positioned well to facilitate appointments, enable case management and ensure continuation of care
- Involvement of Aboriginal staff does not mean that non-Aboriginal staff should not have responsibility for contributing to culturally-secure Aboriginal patient care. Investment in training for cultural competence and mechanisms of monitoring for racism is underscored
- Traditional beliefs and values must be taken into consideration by all health professionals, and where possible attempts must be made to ensure that the individual's cultural needs are met. This will come from cross-cultural awareness training and education of non-Aboriginal people, but working partnerships between Aboriginal and non-Aboriginal staff maximise two-way learning
- Given the many issues of data availability and quality, efforts should be made to improve the basic data infrastructure and monitoring capability of area health services as well as Aboriginal Medical Services
- Successful elements of intervention have been identified such as: community engagement and control, cultural safety, tailoring of information for language and

health literacy, support systems and assistance with transport, accommodation and hospital liaison services

- As many projects comprising the evidence have been undertaken as part of research projects and specifically funded health promotion projects, it is critical that the effective elements of interventions be 'institutionalised' systemically so that access to exemplary and evidence-based interventions is not ad-hoc, a post-code lottery, or dependent on good will
- Addressing health disparities for Aboriginal people will require focus beyond the cancer sector to cross-sector and cross-jurisdictional collaboration
- A life course approach to prevent cancer is needed, underscoring the importance of intervening in a number of settings, e.g. schools and maternity services
- There is a need for more intervention research using Indigenous methods
- Using a standardised taxonomy including descriptors of target population, intervention recipient, intervention content, delivery personnel, method of communication, intensity and complexity of exposure, and mix of program components, context, and desired outcomes will assist in comparing and contrasting interventions.

2 Introduction

2.1 Background

In Australia, Aboriginal and Torres Strait Islander peoples, hereafter Aboriginal, generally suffer poorer health, and experience inferior outcomes when compared to their non-Aboriginal counterparts across all stages of the cancer journey. While improved cancer outcomes have been seen in many areas for the non-Aboriginal Australian population, the same advancements have not been made within the Aboriginal population.[1]

For the period of 2003–2007, age-standardised incidence rates for all cancers combined indicated that Aboriginal Australians are less likely overall to have been diagnosed with cancer than their non-Aboriginal counterparts.[1] While overall Aboriginal Australians are less likely to be diagnosed with cancer than non-Aboriginal Australians, there are a number of specific cancers in which Aboriginal people are overrepresented. For example, the incidence rate for cervical cancer is nearly three times higher in Aboriginal as compared to non-Aboriginal Australians.[1] Aboriginal Australians are also much more likely to be diagnosed with cancers with poorer outcomes such as lung cancer, liver cancer and cancer of the oesophagus.[2]

Lung cancer is the most common cancer in Aboriginal Australians and accounts for the highest number of cancer deaths.[3] Reasons for this can be attributed to the prevalence of tobacco smoking among Aboriginal Australians. In 2004–2005, half of the participants (50%) of the *National Aboriginal and Torres Strait Islander Health Survey* reported being regular smokers, with the rate of smoking in the Aboriginal population at about twice that of the non-Aboriginal population.[4] Although there are considerable efforts at tobacco control in Aboriginal populations[5, 6], it is unlikely that these initiatives will have an impact on lung cancer rates in the short term.

In the context of any review of interventions, it is important to note that there are significant limitations regarding the data quality of cancer within Aboriginal populations.[7] A lack of reliable national data on cancer incidence and mortality for Aboriginal Australians makes it difficult to appreciate the full burden of disease and treatment barriers.[2,8] Despite these limitations there is enough evidence to indicate that cancer is a serious concern within Aboriginal Australians, significant health disparities exist and further work in policy, practice and research is needed.

Aboriginal Australians are also more likely to have a high prevalence of other cancer risk factors, such as: a lack of physical activity; poor diet; high level of alcohol consumption; increased likelihood of practising unsafe sex and hepatitis B carriage.[9] These risk factors not only contribute to the likelihood of a cancer diagnosis, but they contribute to a number of other chronic conditions. Approximately 80% of the mortality gap between Aboriginal and non-Aboriginal Australians can be attributed to chronic diseases, with the level of contribution increasing according to age.[10]

Aboriginal Australians are also less likely than non-Aboriginal Australians to participate in screening programs[11], which is likely to play a role in explaining why incidence rates for cancers overall are lower than non-Aboriginal Australians. This can also explain why Aboriginal Australians are over represented in cancers such as cervical cancer, a condition that has a widely accepted and utilised screening tool.

Despite incidence rates being lower, Aboriginal Australians experience a much higher mortality rate for all cancers than non-Aboriginal Australians.[1,12] Aboriginal Australians are more likely to

be at a more advanced stage of cancer at diagnosis.[13] Mortality rates are particularly high for lung cancer and cervical cancer.[1]

Furthermore, Aboriginal Australians are more likely to receive delayed or incomplete treatment, have lower admission rates and not have access to cancer support services.[11,14] In 2007–2009, just over 1% of hospitalisations for Aboriginal Australians were for cancer despite higher acute care utilisation for Aboriginal people.[10] Reasons for this include low socioeconomic status, remoteness and the lack of culturally appropriate services, cultural and spiritual beliefs and language barriers.[11,15–17]

Australia's history of colonisation and the experience of dispossession continue to plague the ability of the health care system to deliver effective and culturally appropriate services. Experiences of discrimination, racism and the influence of structural inequalities continue to have a negative impact on the health and wellbeing of Aboriginal Australians.[18,19]

As in other areas of Aboriginal health, cancer is a complex and multifaceted issue with numerous issues at the individual, provider and system level affecting the ability to manage cancer effectively and improve outcomes. Once a death sentence, cancer is now a chronic condition, requiring ongoing surveillance and management over several decades.[20] While a body of research has begun to emerge over the last decade, this is an issue that warrants immediate attention and requires further investigation.

2.2 Purpose

The purpose of this rapid review is to inform:

- Development of a Cancer Institute NSW-wide approach for improving cancer incidence and outcomes in Aboriginal communities
- Design and delivery of programs and service
- Identification of knowledge gaps and how these might be filled.

2.3 Review questions

1. What do Aboriginal communities know (including knowledge about what causes cancer) and believe about cancer, its treatment and what the short and long term outcomes are for those diagnosed with cancer?
2. What do Aboriginal communities perceive to be their risk of or susceptibility to cancer?
3. What programs and interventions undertaken in Aboriginal communities have been effective in reducing the risks associated with cancer – including tobacco use, alcohol use, fruit and vegetable consumption, physical inactivity, overweight and obesity, human papillomavirus infection and hepatitis B?
4. What programs and interventions undertaken in Aboriginal communities have been effective at promoting the benefits of early detection of cancer and have resulted in practices which promote awareness of changes to usual condition (such as changes to skin, breasts, bowel motions, coughing), and greater use of screening and early detection services?
5. What programs or services have been effective in improving the participation of Aboriginal people in cancer treatment (e.g. accepting adjuvant therapy, completing treatment prescribed)?

2.4 Indigenous research methodologies

Approaches likely to address the challenges of improving health outcomes for Aboriginal Australians emerge from Indigenous communities and methodologies. The concept of an Indigenous specific research methodology is an ongoing process and is still being developed and theorised. When conducting research with and about Aboriginal people, every step must be genuinely founded on a process of meaningful engagement and reciprocity between the researcher and Aboriginal people.[21] It is critical that historical context of Aboriginal people is understood, and the impact of colonisation is reflected upon continually throughout the research process.[22]

Martin (2003) identifies four principles of an Indigenous research framework[23]:

1. Recognition of Aboriginal world views, knowledge and realities as distinctive and vital to their existence and survival
2. Honouring Aboriginal social mores as essential processes through which they live, learn and situate themselves as Aboriginal people in their own lands and when in the lands of other Aboriginal people
3. Emphasis of social, historical and political contexts which shape Aboriginal experiences, lives, positions and futures
4. Privileging the voices, experiences and lives of Aboriginal people and Aboriginal lands.

When conducting research with Aboriginal populations the following broad categories of rights, respect and recognition; negotiation, consultation, agreement and mutual understanding; participation, collaboration and partnership; benefits, outcomes and giving back; managing research: use, storage and access; and reporting and compliance, must be respected.[21] As a consequence, this will provide a context for evaluating effective interventions.

The National Health and Medical Research Council (NHMRC) Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research are also an important consideration.[24] These guidelines provide guidance to researchers in the conception, design, and conduct of research. The guidelines are developed on the principles of spirit and integrity, reciprocity, respect, equality, survival and protection, and responsibility. It is important to remember that in Aboriginal research we are not only accountable to the participants, but also the wider community.[22] When reporting on research, the documentation is regulated through respect of culturally established protocols including asking permission, using preferred language, terms and expressions, and ensuring the ultimate aim of maintaining relations.[23]

3 Methodology

3.1 Methods

The review proceeded in two stages. At Stage 1, we identified articles from peer reviewed journals and at Stage 2, we identified and synthesised the available grey literature. A health librarian was consulted to develop a search strategy and discuss appropriate databases and search terms.

3.2 Review parameters

The review parameters were defined by the Cancer Institute NSW and the Sax Institute as follows:

- Date: no limit
- Population: all Australian Aboriginal communities were included (urban, rural, and remote)
- Type of cancer: all cancer types were included
- Knowledge: includes knowledge of causes, treatment, risk factors, incidence, detection, survival rates, treatment options, effectiveness of early detection and treatment, and accessing diagnostic and treatment services (from initial treatment to palliative care)
- Attitudes and beliefs: stigma and fear about cancer, and culturally-specific attitudes and beliefs
- Risk perception: overall risk of getting cancer, risk of dying once diagnosed with cancer, and the likelihood of being able to prevent cancer
- Programs and interventions: effectiveness and efficacy (for example, programs and interventions that showed positive impacts but were not implemented adequately); delivered locally and at higher population levels; either single- or multi-component; short-term or long-term change in risk; only studies that describe key elements of the programs or interventions; only include studies that describe community engagement processes
- Early detection effectiveness: evidence of increased rates of self-examination, early symptom recognition and/or uptake of prevention and screening services; include (but are not limited to) marketing campaigns, service re-design interventions, for culturally appropriate promotion and provision of screening programs
- Cancer treatment: all stages were included, from diagnosis to the end of life or long-term survivorship
- Service and treatment effectiveness: evidence of increased participation rates and evidence that the programs or services are culturally appropriate for the target communities
- Methodology: all methodologies were included (quantitative, qualitative, mixed methods)

Stage 1: Peer reviewed articles

Eligibility criteria

To be included, studies needed to have addressed one of the review questions and have been published in a peer reviewed journal. Only articles published in English were included. All studies

retrieved during the literature search were examined for relevance according to the scope of the project.

Types of studies

Quantitative, qualitative and mixed-methods studies of all designs reported in peer-reviewed journals were included. Quantitative studies were assumed to include evaluative studies (randomised or non-randomised), cohort studies, cross-sectional studies and case studies. Qualitative studies are defined as those attempting to make sense of or interpret phenomena in terms of the meanings people bring to them.[25] To ensure a minimum standard of reporting, we required articles to report at least one sample of raw data (e.g. verbatim patient statements). Data could have been collected using any method (e.g. interviews, focus groups, online fora, observation, open-ended survey questions).

To be considered optimally relevant to Question 1 (knowledge, attitudes and beliefs), studies had to investigate what Aboriginal people believe and know about cancer.

To be relevant to Question 2 (perceptions and susceptibility), studies needed to investigate what Aboriginal people believe to be the risk of susceptibility to cancer.

To be relevant to Question 3 (cancer prevention), studies needed to report on the specific programs and/or interventions that were undertaken to reduce the risks associated with cancer. Programs and interventions may include but are not limited to screening programs, health promotion activities and patient education. Programs and interventions that reduce the risk of cancer included tobacco use, alcohol use, fruit and vegetable consumption, physical inactivity, overweight and obesity, human papillomavirus infection and hepatitis B. The studies could have been single-component or multi-component.

To be relevant to Question 4 (early detection), studies needed to report on a program and/or intervention that had been implemented to promote the benefits of early awareness and/or encourage greater utilisation of screening and early detection services. Such programs and interventions could involve marketing campaigns and service re-design interventions. These interventions can be delivered locally and/or at higher population levels.

To be relevant to Question 5 (cancer services and treatment), studies needed to describe or investigate programs and/or services that have been implemented to improve the participation of Aboriginal people in cancer treatment, or improve their access to services. All treatment stages and services were included.

Types of participants and settings

The review predominantly focused on the Australian setting. However if no Australian evidence was available for a review question, and international comparison could have been used where relevant evidence from a comparable population existed (e.g. New Zealand Maori, Canadian Inuits).

Types of intervention

The term 'intervention' was understood at the broadest level and therefore encompassed any activity undertaken to prevent the risk of cancer, increase the likelihood of early diagnosis and improve access to cancer treatment and services. Interventions could have been at the individual, community or national level.

Electronic searches

We searched Medline, PsychInfo, CINAHL, AMED, Health and Medicine Proquest, Scopus, Aboriginal and Torres Strait Islander Health (ATSIHealth), Australian Family and Society Abstracts Database ATSI subset (Informit)(FAMILY-ATSIS), Australian Indigenous Health Infonet and the

Cochrane Database of Systematic Reviews. CareSearch and Google Scholar were also searched and a deep web search using Mednar was undertaken.

Search
Searches used Medical Subject Headings (MeSH) terms or equivalent as well as keywords relating to the population, conditions and interventions. Where necessary truncation was used to ensure a more inclusive search, e.g. aborgin*

- Population: Aboriginal and Torres Strait Islanders, Oceanic Ancestry Group, Indigenous, Aboriginal
- Condition: cancer, neoplasms
- Healthcare Intervention: screening, health intervention, patient education, health services, health promotion, diagnostic services, early diagnosis, program evaluation.

Keywords and MeSH terms were also searched to address Questions 1 and 2, these included: attitude, beliefs, values, view, awareness, culture, fear, anxiety, stress, stigma, social stigma, shame, perception, knowledge.

The reference lists of all included reviews and studies were searched manually for further relevant articles.

Study selection
Articles that resulted from database searching were imported into Endnote (version X4) and electronically coded by a single researcher against all inclusion criteria.

Data collection process
Data were extracted by two researchers using an electronic proforma. We assessed the quality of evidence using the methods described in Appendix G. Unfortunately, methods are not yet available to compare the quality of qualitative studies that use different methodologies[26]. However, we will take the position that rating study quality is nonetheless worthwhile for its potential to inform the development of the field as a whole if not to classify studies relative to one another. In the absence of any universally accepted method, we used the checklist developed by Kitto et al. 2008 which provides criteria for assessing clarity of aims/research question, justification of the approach used, procedural rigour, representativeness of the sample, interpretation of the data, reflexivity and evaluative rigour, and transferability of findings.[27]

Stage 2: Grey literature

Eligibility criteria
To be included, studies needed to have addressed one of the review questions; only reports and publications in English were included.

Information sources
Peak professional bodies and relevant government and non-government websites were systematically searched for relevant publications. These included: Australian Institute of Health and Welfare (AIHW), Cancer Australia, Cancer Institute NSW, Cancer Council (National and States), Australian Indigenous HealthInfoNet, The University of Tasmania Indigenous Health Theme Bank and the Australian Medical Association Report Cards on Indigenous Health.

Google Scholar, Google and CareSearch were also searched for grey literature, as was ATSIHealth.

Study selection

Returned publications were manually entered into Endnote (version X4) and electronically coded by a single researcher against inclusion criteria.

Data collection process

Data were extracted by one researcher using an investigator-developed electronic proforma.

4 Results

4.1 Overview of results

Overall, robust data, according to traditional metrics of assessment, such as systematic reviews, are not available.[28] However a number of descriptive studies provide some important insights.[29]

4.2 Answer to Question 1: Knowledge, attitudes and beliefs

Key findings

As in other Indigenous communities around the world cancer is not seen as a priority amongst Aboriginal people in Australia nor is it well understood.[30] Many see cancer as a western concept, and lack understanding and knowledge about its causes, available treatments and the outcomes.[2] In Australian Aboriginal communities there is generally a silence around cancer.[31] This may stem from the fact that for some Aboriginal communities there is no word for cancer and the concept of cancer is not seen in Aboriginal story telling.[32] Community members' unfamiliarity with different types of cancer, symptoms, risk factors, screening, treatments, and outcomes was described by one Aboriginal health professional who stated, "*a lot of Indigenous people...I suppose 70 to 80 per cent, wouldn't really know properly*".[33]

The rapid review identified that there is a considerable range of beliefs, thus indicating the importance of person-centred care when caring for Aboriginal people with cancer. There was an overarching theme of fear when discussing cancer.[32,34,35] This fear was described across all areas of the cancer journey from screening, diagnosis, treatment, management and palliative care; expressed by one Aboriginal person who described cancer as a "*scary word in the Aboriginal communities*".[22]

Unlike other areas of Aboriginal cancer research, there has been a significant amount of qualitative research done in understanding knowledge, attitudes and beliefs. Despite this heightened investigation, the evidence and recommendations have been slow to be incorporated into practice, but some emerging work is being undertaken.[36] It is important to recognise that in Australia, there is no single Aboriginal or Torres Strait Islander culture or group and that there are many diverse communities, language groups and kinships. A person's understanding is influenced by their own personal experiences and broader social, cultural and structural factors[34], therefore the following results may not be applicable to all Aboriginal communities.

The majority of research that was able to be accessed for this review has been conducted in the Northern Territory (NT) (n=10), Western Australia (WA) (n=6) and Queensland (n=5), with a focus on cancers that affect women such as breast and cervical (n=7). This is the case despite lung cancer being the biggest cancer killer, and that New South Wales (NSW) has more Aboriginal residents than any other State or Territory in Australia.[3,37]

Consistent with the review conducted by Newman and colleagues (2008), this review found no research which focused specifically on the knowledge, attitudes and beliefs of Aboriginal men.[38]

The rapid review identified that there are a range of views about cancer; a finding not surprising given the diversity of the Aboriginal population in Australia. When thinking about cancer, it appears that for many Aboriginal people there is a complex interplay between Western biomedical concepts and traditional values and understandings.[32] McGrath and colleagues 2006 found that participants in their study from rural areas had some basic knowledge around the biomedical notions of cancer.[32] Manderson and Hoban 2006 found that people from urban areas of Queensland were more likely to think of health in physical and biological terms, rather than in spiritual or cultural terms.[34] In a Queensland study, researchers interviewed Aboriginal women from urban, rural and remote areas and found that in general, there was a lack of understanding regarding the biological processes of breast cancer.[39] On a more positive note, researchers found that most women could describe at least one symptom of breast cancer, although results indicated that women under the age of 40 years were generally better informed on breast cancer symptoms.

Of those women who had found a lump, many chose not to seek professional advice in the hope that the lump would go away.[39] Similar results were found in a study conducted by Shahid and colleagues 2009, where respondents reported a slow reaction to recognition of cancer symptoms and delay in getting them checked, irrespective of geographical location. This finding indicates that even where women may be aware of the symptoms, delays still occur in accessing medical advice.[22]

Although not apparent in all Aboriginal communities, there is evidence that some Aboriginal people believe cancer to be contagious.[22,32] An AHW from a rural setting in WA stated, "*I've seen husbands wash their hands after touching their wives, or some people don't want to come too near the cancer patients because they fear they can catch the disease*".[31]p.283 Although not often explicitly stated, this belief is displayed through distancing behaviour.[22] This leads to the feeling of shame, isolation and ostracism. There are also misconceptions around cancer, which has led to a degree of stigma around the disease. For example there is a perception that cervical cancer is a 'dirty disease' because of the link with the human papilloma virus (HPV).[31] The associated stigma means that Aboriginal people are less likely to talk openly about their cancer.[31,40]

Causes of cancer

Many blame the impact and devastation of colonisation for cancer, arguing that "*cancer is a disease brought by the white man*".[41,42] A commonly held view was that traditional food and health care practices were degraded when Australia was colonised, making Aboriginal people increasingly vulnerable to many diseases including cancer.[31] One participant from a study conducted in the Northern Territory discussed the destruction of colonisation on Aboriginal communities, *"... I don't believe on that family because the cancer's everywhere. We never had before and soon as we got restaurant things, you know, like fat cooking and all that in the machine here and full of fat and all that things, you know ... Cigarette smoke and all sorts of drugs comes in into our body and like a flour, sugar, everything in, you know*".[32] Prior (2009) found that this view of 'white mans' destruction was particularly expressed by the older women.[31]

It was identified from the literature that Aboriginal people also believed cancer to be the result of lifestyle factors such as diet, stress, smoking, alcohol and lack of exercise.[39] Aboriginal women in Queensland described the causes of the cervical cancer being related to low socioeconomic status and inequalities, such as low employment levels, poor living conditions and low education levels.[43] Stress, in particular, was perceived by some Aboriginal people to be a cause of cancer.[43,44] This is significant given the pervasive and high levels of stress experienced by many Aboriginal people.[45]

Although many Aboriginal people may know about the general environmental and biological causes of cancer, traditional beliefs may remain strong.[31] The dilemma between traditional

beliefs and biomedical facts is shown in an elders statement, "*smoking, that will give you cancer, don't know, maybe bad spirits, when people get into trouble, get stressed up, they make bad things happen*".[31]

Those that have more traditional beliefs, believe that 'payback' plays a role in the aetiology of cancer.[43] This is the belief that the spiritual forces of 'bad spirits' or 'black magic' are aroused as 'payback' to inflict the victim as a form of punishment for a wrongdoing.[22,31,32] However, one study conducted in Queensland, found that this view was generally only held by those from more remote areas.[39]

The work of Prior 2009[31] and Shahid and colleagues 2009[22] both raised the issue of Christianity. A number (n=8) of participants interviewed by Shahid and colleagues 2009 believe that it was God's choice, and thus beyond the control of the individual.

Treatment

Many Aboriginal people believe treatment to be futile and doubt its efficacy.[39,41,46] This is likely due to factors including the perception of cancer as incurable[47], the lack of knowledge about the benefits of treatment, a cultural divide and the lack of communication and understanding between the patient and provider.[15,42] Those that had received treatment for cancer found the process to be disjointed and a disempowering experience.[39] The role of Aboriginal health professionals and Indigenous Liaison Officers (ILO) in navigating treatment options and decisions is of great use and importance to Aboriginal people. A study conducted by McMichael and colleagues 2000 found that women who had been assigned an ILO described their role and support as invaluable.[39]

A review conducted by van Schaik and Thompson 2012 identified that in relation to cancer treatment, overall Aboriginal people are concerned with toxicity, side-effects and potential disfigurement from treatment.[15] Confusion around the medical terminology, coupled with shock of diagnosis may impede understanding of treatment options. Although low levels of health literacy can challenge decision-making regarding treatment options[48], one woman from rural Queensland expressed her need for additional information, "*We just know about how to find lumps in the breast, not about surgery. They don't go into that. I'd like to find out now though, so I know what to expect*".[39]

A study undertaken in Queensland found that most of the women took the pragmatic view that surgery was a necessity for breast cancer, however some women were uncertain of the effectiveness of biomedical treatments, and were concerned with the effects of disfigurement.[39]

Aboriginal people may be afraid of or suspicious of treatment[49], and often feel that the treatment is culturally irrelevant[47] in that their traditional and cultural values were not taken into consideration.[42] It was identified that many Aboriginal people fear the hospital environment, as it can be sterile and alienating.[16,50] It is also a place that is often associated with death and dying.[51] Furthermore, the journey to hospital can be challenging, particularly for those from rural and remote areas; many feel scared and disorientated before they even arrive at the hospital.[17,50] Typical hospital practices, such as teaching sessions and ward rounds were reported to contribute to the increased level of discomfort.[17] A lack of knowledge and understanding of the use and effects of treatments is also likely to result in fear.[52]

Many described feeling vulnerable, powerless and exposed within the Western medical system, Women reported feeling embarrassed about declaring preferences for traditional approaches to treatment because they feared being judged negatively by hospital staff.[31] Women also experienced shame when presenting to hospital, often having to expose themselves and be subjected to cultural embarrassment. Although the gender of the examining professional was important, presence of a female health physician may not be enough. One Aboriginal woman

from WA referred to the embarrassment of letting another woman touch her breasts or private parts and described her concern of being labelled a "*lesbian".*[33]

Treatment adherence is likely to be affected by the hospital experience. Many Aboriginal people reported discrimination and a lack of respect by medical staff and racism within the system.[39,43,53,54] A study of 40 women in Queensland described a nearly universal distrust of doctors and of the medical institution.[43] Personal stories of bad experiences are often shared within the community, reducing the likelihood that Aboriginal people will seek medical attention or undergo treatment when symptoms arise.[35]

There is also a fear of judgement by health professionals about lifestyles and living conditions.[31] In contrast to this scepticism, Shahid and colleagues 2009 found that those interviewed had a high degree of faith in doctors, to the point that they have unrealistic belief that medical professionals could 'fix' their condition; at times referring to doctors as gods.[22] Expectations of being cured at the conclusion of treatment and that they could then get on with their life as normal demonstrated lack of understanding and inappropriate expectation.[22]

Despite knowing the benefit of receiving treatment, many women defer receiving treatment in order to meet their family and community responsibilities.[47] Attending treatment means being away from their family and community.[17,44,47] Aboriginal women see themselves as the emotional and operational centre of the family and tend to care for others before themselves. Being away from their family and not being able to perform their daily role is therefore distressing for themselves as well as their family.[39,43] Women, from rural and remote areas, stated that they would unlikely have reconstructive surgery as it meant spending time away from their family and children.[39] The timing of treatment must therefore take into account personal preferences and circumstances.

Treatments (such as chemotherapy) that may make the patient sick are also seen as undesirable as it limits their ability to perform in the community.[39] This is particularly the case where treatments have debilitating side effects and impede on a woman's ability to look after her children and family.[39] Quality of life and the capacity of Aboriginal people to perform social and domestic roles is seen as criteria for wellness[38], therefore when the treatment makes them sick they don't believe that it is beneficial. Quality of life is an important consideration for many. A woman from rural WA stated, "*I know a couple of people who chose the bush medicine once they read up about chemotherapy and the two per cent of people that chemo cured, they took their chances with the bush medicine, and they are still going. It's either the quality of life or being sick from the chemo, that's what they weighed up".*[44]

Women from Queensland reported fear of surgery in relation to breast cancer. Breast cancer surgery represented a degradation of both the spiritual and physical integrity of the woman's body, thus compromising her position in society and her status as a woman.[31,39] Many of the participants stated that if they were confronted with the treatment decision, they would refuse a mastectomy, as the breast was a vital part of their 'womaness' and could threaten relationships with their husbands or partners.[31] The importance and symbolic nature of the breast was described by a young Aboriginal woman from a rural area, who stated, "If you were young and you lost it you couldn't breast feed, so that is taking a part of your motherhood, a part of nature away from you, and that is a lot to deal with. Then again, your husband is going look at you stupid because you are only half a woman".[39] The issue of 'womaness' and 'womanhood' has also been linked to hair, therefore treatments such as chemotherapy are also feared.[53]

If one is to believe that cancer is the result of payback or it was God's choice, they may be less likely to undergo treatment.[35] In these cases, traditional medicine and Aboriginal healers were essential to the health care of the sick person, either with or instead of Western medicine.[42]

A cancer diagnosis for many may mean returning to cultural roots, "I said no to surgery. I don't want them cutting me inside, leaving me in a mess. I'm better off without that. So I came here to end my days back where my family live, and where my parents lived".[31] The 'mess' this participant referred to was a colostomy bag which she considered would damage the relationship with her husband as well as her self-image as a woman.[31] This belief demonstrates the importance of being a woman and having relationships. Families, the community and social networks play an important role in making decisions about treatment options.[31,34,55]

Healing is associated not just with the physical, but with the mental, emotional and spiritual domains of Aboriginal people. For this reason, some Aboriginal people use bush medicine to be connected to their traditional culture and spiritual values.[44] For others, the use of traditional medicine brought them peace of mind during their illness.[44] Although it should be noted that not all Aboriginal people have access to bush medicines or know how to get in contact with tradition healers, particularly Aboriginal people living in urban areas.[44] Bush medicine may also be used by some as a preventative measure to address stress and other factors believed to cause cancer.[44]

Outcomes

Cancer is seen amongst Aboriginal people as a deadly disease with poor outcomes[41]. For many, it is seen as a death sentence.[22,32,49,56] There are many examples in the literature of these fatalistic attitudes. "*When I hear the word (cancer) I feel fear. It is the big C you know, frightening, it means you're going to die." [31] "What can be done about it (cancer)? It can't be cured, can it? No one can stop it*".[31] This pessimistic view is not unique to Aboriginal Australians, with Indigenous people from other countries sharing these fatalistic beliefs.[30] Given the poor outcomes that are seen in Aboriginal communities, and the fact that there is poor visibility of survivors, it is not surprising that Aboriginal people have this view about cancer.[22] Prior 2009 reported a health worker stating, "*they think cancer means death because they only know people who have died from cancer*".[31] p.283

There are few stories of survivorship of Aboriginal people with cancer, and many Aboriginal people may have known someone in their community who was diagnosed with cancer and then rapidly declined.[47] In many cases, diagnosis only occurs at an advanced stage and then death follows quickly after.[42] Shahid and colleagues 2009 therefore recommended that Aboriginal cancer survivors be more visible and vocal about having had cancer treatment and surviving.[33]

There are no studies reported on Aboriginal peoples' knowledge, attitudes and beliefs of long term outcomes of cancer.

Despite significant advances being made in breast cancer outcomes for the non-Aboriginal population, the review identified that some Aboriginal women still hold the belief that breast cancer is incurable. One woman from rural Queensland stated, "*It is a killer to me. A lot of people say that they can treat it and get rid of it, but they can't. You always hear on the news that they have found a treatment for it, but I think cancer is one thing that they can't find treatment for*".[39] This has a significant impact on the likelihood of an Aboriginal woman attending screening, in that they assume the outcome of an abnormal test will be death.[39] Thurecht 2000 found similar results, with a participant stating, "*Why would I go to find out I am sick? They can't do anything for you anyway, these doctors. They speak another language and make you feel stupid, but they don't know themselves. They do all these tests but they don't know how to fix it up if you got cancer. If you are going to die, you'll die anyway*".[43] For some cancers these attitudes are also evident in health professionals, particularly for those cancers with high mortality rates. Experts who participated in a national consultation suggested that lung cancer is not always seen as a treatable health issue within the Aboriginal community and amongst primary healthcare professionals.[54] This fatalistic view hinders the likelihood of accessing early diagnosis and engaging in treatment.

Palliative care

A study conducted in the NT reported that there is little understanding of palliative care and hospice. This was the case for both Aboriginal people and health professionals who work in Aboriginal healthcare.[57] Those that had heard of palliative care generally experienced it through a community or family member's condition. In general, Aboriginal people prefer to receive palliative care and die at home.[51,55,58,59] This must be something that should be taken into serious consideration by palliative care services, as some Aboriginal people may refuse palliative treatment in fear that they will then not return home.[50]

Prior 2009 reported that whilst women in palliative care felt uncomfortable with the excessive attention of the multidisciplinary team, an AHW confirmed that it was uncharacteristic for Aboriginal women to attract attention to themselves.[31] This is particularly the case for women from rural and remote areas. The cultural distress can have implications on the likelihood of receiving palliative care and attending hospice.[57] For those in hospice or palliative care facilities, it is therefore desired that traditional practices such as 'singing' and 'wailing' be respected and, when requested, a smoking ceremony be conducted.[57] Areas where large family groups can congregate and mourn should also be provided. Bush medicine has been described as being used for palliation as well as treatment, often signifying a re-connection to land, and spiritual values.[22] Palliative care facilities must therefore take into consideration these specific cultural and traditional needs.

It is important to recognise that not all experiences reported in the literature were negative, with some Aboriginal people reflecting on the positive experiences of palliative care and home nursing services.[17,31,35] Participants from rural and remote areas of Western Australia valued the providers' friendly attitudes and caring natures [35]; thus suggesting that the nature of care is highly dependent on the individual provider.

Identified gaps in the literature

- There is very little focus on the knowledge, attitudes and beliefs of Aboriginal men
- There has also been little investigation into the differences between urban, rural and regional knowledge, values and attitudes. Although attempts have been made, it was reported to be difficult to map ideas and values based on geography and location.[22] This suggests that knowledge, attitude and beliefs are impacted upon by acculturation and education
- There are no studies that address the knowledge, attitudes and beliefs of Aboriginal cancer survivors.

Implications

- Education about risks, symptoms and treatments for cancer must be strategically disseminated to Aboriginal communities in a culturally appropriate manner
- Aboriginal Health Workers are in an ideal position to provide valuable and culturally appropriate information on the causes of cancer, the benefits of treatment and to educate the Aboriginal population on the fact that cancer is not a death sentence[33, 35]
- Health professionals should discuss with Aboriginal people undergoing cancer treatment the integration of traditional health care beliefs and healing practices in treatment options[44]
- Stories of survival need to be shared, as does information about patient journeys and experiences. This should be disseminated in a culturally appropriate manner, with information specifically targeted at Aboriginal people[33]

- There is a need for non-Aboriginal health professionals to undertake and engage in cross-cultural awareness, education and training to ensure that Aboriginal peoples' fears about treatment and health care facilities are reduced. This should include specific information on the range of beliefs and fears that Aboriginal people may have about cancer
- Research to explore the understanding and beliefs about cancer in Aboriginal men is necessary.[38]

4.3 Answer to Question 2: Perceptions and susceptibility

Key findings

The Health Beliefs Model argues that actions in relation to health issues have a major impact upon behaviours.[60] Therefore, perceptions of what cancer is and how it manifests, what causes it, whether it can be prevented or treated, and the value of screening programs will have a significant impact upon participation in various cancer control activities.

A study conducted by McGrath 2006 in the NT found that Aboriginal people perceived the incidence of cancer to be low among the Aboriginal population.[32] Similar results were found in relation to breast cancer, a review of the available literature identified that Aboriginal people do not have a good understanding of the risk of breast cancer.[61]

Similar results were identified for bowel cancer. A report prepared by Christou and Thompson 2010 for the Western Australian Bowel Cancer Screening Implementation Committee found that perceived susceptibility to bowel cancer was quite low, with only one third of their sample believing they were at risk of bowel cancer, despite the majority being over the age of 45 years.[56] Only 14% of the participants thought their risk of getting bowel cancer in the future was high or very high. When asked at what age a person should start getting tested for bowel cancer, only 19.6 % said over 50 years, while 35.9% thought people of all ages should get tested, 18.5% thought those under 50 years should be tested and 26% did not know.[56] When asked if they thought Aboriginal people had the same chance as non-Aboriginal people of getting bowel cancer, a third of participants said 'no' or were unsure. Overall, participants were aware of the fact that bowel cancer affected both men and women, and that smoking and being overweight were important risk factors.[56] While 72.8% agreed that bowel cancer risk increases with age, a large proportion (21.7%) were unsure.[56] Just over half (56.5%) of the participants believed that bowel cancer could be present without symptoms. Those who participated had higher knowledge scores, were significantly more likely to have a higher income, higher education levels and see a doctor more regularly, demonstrating socio-demographic variations associated with cancer knowledge and understanding.

For breast and cervical cancer, it was found that younger women think that cancer is a disease that will not affect them, and that it only affects older people.[39,42] In contrast, Manderson 2006 found that older people think they are too old to have pap smears.[34] The available literature therefore highlights that many people are unaware of their risk and susceptibility of cancer. There is also a lack of awareness of certain cancer symptoms such as weight loss, anorexia and bleeding.[22,56]

Not only does it appear that many Aboriginal people feel that cancer is a disease that won't affect them, it is likely that cancer is a disease that is not considered important to many Aboriginal people, as it may be overshadowed by an increased focus on other chronic conditions and diseases.[61] For many Aboriginal people, cancer (and health in general) may not be their priority given struggles with poverty, unemployment, poor housing, or violence.[62]

Some Aboriginal people believe that the risk of cancer is beyond their control. "*I don't think that it's something you can prevent, it's just people are chosen. ... you can go and have tests every six months, and one day you could just have it and it's been there the whole time...*" [22]

Aboriginal women are less likely to engage in preventative measures and are only likely to respond when symptoms manifest.[34] Suggesting that Aboriginal people may undervalue the role of screening programs. A review conducted in 2010 found that Aboriginal women have limited knowledge about the benefits of early detection of cancer.[46] There is also a great deal of ambivalence within the Aboriginal population on the benefits of participating in screening procedures.[22] However, when symptoms do present, advice might not be sought until symptoms are extreme or debilitating, possibly due to Aboriginal people in general having a higher pain threshold.[52]

Participating in screening procedures is closely related to the reluctance to spend time away from their family or community. McMichael and colleagues 2000 identified that preventative measures were low on the priority list of Aboriginal women, and illness and disease was only considered an issue when it affected their ability to perform as a mother, and women in the family and community.[39]

Some Aboriginal women believe that breast cancer screening procedures are only for those who have found a lump or for those who have a family history of cancer. While this is important as it highlights that there is an understanding of the importance of family history, it also highlights the perception that not every woman can be affected by breast cancer.[39] In relation to bowel cancer, Christou and Thompson 2010 found that only 55% of the participants identified having a close relative with bowel cancer as a risk factor.[56] While some may be aware of the risk of cancer, the underlying shame in undergoing many screening procedures such as a pap test or a colonoscopy is too overwhelming.[43,56] For many women, it is the embarrassment of having the test, but for others it is an underlying foundation of shame that they live with every day, which is the result of disempowerment and dispossession.[43] Also relevant is the pride in their body and the embarrassment that the screening test invokes.[43] Trust in the science, the institution and the provider were identified as an important factor in the likelihood of a woman having a pap smear.[43]

The process of self-examination is not recognised in Aboriginal culture.[49] When asked by a physician about the abnormalities under her arms and neck she responded, "*I asked what lumps, I hadn't even felt any lump".*[22] A study conducted in Queensland found that the Aboriginal participants lacked confidence in their self-examination technique and the ability to recognise symptoms.[39] It was also common that the women did not examine themselves regularly enough in order to recognise a change. Due to the busyness of their houses, women also said that they rarely had a private moment to examine themselves.[39,61] Women also reported feeling shame and embarrassment about performing breast self-examination.[61]

While shame and embarrassment around the procedure is often the cause for not participating in screening procedures, other reasons such as the 'fear of knowing' or the 'fear of having their breast squashed' have been cited.[22] McMichael 2000 also found that women prefer to not participate in screening programs because they prefer not to know the outcome.[39] However Christou and Thompson 2010 found that, in general, participants preferred to know if they had bowel cancer.[56]

Identified gaps in the literature

- There is very little focus on what Aboriginal men perceive to be their risk of or susceptibility to cancer

- The focus of the literature has been on women's cancer such as cervical and breast cancer, with minimal investigation into the perceptions and susceptibility of lung cancer

Implications

- Knowledge about risk factors and susceptibility has shown to increase with education[56], therefore a greater focus on education and health promotion needs to occur to educate Aboriginal people on their risk of cancer, and the impact of lifestyle habits such as smoking and diet on the likelihood of getting cancer. This would include the development of culturally relevant resources
- As in all areas of Aboriginal health, Aboriginal health workers are critical to improving the health and welfare of the Aboriginal population. Aboriginal health professionals should therefore be trained to provide cancer education sessions to the community. The education package should include information on symptoms and early warning signs, the importance of participating in screening programs and the importance of healthy lifestyle
- Create opportunities to utilise existing events (such as Adult Health Checks funded by the Medicare Benefits Schedule in general practice) to educate Aboriginal people on risk factors and susceptibility[63]

- Given the mortality rates for lung cancer within the Aboriginal population, further community-based participatory research must occur to investigate the perceived risks and susceptibility to lung cancer. Culturally appropriate smoking cessation programs should also be implemented in Aboriginal Medical Services (AMS) and mainstream health services.[54]

4.4 Answer to Question 3: Cancer prevention

Key findings

Intervention characteristics are described in Appendix C.

Only studies that described key elements of the programs or interventions and described community engagement processes were included in this review. Programs and interventions included those delivered locally and at higher population levels, predominantly multi-component, with short term changes in risk factors. Programs and interventions identified as effective in reducing risks associated with cancer predominantly centred around tobacco smoking and to a lesser extent human papillomavirus infection. There were few interventions targeting alcohol use, fruit and vegetable consumption, physical inactivity, overweight and obesity, and hepatitis B.

Tobacco

The following effective smoking cessation interventions were multi-component, individual or group format, involved AHWs, and were conducted in Aboriginal health or community venues.

A multi-component intervention incorporated provision of free nicotine replacement therapy (NRT) patches in an Aboriginal community health centre in the NT.[5] Participants self-selected into either a brief intervention only arm or a brief intervention and weekly dispensation of patches arm. After six months, six participants (15%) reported that they had quit smoking in the intervention arm and just one (1%) in the non-intervention group. The majority of the remaining participants (76% in intervention versus 51% non-intervention) reported cutting down their smoking.

DiGiacomo and colleagues reported a high intensity smoking cessation program at an urban Aboriginal Community Controlled Health Service (ACCHS).[64] The intervention consisted of an unlimited number of weekly cessation counselling sessions (with a non-indigenous health professional) and weekly dispensation of free nicotine replacement therapy patches following a cardiovascular screening and spirometry test administered by AHWs. Nicotine dependence, smoking behaviour, and contextual information regarding family, work, living situation, and health status was discussed. Of the 32 clients who made quit attempts, three were abstinent at six months (10%). The majority of clients reported stressful events as causing relapse, leading the authors to conclude that stress management strategies should be incorporated into smoking cessation interventions for Aboriginal Australians.

Mark and colleagues conducted quit smoking support and information groups (n=22) with 115 urban Aboriginal people.[65] Groups were held for 2 hours per week for 4 weeks. Participants had the option of receiving 3 weeks of free NRT and were encouraged to purchase a further five weeks. The intervention was AHW facilitated, used culturally-specific resources, had a men-only group option, provided transport, and featured discussions on issues related to quitting. The quit rate at program end was 14% and others reported having cut down. At the three-month follow-up, 6% reported abstinence. As a result of the groups, most participants were more confident to make another quit attempt.

Adams and colleagues conducted a group-format intervention based in a rural ACCHS facilitated by an AHW and community nurse.[66] The two half-day classes included group discussion on understanding smoking behaviour, preparing to quit, and the quitting experience. Participants received a QuitLine course booklet, behaviour modification items, the opportunity to register for telephone support, and access to subsidised NRT or bupropion as part of a general practitioner (GP) management plan. The short course spanned three weeks and ran several times a year depending on need. Over a two-year period, five courses were attended by 32 participants, six of whom quit smoking (19%).

Although cessation rates traditionally indicate effective interventions, other outcomes are important in establishing efficacy in Aboriginal populations. These interventions demonstrated acceptability programs to increase community engagement in smoking cessation. Given that multiple quit attempts are indicators of eventual cessation[67], providing support for these quit attempts is likely to improve cessation rates in the long term. Mark's intervention, in particular[65], described the positive feelings participants had towards another quit attempt, possibly highlighting the utility of higher intensity programs that can provide an extended period of support and discussion regarding quitting smoking. Higher intensity interventions and follow-up support have been shown to increase quit rates slightly.[68] Enabling access further supports the normalisation of quitting smoking as more individuals make quit attempts and diffuse the experience throughout the community. Efficacy may also be demonstrated by capacity built within the Indigenous health workforce[69] and the development and strengthening of relationships with non-Indigenous partners.

Predominantly, the reviewed studies employed multi-component interpersonal interventions utilising a form of counselling in combination with pharmacotherapy – an evidence-based method.[70] These were employed in conjunction with the following elements to promote acceptability and accessibility of interventions for Aboriginal people:

- Conducting interventions in culturally-safe community settings
- Community consultation in planning and implementing
- AHW-facilitated groups, recruitment, screening, and follow-up
- Culturally-tailored resources

- Collaborative and multidisciplinary teams
- Complementary workplace policies and management support
- Ongoing support and follow-up
- Free NRT
- Transportation provided
- Self- or health professional/AHW referral
- Flexibility in allowing multiple attempts
- Informal atmosphere
- Holistic focus
- Integrated with Medicare initiatives.

Various study designs, measurement intervals, cessation criteria, and multi-component programs precluded comparison of cessation rates and assessments of intervention effectiveness. The only pharmacological aides used in these interventions were NRT patches. Other pharmacotherapies such as varenicline, bupropion, and other forms of NRT or combinations of methods, have yet to appear in peer-reviewed literature describing outcomes for interventions in Aboriginal Australians. However one study by Richmond and colleagues showed promising results of bupropion in conjunction with NRT in a male prison population prisoners, 50% of whom were Aboriginal.[71]

None of the interventions in this review assessed efficacy of pharmacotherapy alone, but rather most were multi-component; an evidence-based strategy to improve cessation rates.[72] Despite the absence of comparison groups in most of these studies, results appeared to confirm previous evidence that the combination of counselling, particularly multiple sessions, and medication is more effective for smoking cessation than either medication or counselling alone.[72]

Several of the reviewed articles offered insights regarding issues that arose during program implementation. These insights can inform future design and delivery of interventions, thereby underscoring the utility of publishing evaluations in peer-reviewed forums. For instance, Mark and colleagues[65] noted difficulties in following-up participants and the need to plan ahead for this potential challenge. Mark and colleagues also highlighted the importance of addressing the combined use of marijuana with tobacco, as this can challenge quit attempts.[65]

Aboriginal health worker brief intervention training

As noted above, engagement of AHWs in smoking cessation interventions is an effective element to facilitate Aboriginal people's access to said interventions. *SmokeCheck* is culturally appropriate evidence based training package for AHWs and other health professionals who work with Aboriginal people.[73] This program provides training in delivering brief interventions to assist smokers to quit. As a result of the NSW *SmokeCheck* program, AHWs reported significant increases in confidence to deliver cessation advice. Pre- and post-evaluation of clients seen by *SmokeChe*ck-trained health workers indicated increased motivation to reduce quit and reduce daily smoking.

Tobacco control media campaigns

Mainstream anti-smoking mass media campaigns can positively influence Aboriginal Australians thoughts and behaviours regarding quitting smoking.[74,75] For example, evaluation of the *Bubblewrap* campaign indicated the majority of smokers spoke with family or friends about quitting as a result of this campaign and over 25% sought further information on quit attempts from their GPs.[74] Efficacy of media campaigns on Aboriginal Australians is limited, however Ivers' study 2005 on television advertisement in remote communities showed a good recall of key messages.[75]

An anti-smoking social marketing campaign (*Break the Chain*) targeting Aboriginal people(s) aged 16–40 years was implemented as complementary, yet separate to the National Partnership Agreement on Preventive Health Tobacco Social Marketing Campaign (NPAPH) in 2011.[76] The *Break the Chain* campaign was a 45-second TV commercial appeared on both mainstream and Indigenous television and supported by radio and print advertising featuring an Aboriginal woman talking about the negative impacts of smoking on the health of her relatives. Aboriginal and Torres Strait Islander People(s) were more likely than average to recall seeing *Break the Chain* (69%) (10% versus 3% for all smokers-unprompted) (69% vs. 55% general community-prompted). Reflecting the on air presence of *Break the Chain*, in July smokers from an Aboriginal and Torres Strait Islander background were more likely to intend quitting in the next month than were smokers in general (35% versus 19%); and versus 21% of Aboriginal and Torres Strait Islander smokers in March.[76] Interventions that include media, retail outlets, and schools have been described as increasing impact of community-based interventions.[77]

Alcohol use

One alcohol education program tailored for Aboriginal people was identified which aimed to minimise alcohol-use-related harm by teaching people how to drink sensibly and highlights the connection between drinking and committing crime.[78] The prison-based program was delivered in five 2-hour courses involving verbal and video presentations, small group discussions, and role plays in which prisoners act out the effect that their consumption of alcohol has on themselves and their victims.[78] Upon follow-up, intervention group participants reported more positive outcomes than non-intervention group participants in terms of health, drinking behaviour, personal dispositions, and relationships.

Nutrition and physical activity

No Aboriginal-specific interventions were identified in peer-reviewed literature that evaluated fruit and vegetable consumption or physical activity specific to cancer prevention, however, diet and physical activity intervention were evident in initiatives to reduce risks and burden of cardiovascular disease and diabetes.[79,80] The Looma Healthy Lifestyle Program is an example of a sustained community-directed initiative where the priorities of improving diet and exercise were set by a remote Aboriginal community in northwest Australia. This was a multi-component program that encouraged physical activity with regular hunting trips, sport (3/week), walking groups (3-4 hours/week), and informal education concerning diabetes with dietary advice on decreasing saturated fat and sugar intake and increasing fruit and vegetable intake. Following this initial phase, family groups enacting these activities began independently and the intervention was disseminated into the wider community where all were welcomed. Widespread uptake of these initiatives encouraged normative change and enablement and additional initiatives were enacted in both intervention and non-intervention groups. The one local community store had a management policy change and prioritised a healthier food supply. The intervention was measured by cross-sectional risk factor surveys at 2-year intervals measuring fasting cholesterol, body mass index, glucose tolerance, plasma insulin and smoking status. Nutrient intake was estimated from analysis of food turnover in the community store. Weekly body weight and glucose check were conducted if requested. Results indicated reduced prevalence of heart disease risk factors related to diet. The program was maintained following the evaluation with community members leading it. Ongoing commitment from AHWs and other community groups as well as prompt feedback to the community by the researchers contributed to community support and program longevity.

Human papillomavirus (HPV)

Australia has a 3-tiered HPV vaccination program that includes school, general practice, and community provider-based programs for women aged 13–26 years. The HPV Vaccine and Aboriginal Communities Project aimed to understand the attitudes of parents, GPs, and AHWs regarding the HPV vaccine. Important factors in this outcome were development of culturally appropriate educational materials, involvement of the target community in all stages of the

resource development, education of the community and implementation of the health intervention. Additional tailored HPV resources are being developed for Aboriginal communities.[81]

The Women with HPV in Indigenous and non-Indigenous, Urban and Rural populations Survey (WHINURS): The HPV Project, involved developing and testing participant information and consent materials and procedures for use in the recruitment of Aboriginal women in collaboration with a remote Aboriginal health service.[82] Appropriate resources developed included a flipchart, information brochures and consent form.[82] Despite these, challenges persisted in vaccinating 15–26 year olds in GP clinics, particularly in urban Aboriginal populations as opposed to rural/remote populations.[83] Key factors in improving vaccine uptake included knowing the community, making good use of medical software, and persisting in Indigenous identification. Success in engaging Aboriginal women in the HPV vaccine delivery program was reported as a result of a multi-pronged approach to vaccinating different age ranges, fully funded vaccine coverage, having community buy-in, staff who believe in the vaccine, and having the PIRS e-health tracking system whereby recall mail outs and targeted approaches could be used, in addition to patients presenting themselves. Another critical element has been the true collaboration with Aboriginal people and the education, mentoring and empowerment of Aboriginal women that occurred through the WHINURS project.[84]

Identified gaps in the literature

- In addition to the lack of trials of varenicline or bupropion in the Aboriginal population, there have been no evaluations of Aboriginal people's use of mainstream Quitlines, nor evaluations of effects that restrictions on tobacco advertising and packaging, taxation and pricing changes, smoke-free areas legislation or policy, or restricting sale of tobacco to minors have had on Aboriginal Australians
- Investigation of strategies for facilitating the uptake of HPV vaccination are warranted
- As the two major risk factors for primary hepatocellular carcinoma (liver cancer) are infection with the hepatitis B virus and excessive consumption of alcohol, integrative approaches to risk reduction are warranted
- Evaluation and analysis of cost-effectiveness of prevention interventions for Aboriginal people are needed, although this would require large trials

Implications

- Priorities for health promotion activities should be based on community-directed priorities and involve Aboriginal ways of working and knowing
- Addressing social determinants of health and providing safe and appropriate housing and sanitation is warranted
- Engaging Aboriginal Health Workers and community governance structures is critical
- Investigation using indigenous methods to obtain an understanding of better ways of approaching program delivery
- Culturally appropriate support and information tailored to specific communities and health literacy
- Aboriginal Health Worker/Aboriginal Worker engagement in program development, delivery and evaluation
- Multi-layered strategies using print, electronic media and community engagement, informed by principles of cultural competence and promoting health literacy should be considered

- There is likely to be efficiencies in creating clarity in messages across disease groups rather than multiple, disparate programs delivering similar messages.

4.5 Answer to Review question 4: Early detection of cancer

Key findings

A detailed review of all cancer-related literature in Aboriginal populations is reported in a recent Cancer Australia report.[11] According to the brief of the review, only studies describing key elements of the programs or interventions and specifying community engagement processes were included in this review. Programs and interventions included those delivered at the community or at higher population levels. A small number of programs and interventions were identified that have been effective in promoting the benefits of early detection of cancer through uptake of prevention and screening services for Aboriginal peoples. Key findings are summarised in Appendix D.

Multi-/single component clinical interventions – cervical screening

Three descriptive studies depicted interventions aiming to increase rates of cervical screening and were conducted at Aboriginal health facilities; two in remote areas of WA[85,86] and one in an urban area of North Queensland.[87] AHWs played key roles in each of these interventions, receiving training in conducting pap smears, recruiting and following up women, undertaking pap smears on participants. Two of the three studies utilised computer recall systems to facilitate recruitment or recall of participants for screening. One of these interventions also included outreach screening services to a more remote area. These interventions also highlighted the importance of incorporating a holistic approach and taking time to talk with the participants.

In order to facilitate privacy and confidentiality, one intervention was held in a designated room at the back of a health service with a lock on the door and curtains installed.[86] Each of these interventions used a range of methods for advertising the study to facilitate recruitment including posters, radio announcements, and one added the program to the audio recording played when patients are waiting for their call to be answered. In all cases, these interventions increased rates of cervical screening as compared to the pre-intervention rate. Increases in accessing high risk women and continued increase in uptake of screening in the months following the study were demonstrated. A total of 582 Aboriginal women, aged 15–69 years participated in these three intervention studies and had pap smears over periods of 4–21 months. The majority of participants were in the 20–39 year age group, although the next largest age group representation was 40–69 years. It was noted that computerised recall systems had significantly increased the sustainability of pap smear and other recall processes, particularly in remote settings with disadvantaged and mobile populations. The high turnover of health professionals in these areas underscores the importance of information management systems.

The multi-component nature of these interventions made it difficult to assess some aspects, such as whether opportunistic process or active screening activities were more effective in increasing screening rates. Additional elements that enhanced acceptability of interventions were AHW involvement and time spent in developing relationships with the women, strong female representation, a holistic focus, trusted health professionals at clinics, and provision of a private and confidential environment.

Service re-design

In a service re-design initiative using a community based participatory approach, a female Indigenous worker and female GP developed and implemented local plans aimed to improve

service coordination and access, GP knowledge, recall systems, and health promotion.[88,89] Various activities were implemented over 15 months in three pilot sites (urban, rural, and remote). Increased cervical screening was documented in one site and a trend toward increased breast and cervical screening in another. All sites reported an improvement in service communication and cooperation and links between GPs and ACCHS were strengthened. Pre and post evaluation in two sites showed a change in awareness and attitude. All sites had issues around recall and reminder systems. Two of the three sites engaged in health promotion activities and reported improvements in participation. Collaboration between service providers, community participation in planning and delivery, an indigenous health worker raising awareness in both the women and GPs, and a female GP providing a holistic service were key factors in the project's success.[88–90]

Another study reported use of health promotion and clinical training and education approaches to increase the cervical screening rates for Aboriginal women in a rural area of NSW.[91] This involved collaboration and consultation with local communities, developing a community education program, increasing skills of AMS staff, and providing a safe environment for cervical screening. This initiative was linked to a Women's Wellness Day, where resource bags containing health information and products were provided to attendees. Evaluation of attendance and screening data revealed an increase in pap smears in Aboriginal women from the community as well as several opportunities for capacity building in AHWs.

Support and education groups

Aboriginal women in the South Western Sydney area participated in education session and discussion regarding breast cancer and screening processes.[92] These groups were described as women's gatherings wherein Indigenous ways of knowing were paramount in the program design and implementation. The Aboriginal project officer established relationships with a range of communities. Women's understanding of screening and its benefit increased from 30% (pre-intervention) to 93% (post-intervention). Participants reported their fear of the screening process diminished as did their concern over cultural inappropriateness of screening facilities.[92]

The Healthy Women's Initiative (HWI) Project investigated several models of women's health services that encouraged participation in the cervical screening pathway within remote Aboriginal and Torres Strait Islander communities.[93] The project utilised a Talking Circle to engage women in the identification and development of key priorities and actions to improve their and their families' health. This project included education and health promoting information on cervical screening and sexual health services, and access to services upon diagnosis, treatment, and follow-up care and ongoing support. The impact of the project on screening was an 11.9% increase in Pap smears in the pilot communities during the life of the project.[93]

In-reach initiative

One initiative that facilitated Aboriginal women's screening for breast cancer involved a bus trip to BreastScreen NT and was facilitated through partnerships between health services and the local Wadeye Aboriginal community.[94] Tailored information resources and an AHW helped to recruit women for the trip (as part of Well Women's program). A nurse drove the group of Aboriginal women to Darwin for screening. The central location meant women could shop or visit family in hospital while awaiting screening. This initiative became an annual event and has served to increase understanding of the importance of screening and was perceived as a break from the women's usual responsibilities.

Community event

Another event involved the BreastScreen NSW mobile unit which was initiated by and situated in the La Perouse community in NSW.[95] Up to 300 women, many of whom were Aboriginal, undertook screenings during this 10-day event that centred on raising awareness and provided opportunistic interventions and information for men as well. Area Health Service health

professionals and AHWs worked together to provide health information and education and free walk-in health screenings. Well-known Aboriginal sportsmen were invited to talk to the men and a cultural activity was offered. This initiative addressed health of more than just one member of the family, signalling the utility of whole-of-family approaches. There was no evidence identified that specifically termed the approach of engaging community champions, however key community figures, ranging from AHWs to celebrities, were important to recruitment and engagement of community members in several initiatives.

BreastScreen SA 2010 has implemented various initiatives to tailor their services for Aboriginal and Torres Strait Islander women.[96] These included consultation and collaboration with government and Aboriginal organisations, liaising with Aboriginal services and communities state-wide, organising group bookings for screening and a funded community bus, advertising availability of this transport and disseminating other promotional resources, engaging with the Aboriginal community including through media, seminars and workshops, educating general practitioners, and permanently employing a full-time AHW to oversee and implement an education program. Rates of Aboriginal women's participation in screening have increased from 30% (1996) to 48% (2000).[96]

Resource

One study described the development, implementation and evaluation of a flipchart and education session designed to facilitate understanding and increase participation in bowel cancer screening in Aboriginal people as part of the National Bowel Screening Program.[56] An Aboriginal person implemented questionnaires, information on bowel cancer, risk factors, symptoms, screening and follow-up procedures. The flipchart was well liked by patients and helped to increase knowledge, but attitudes and intentions to screen did not appear to change. Greater risk perception was linked to intention to screen which supports implementation of health promotion workshops/sessions on screening. Although not evaluated, BreastScreen WA developed several Indigenous-specific resources with messages and logos that emphasised intergenerational bonds of women in an aim to encourage Aboriginal and Torres Strait Islander women to have regular breast X-rays. No other generational approaches to promoting screening were identified.

Identified gaps in the literature

- There is limited research that explicitly seeks to examine the impact of Indigenous-specific factors on screening and engagement[97]
- Limited dialogue and discussion of engaging mainstream models to be tailored and responsive to the needs of Aboriginal Australians
- Currently there is little integration of cancer screening with other chronic care services
- There is no consensus on early screening for liver cancer (e.g. regular measurement of serum α-fetoprotein levels and liver ultrasound examination) and chest X-Ray for lung cancer in general practice[63,98]
- No evidence of using generational approaches or community champions to promote screening was identified.

Implications

- Health care screening based on community-directed priorities should be prioritised
- Investigations should use indigenous research methods and approaches to obtain an understanding of better ways of approaching program delivery[99]
- Culturally appropriate support and information should be tailored to specific communities and health literacy[14]

- Aboriginal Health Worker/Aboriginal Worker engagement in program development, delivery and evaluation is important[100]
- Engagement of Aboriginal Health Workers is essential in engaging communities and developing trust[100]
- Indigenous ways of knowing and approaches to health care and holistic views of illness in developing programs that can address whole-of-family are necessary
- Multi-tiered recruitment and engagement strategies including opportunistic interventions, group and/or individuals formats are necessary
- Engage community members by taking the programs to communities[101]
- There is a greater need for interventions that promote accurate and individualised risk assessment approaches
- Gender specific approaches to programs (e.g. group bookings for screenings) are dependent on the local community and individual needs.[89]

4.6 Answer to question 5: Cancer services and treatment

Key findings

Both the published and grey literature suggests that the majority of efforts to date have been invested in prevention and screening initiatives.[2,9,38] With respect to treatment and care, perhaps because of the presentation and the severity of illness, most literature has focused on palliative care. However, improving outcomes demands an increased focus on earlier diagnosis and the treatment of cancer.

Cancer treatment means engaging with mainstream services. There have been a number of initiatives to increase collaboration between cancer and Aboriginal Health services (such as Calvary Mater Newcastle/Hunter New England Area Health Service and Greater Southern Area Health Service). Aboriginal peoples' experiences with cancer care are likely to be strongly influenced by a lack of trust and experience of systemic racism and adverse experiences with the public health care system.[18,102,103] To improve cancer outcomes for Aboriginal people, logistical, infrastructure and cultural safety issues must be addressed. One way of ensuring this could be by dedicated support to better coordinate cancer diagnostic and treatment services with primary healthcare services.[104] A challenge for this is the relatively small number of people needing support for cancer treatments at any one time. This therefore requires collaborative links that are flexible and responsive, such as pop-up models evaluated in palliative care.[105]

In maximising the participation of Aboriginal people in cancer treatment, it is important for health professionals to recognise that although Indigenous peoples share many cultural similarities, they should not make assumptions about the appropriateness of care. Culturally appropriate care will vary between individuals and groups. It is necessary to consider the differences between remote, rural and urban populations. This is particularly important in determining culturally appropriate approaches to care delivery, the role of family and AHWs, and preference for care by same sex health professionals.[106]

Undeniably, factors such as nihilism and fatalism are also powerful forces that predispose to not engaging in treatment.[22,33,44] Cultural differences, marginalised identities, racism and inappropriate understanding and care also limit engagement with mainstream services.[107–109] A review undertaken by van Schaik and Thompson 2012 suggests that Aboriginal peoples' beliefs about treatment efficacy for cancer involve five themes: (i) concerns about the toxicity of treatment; (ii) disconnect with the physician; (iii) fears about absence from home during treatment; (iv) different beliefs about disease aetiology; and (v) biomedical cancer treatments failing to address holistic health.[15] These findings provide a strong direction for reconfiguring care delivery. Implicit in these themes is the need to address patient, provider and health care system factors. In a study undertaken by Thompson and colleagues 2011 on hospital design to meet the needs of Aboriginal Australians, although the architectural considerations were important, issues of trust in health care professionals and the health care system were identified as the primary concern.[16]

Recurrent themes in the literature are that initiatives for Aboriginal people are likely to be most effective when planned and implemented in a community controlled setting. [110,111] This also means that mainstream health services should include Aboriginal people in their governance structures to promote culturally acceptable services. This should go beyond tokenistic representation on committees to active engagement of Indigenous people in health care planning and delivery. All service providers should have high quality, relevant cultural competence training.[107] Available data suggests the importance of outreach health services where possible and that appropriate transport and accommodation should be available when remote residents need to travel to metropolitan centres for care.[112-114] However, these needs are not restricted to remote Aboriginal Australians with even urban people likely to need

assistance with navigating the health care system, transport, childcare and home help in order to participate in treatment.

One program in Western Australia endeavoured to improve access and engagement with the health system. The Indigenous Women's Cancer Support Group allowed women with cancer and their carers to talk about their experiences and concerns and facilitated access to screening and treatment by having group members accompany women to appointments.[126] Group members provided instrumental support for each other by assisting them with shopping or cleaning once home from treatment. Meetings took place fortnightly and were informal small group sessions, with flexible content and provided an opportunity to ask questions to various invited health professionals, who could better get to know these women. The program was publicly advertised on radio, newspaper, and stalls at community events. After time, word spread to women in other areas who sought out this group, demonstrating its acceptability. Participants reported an increased sense of connectedness that lessened the women's feelings of isolation that resulted upon their cancer diagnosis. [126]

Available information emphasises the importance on interpersonal relationships, cultural sensitivity acknowledgement and respect for Aboriginal family structures, culture and life circumstances, and the acknowledgment of the importance of land and community. These factors are critical but difficult to achieve in the highly bureaucratic health care system. The mismatch between Aboriginal beliefs and cultural considerations and the approach of the Western biomedical focus are an important explanation of Aboriginal people's underuse of health services and lower adherence to evidence based cancer care strategies.

Cost is an important factor in influencing access to medicines and medication adherence rates.[115] Furthermore, for cancer treatments, some high-cost drugs are unsubsidised.[116] The costs of medicines and the challenges in getting to a pharmacy can lead to non-adherence.[115] Although the Pharmaceutical Benefits Scheme (PBS) Safety Net minimises the cost of medications for Australians, these mechanisms are not always accessed by Aboriginal people. A lack of awareness of schemes, high rates of unrecorded concession and Safety Net status, shame and embarrassment in accessing medications in culturally alienating settings and poor health literacy can contribute to poorer access.[115] It is also important to remember that Aboriginal people have extended social and family obligations which may mean that they are frequently mobile, further complicating access, storage and continuity of medications.[117] A diagnosis of cancer is often just another step in their cumulative disadvantage. Moreover, given the high comorbidity burden of Aboriginal people, they are frequently on multiple medications and already experience a high cost burden.

The Subsidising PBS Medicine Co-payments scheme has been designed to provide additional financial assistance to improve Indigenous people's access to PBS medicines.[115] This program has built on the QUMAX (Quality Use of Medicines for Aboriginal and Torres Strait Islander People) program designed to increase access to medicines.[117] Although not specifically targeting cancer, this model is important considering the higher costs associated with a cancer diagnosis. While to date there has been little formal publication of the outcomes of these recent changes, anecdotally they have improved the access of many Aboriginal people to subsidised medicines, although little information specific to cancer treatments is available.

To date there has been limited evaluation of survivorship in Aboriginal Australians. The costs of survivorship are also important to consider in the context of adjuvant therapy and ongoing monitoring.[118]

In an Australian qualitative study to identify barriers in cancer care coordination with a small Aboriginal sample, the following factors were identified: (i) recognising health professional roles and responsibilities; (ii) the 'falling through the cracks' during the transitioning of care; (iii)

inadequate communication between specialist and primary care; (iv) inequitable access to health services and (v) scarce resources.[119]

Ensuring treatment adherence and persistence is largely dependent on recognising that the individual is dealing with a chronic not an acute condition.[119–121] Although there is scant discussion in the literature of cancer as a chronic illness, particularly around long term care, a review of models for other diseases and in other settings may prove instructive for showing a way forward.[122,20,122] A recent program in SA has demonstrated that people involved in structured chronic condition management strategies improved the health and wellbeing of Aboriginal clients.[123] Some important insights into barriers and enablers of this approach have been identified that could readily be adapted to cancer care as shown in Table 1.

Cancer Australia, in partnership with all the states and territories, has developed the Cancer Service Networks National Program, (CanNET) to better link regional and metropolitan cancer services. CanNET aims to improve access to quality, clinically-effective cancer services throughout Australia via:[124,125]

- Active consumer engagement
- Agreed referral pathways
- Multidisciplinary care and primary care involvement
- Clinical leadership
- Continuing professional development
- Quality assurance
- Role redesign.

Table 1: Barriers and enablers to implementation of a chronic care program tailored to Aboriginal needs[123]

Health system/service	• Access to appropriate and affordable health services (transport assistance; mobile clinic locally available services; cultural safety; bulk billing) • Effective clinical information management system • Coordination and team care arrangements such as point-of care pathology testing and multiple appointments arranged for same day) • Facilitation of peer support
Staff-related	• Staff capacity and training • Engagement with Aboriginal community-controlled service; taking time to develop trust and rapport; promoting local services; holistic client focused approach • Encouragement and support for clients (support and advise clients but don't dictate; motivate clients to set achievable goals; clients set extent and pace of involvement in chronic disease management; be available and genuinely care).
Client related	• Client knowledge of conditions and their management (acceptance of chronic conditions; body awareness; desire and opportunity to learn more; information provided in appropriate forms) • Commitment to lifestyle change • Family and peer support

There are a number of studies investigating models of care for Aboriginal people. Although some palliative care models such as the *Living Model* and *Territory Palliative Care*[127–129] have been developed in Australia, these approaches emanate from rural and remote areas in Northern Australia. Although some elements of these models are relevant, it may be challenging to adapt these to regional and metropolitan communities in NSW. To date there has been limited evaluation palliative care approaches in NSW.[130]

Best practice recommendations highlight the importance of palliative care services undergoing a process of collaboration, consultation and liaison with communities.[131] Key elements of improved service delivery emphasise communication, consultation, decreasing barriers such as mistrust, transportation and increasing the cultural competence of staff.[132] Advanced care planning may need simplification of language and the use of trusted community members. Kinship and the extended family care network are important considerations.[57,59] When death is imminent, 'return to country' may be of importance, and a specific protocol to fulfill patients' wishes is needed.[50,59] Housing and access to social services are often important considerations.[133] Ensuring awareness of the wide range of additional benefits available are important (e.g. carer support, medication safety net).[117,134] Additional financial support may be needed to meet the costs associated with palliative care.[135] Medicare Locals involving the community controlled sector show promise for increasing engagement, structure and communication.

There is a need for cultural competence and recognition of racism in model of care development.[136] As well as changes to the physical structures of health care services, cultural change is of vital importance.[36] Involving AHWs and community leaders is critical in developing collaborative models.[137] Increasing numbers of empowered Aboriginal health personnel as valuable members of the health care team is important in increasing the acceptability of

services.[138] It is essential to involve the ACCHS in developing new and better models offering integrated care.[139,140]

The Program of Experience in the Palliative Approach (PEPA), funded by the Federal Government, aims to improve the quality, availability and access to palliative care for people who are dying, and their families, by improving the skills and expertise of health practitioners and enhancing collaboration between service providers.[141,142] This program offers: supervised clinical placements in specialist palliative care services (community and inpatient); integration of learning into practice; post-placement support; tailored workshops and a specifically focused Indigenous program. A review of this program was not accessible in the public domain.

Exploring telehealth and reducing the need for visits to urban centres is an important consideration. There is promising work being conducted North Queensland.[143] Aboriginal people often face issues around the continuity of care. This was reported in a Western Australian study where communication breakdowns were identified between local hospitals or clinics and the metropolitan treatment hospitals.[35] Sometimes appointments were made by the metropolitan hospital for treatment and follow-up with little understanding of where the person lived, and the cost and time involved with travel.[35] Thompson and colleagues 2011 suggest that involving the local doctor or clinic before making the appointment could help the patient with the necessary support to make follow-up appointments.[35] In particular bulk billing needs to be facilitated and negotiated for specialist appointments.

Identified gaps in the literature

- Little research that explicitly seeks to examine the impact of Indigenous-specific factors on health literacy[97]
- There has also been little investigation into the differences between urban, rural and regional knowledge, values and attitudes
- Effective means of communicating the need for completion of treatment to achieve maximal benefit [97,144]
- Evaluation of mainstream models that are tailored and responsive to the needs of Aboriginal Australians, such as breast cancer and lung cancer support models.[145,146]
- There are limited cross cultural studies of cancer survivorship[147]

- Important gaps in reporting for public hospitals include indicators of equity of access to services[148]
- Indigenous people and indicators of continuity of care.[149]

Implications

- Aboriginal Health Workers are in an ideal position to facilitate appointments and enable case management yet the increasing pressures on them and limited resources need to be considered[100]
- There is limited rigorous implementation of strategic interventions available generally (such as breast care nurses) in Aboriginal settings. Tailoring and targeting to communities is required
- Health professionals should discuss with Aboriginal people undergoing cancer treatment their wishes for the integration of traditional health care beliefs and healing practices into treatment options[15,150]

- Case management approaches such as the Navigator Model have provided assistance with increasing treatment uptake and completion in other underserved populations and need to be explored[151–153]
- Integration with chronic care services is needed given the likely high burden of comorbidity[9,154]
- Particular attention should be given to the different needs and experiences of Aboriginal people in urban or rural/remote areas[38]
- Engagement of a range of health care providers particularly community pharmacists and recognition of cost as a barrier to treatment[115,117,155]
- Case conferencing (either by video or telephone) between cancer specialists, doctors, Aboriginal Health Workers and other primary care providers would be useful for enhanced coordination of an individual's treatment, management and care.[35]

The refinement of measures of access (how Aboriginal people can obtain services and their appropriateness (i.e. how well services meet clients' needs) is needed. Efforts to identify the extent of any Performance Indicators should consider equity, efficiency and effectiveness and should be aligned with National Indigenous Reform Agreement.[156] Garvey and colleagues suggest the need for improving basic data infrastructure and monitoring capability to measure progress and improve cancer care delivery.[157]

5 Conclusions

Despite the need for improvements in data quality and availability, the burden of cancer in Aboriginal Australians is profound. The patterns of incidence and mortality are largely explained by the higher prevalence of risk factors and entrenched health and social disparities. As a priority there is a need to address tobacco smoking to ensure that effective programming involves addressing the social and cultural role of smoking in Aboriginal people. Although this is part of a broader national strategy, elements of tobacco control interventions need to pervade all health interactions. The later diagnosis of cancer in Aboriginal people compared with non-Aboriginal people, and the differences in treatment outcomes after adjustment for cancer stage at diagnosis underscore the structural inequalities that currently exist within the Australian health care system. As mentioned above, there are limited intervention studies in cancer. In spite of this there is clear documentation of the barriers and enabling solutions. Collaboration between mainstream health and social services and Aboriginal organisations; cross-discipline and cross-jurisdiction are required to develop innovative and collaborative solutions. Emerging literature to address health disparities underscores the importance of a life course approach. Addressing preventive strategies early in school is likely to leverage some benefit.

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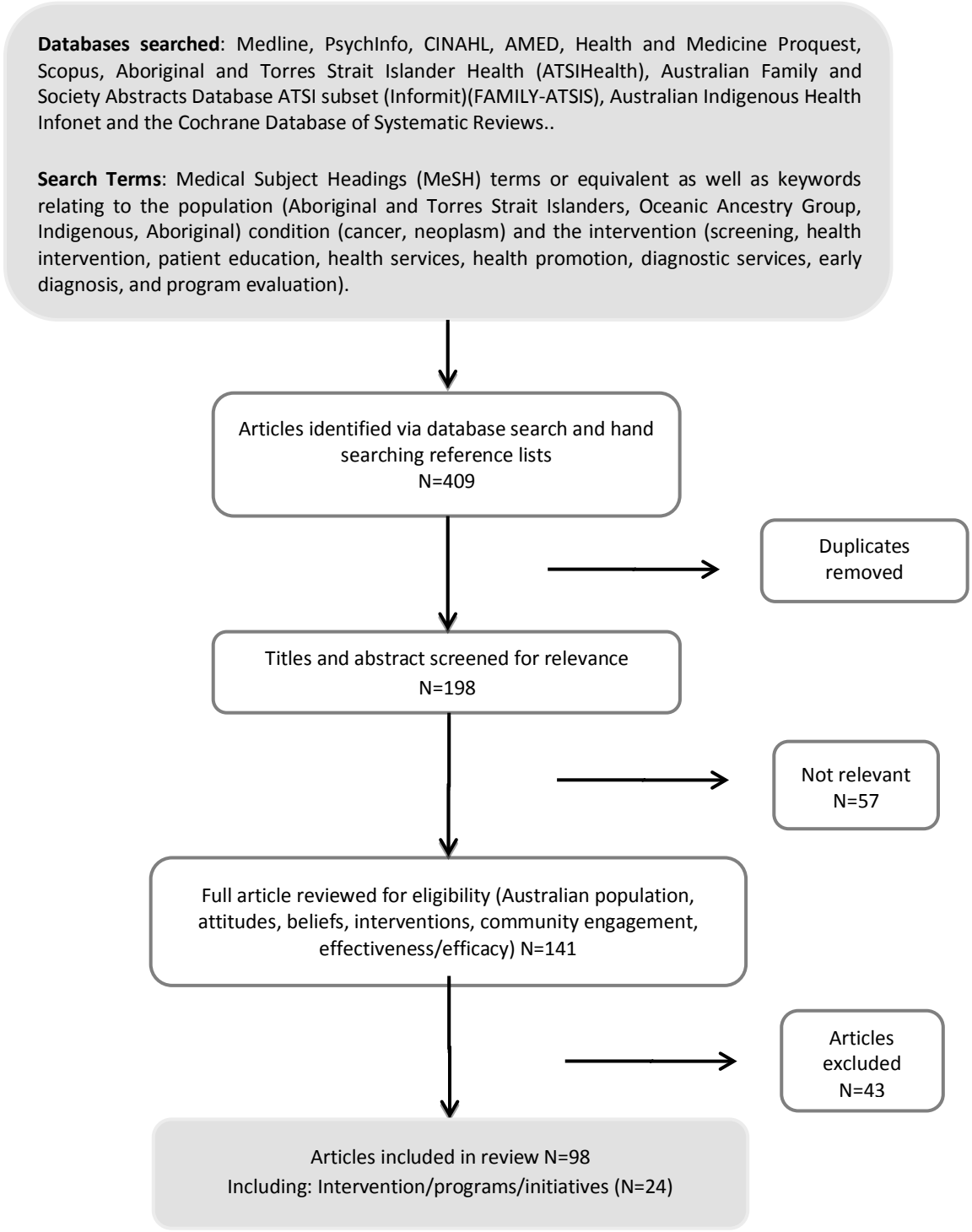
7 Appendices

Appendix A: Search strategy

FLOWCHART OF LITERATURE SEARCH



Appendix B: Search terms

1. Medline search terms

Oceanic Ancestry group or Indigenous or aborigin*
Cancer or Neoplasms
Health Services or health intervention or health promotion or patient education

2. MeSH headings

Access to Information
Attitude
Breast self-examination
Cultural characteristic
Culture
Death
Diagnostic Self Evaluation
Diagnostic Services
Diagnostic Techniques and Procedures
Diet, reduction
Early Detection of Cancer
Early diagnosis
Ethnology
Etiology
Exercise
exp advance care planning/
exp attitude to death/
Fear
Harm reduction
Health Care Quality, Access, and Evaluation
Health Services, Accessibility
Health Services, Indigenous
Hospices
Incidence
Internal-External Control
Knowledge
Motor activity
Neoplasm
Palliative Care
Perception
prevention & control
Program Evaluation
Risk
Risk Factors
Risk Reduction Behaviour
Self-examination
Signs and Symptoms
Social Stigma
Survival
Survival rate
Terminal Care
T+erminally ill/
Therapeutics
Treatment Outcome
Vaginal Smears
Weight Loss

3. CINAHL

Several of the terms in CINAHL are the same as those in Medline but there are some differences. Major headings were used as well as keywords.

(MH "Patient Education") OR patient education
(MH "Nursing Interventions") OR health intervention
(MH "Health Promotion") OR health promotion
(MH "Aborigines") OR (MH "Indigenous Peoples") OR aborigin* australian aborigin*
(MH "Health Services, Indigenous") OR (MH "Indigenous Peoples") OR indigenous
attitudes or knowledge or beliefs
(MH "Tobacco") OR tobacco
smoker*
(MH "Smoking") OR smoking OR (MH "Smoking Cessation Programs") OR (MH "Smoking Cessation")

4. Informit

Selected both the Health and Indigenous subsets and searched for:
indigenous or aborigin*
cancer or neoplasm
patient education or health promotion or health intervention
risk factors
attitudes or knowledge or beliefs

5. Other keywords

Holistic Health
Attitude to health
Caregiver
Carer
Cultural competency
Delivery of health care
Health knowledge attitudes, practice
Medically underserved
Neoplastic syndromes
Patient acceptance of health care
Professional-patient relations
Rural health
Spirituality
Socioeconomic factorsx
Social support
Prejudice
Racism
Morbidity

Appendix C: Cancer prevention activities and programs

First author (Year)	Title	Peer-review (PR) /Grey	Intervention type	Intervention details	Setting/ geographic location	Sample characteristics	Evaluation design/methods	Outcomes	Key factors	Quality of evi-dence
TOBACCO										
Ivers (2003)	A study of the use of free nicotine patches by Indigenous people	PR	Multi-component Brief intervention	5-minute brief intervention using flip-chart; readiness to quit; 10 weeks supply of NRT patches given 1/week	Health service; NT	111 (60 male; 51 female); 56 <30 years, 65 older than 30; 40 in NRT group, 71 in BI only group	6 month follow-up questionnaire to assess number of patches used; changes in smoking behaviour; and attitudes to tobacco use, side effects and barriers to using nicotine patches	Six (15%) quit in patches group (CO valid 10%), 1 (1%) quit in BI group; 76% in patches reported cut-down vs 51% BI group; Main barriers presence of people smoking around them; no participants completed full course of patches	AHW involvement; free patches	IV
Adams (2006)	Evaluation of Rumbalara's 'No More Dhonga' short course in giving up smokes	PR	Multi component Short course	2 half-day classes in 3 weeks w/group discussion run by trained Quit Facilitators; NRT or Zyban; Quitline support (optional); and Quitline course booklet; GP appt; follow-up phone call by facilitator	ACCHS; (rural) Victoria	Clients of Rumbalara Aboriginal Health Service; Victorian Koori population; 32 participants; 19 were ACCHS staff	Pre- and post-study of smoking abstinence 2 years after course started; no follow-up described	5 courses ran over 2 years; 6 (19%) quit, 2 of which are AHWs; likely increased quit attempts, skills and knowledge in the local Koori community	AHW facilitators; ACCHS-based	IV

First author (Year)	Title	Peer-review (PR) /Grey	Intervention type	Intervention details	Setting/ geographic location	Sample characteristics	Evaluation design/methods	Outcomes	Key factors	Quality of evi-dence
TOBACCO										
Ivers (2006)	Evaluation of a multi-component community tobacco intervention in three remote Australian Aboriginal communities	PR	Multi-component community	Various initiatives: sports sponsorship, health promotion campaigns, training health professionals in the delivery of smoking cessation advice, school education about tobacco, and policy on smoke-free public places	6 Aboriginal communities (remote) NT	920 in intervention community	Surveys measured changes in prevalence of tobacco use, changes in knowledge, and attitudes to cessation	Tobacco consumption decreased in one intervention community compared with the matched control community; no significant change in the prevalence of tobacco use, although knowledge of the health effects of tobacco and readiness to quit increased	Aboriginal project officers, community-developed interventions	IV
DiGiacomo (2007)	Stressful life events, resources, and access: key considerations in quitting smoking at an Aboriginal Medical Service	PR	Individual face-to-face counselling	Unlimited weekly sessions (1/week); free NRT patches; CVD screening	ACCHS; urban NSW	32 Aboriginal clients of ACCHS	Continued abstinence at 6 months via self-report	10% remained smoke-free for 6 months; pervasive and enduring stress identified as important consideration in smoking cessation interventions for Aboriginal peoples	AHW involvement; ACCHS-based; free patches; flexible, ongoing support	IV

First author (Year)	Title	Peer-review (PR) /Grey	Intervention type	Intervention details	Setting/ geographic location	Sample characteristics	Evaluation design/methods	Outcomes	Key factors	Quality of evi-dence
TOBACCO										
Mark (2004)	The Koori Tobacco Cessation Project	PR	Group	4–6 sessions (1/week); 3-month telephone follow-up; 2 weeks free patches	Community venue; suburban NSW	115 completed pre-course survey/36 completed post-course/15 completed 3 month survey	Self-report cessation at course end; Abstinence at 3 months	44% (16 of 36 post-course survey completers) not smoking; 6% (15 of 115 pre-course survey completers) abstinent at 3 months	AHW involvement; free NRT patches	IV
Boyle (2010)	Awarenesss and impact of Bubblewrap campaign	PR	Media campaign	30-second TV ad broadcast on metropolitan, non-metropolitan and Indigenous stations in Western Australia	Urban and remote WA	Evaluation targeted Aboriginal people in WA; 198 Aboriginal adults	Survey via face-to-face interview	The majority of participants (59%) said that, as a result of the advertising, they had talked to family and friends about quitting, and 26.5% got more information about quitting from their doctor or health worker as a result of the advertising	Relevant and memorable message; TV-based; widespread	IV
Ivers (2005)	Television and delivery of health promotion programs to remote Aboriginal communities	PR	Media campaign	Part of The Tobacco Project - health promotion program	3 Remote Aboriginal communities NT	351 participated in pre- & post-community surveys; 91% Aboriginal; 50% were male and 15% were aged < 18 years, 46% aged 18–34 years; 39% aged >35 years	Community survey to identify any changes in smoking behaviour and exposure to anti-tobacco interventions (including television campaigns over intervention year)	Exposure was high among both smokers and non-smokers (86% vs. 85%); exposure to individual tobacco interventions was not associated with an increased chance of cessation during the intervention year	Aboriginal project officers, community-developed interventions	IV

First author (Year)	Title	Peer-review (PR) /Grey	Intervention type	Intervention details	Setting/ geographic location	Sample characteristics	Evaluation design/methods	Outcomes	Key factors	Quality of evi-dence
TOBACCO										
Myers (2011)	Break The Chain	Grey	Media campaign	45-second commercial featuring Aboriginal woman describing health of family	Australia-wide	Targeting Aboriginal Australians	Computer Assisted Telephone Interviews	69% of Aboriginal people recalled ad; 10% unprompted	Tailored for Aboriginal people; Aboriginal representation	IV
Qld Health (2007)	SmokeCheck Evaluation Report 2006	Grey	Health worker training	Training in brief intervention of health workers working with Aboriginal people	Queensland	761 health workers at over 40 sites across Queensland	Treatment versus control, pre/post	The pre- and post-training evaluation revealed statistically significant outcomes for Health Workers; clients receiving the SmokeCheck advice compared with those not receiving it reported statistically significant reductions in daily cigarette intake	Tailored for Aboriginal Health Workers; widespread delivery; developed with community	III-3

First author (Year)	Title	Peer-review (PR) /Grey	Intervention type	Intervention details	Setting/ geographic location	Sample characteristics	Evaluation design/methods	Outcomes	Key factors	Quality of evi-dence
TOBACCO										
NSW Health/ Cancer Institute NSW/ USyd (2008)	Smokecheck Final report (Phase 1)	Grey	Health worker training	Training in brief intervention of health workers working with Aboriginal people	NSW	519 people were trained in 63 workshops, including 35 per cent (n=199) of the NSW AHWs workforce. Forty eight per cent (n=250) of the participants identified themselves as Aboriginal	Process measures and a quasi-experimental design to assess the extent to which the training program met its intended objectives and its impact	Statistically significant knowledge, skills and confidence increase; perceived it is easier to offer this advice after participating in a SmokeCheck training workshop increased by 25 per cent (from 33% to 58%) (p=0.039); number of AHWs who live in smoke free homes increased by 11 per cent (84% to 95%) (p=0.045)	Tailored for AHWs; widespread delivery; developed with community	IV
ALCOHOL										
Crundall (1997)	A prison-based alcohol use education program	PR	Education program	Pilot education program (adapted version of Ending Offending course); aims to minimise alcohol-use-related harm by teaching people how to drink sensibly; delivered via structured course	Two prisons in the NT	45 male prisoners in intervention group (87% Aboriginal; mean age 27.7 yrs); 13 in non-intervention group (100% Aboriginal; mean age 32.5 yrs)	Two questionnaires assessed intervention and non-intervention prisoners and key informant perceptions regarding impact on alcohol consumption, disruptive behaviour, criminal activity, family relationships, time use, general health, coping	Intervention group reported more positive outcomes for all nine dimensions. After prison release, non-intervention group was drinking more, spending less time meaningfully occupied, and had worse general health	Aboriginal men involved in tailoring interventions and follow-up	IV

First author (Year)	Title	Peer-review (PR) /Grey	Intervention type	Intervention details	Setting/ geographic location	Sample characteristics	Evaluation design/methods	Outcomes	Key factors	Quality of evi-dence
HPV SCREEN										
Condon (2005)	Women with Human Papillomavirus in Indigenous and non-Indigenous, Urban and Rural populations Survey (WHINURS)	Grey	Resource development and testing	Pilot study to develop and test participant information and consent materials and procedures for use in the recruitment of Indigenous women	Two remote communities in NT	Aboriginal health clinic staff and the Steering Committee members contributed to resource development	Not provided	Development of resources to facilitate recruitment to screening including a flipchart, information brochures and consent forms; raised profile of cervical cancer and HPV among women and health providers	Aboriginal women involved in development of culturally appropriate educational materials	IV
Heffernan (2008)	The HPV Vaccine and Aboriginal Communities Project 192: Investigating cross-cultural responses to the introduction of the HPV vaccine	Grey	Resource development and testing	This project sought to understand the attitudes of parents, General Practitioners, and AHWs regarding the HPV vaccine	Two Aboriginal regions in Victoria and Central Australia	Anglo, Chinese, and Aboriginal participants; including two Aboriginal regions	Project commenced in late 2004. Data collection and analysis was completed in 2007 with final report due mid-2008	Development of resources in several languages common to this region; high levels of vaccine uptake and empowered health professionals, particularly AHWs	AHW involvement; development of culturally appropriate educational materials; Community involvement at all stages	IV

First author (Year)	Title	Peer-review (PR) /Grey	Intervention type	Intervention details	Setting/ geographic location	Sample characteristics	Evaluation design/methods	Outcomes	Key factors	Quality of evi-dence
HEALTHY LIFESTYLE										
Rowley (2000, 2001)	Looma Health Lifestyle program; Effectiveness of a community-directed 'healthy lifestyle' program in a remote Australian Aboriginal community	PR	Multi-component community	Walking groups, hunting trips, sport, informal diabetes education; encouraged normative change and enablement; additional initiatives were enacted in both groups; diet advice, store management policy changes	Looma Aboriginal community northwest Australia (remote)	Aboriginal men and women community members; 200 at baseline, 185 at two-year and 132 at four-year follow-up	Three cross-sectional community-based surveys of adults every two years measuring fasting cholesterol, body mass index, glucose tolerance, plasma insulin and triglyceride concentrations, smoking; nutrient intake based on food turnover in single community store; weekly body weight and glucose check, if requested	Significant reductions in fasting insulin, no change to overweight or diabetes; improvements in dietary intake and level of physical activity; significant reduction in hypercholesterolemia; no significant change in smoking status; increase in the density of fresh fruit and vegetables and carotenoids in the food supply at the community store	Community directed intervention; ongoing commitment from AHWs and other community groups, analysis and feedback to the community prompt	IV

Appendix D: Programs and interventions for early detection

First author (Year)	Title	Peer-review /grey	Target behaviour	Intervention type and details	Evaluation design/ methods	Setting/ geographic location	Population and sample character-istics	Outcomes	Key Factors	Quality of Evi-dence
Gilles (1995)	A community-based cervical screening program in a remote Aboriginal community in the Northern Territory	PR	Cervical screening	*Multi-component cervical screening program* – education, cervical smears, BSE, advice on contraception, investigation of infertility and active contact tracing, treatment and surveillance of STDs; holistic approach; culturally appropriate environment and posters; focus on health rather than STI and sickness; separate secure room at clinic; mean contact 1 hour; 16 months	Descriptive; # screenings pre-post	Aboriginal community women's health service/ Aboriginal reserve, NT (remote)	316 Aboriginal women; aged 40–69 yrs (n=96); aged 15–39 yrs (n=218)	Screening rate increased from 51% to 78%; high acceptance, only 2% refusing; over 70% smears were done by the nursing staff in clinic	AHW involvement and time spent in developing relationships with the women, strong female representation, trusted health professionals at clinics, and provision of a private and confidential environment	IV
Panaretto (2006)	Cervical smear participation and prevalence of sexually transmitted infections in women attending a community-controlled Indigenous health service in north Queensland	PR	Cervical screening	*Community based health promotion program (Well Women's Program)* – questionnaire, STI screen, pap smear, AHW with specialised training (pap testing), advertised on posters, 'on hold' message in clinic, local indigenous radio health segments; Pap register was cleaned in computer patient management system, monthly recalls sent; prospective data collection over 21 months	Descriptive; # screenings pre-post	ACCHS/ Townsville, Queensland (urban)	145 Aboriginal and Torres Strait Islander women aged 20–69 yrs; 30% of whom were aged 40–69 yrs	Pap smear participation among eligible women at TAIHS increased from 20.9% pre TV project to 28.6% during the project and 35.6% in the 12 months post completion of the TV project ($p<0.0001$), an increase of 70.3%	AHW involvement; holistic focus	IV

First author (Year)	Title	Peer-review /grey	Target behaviour	Intervention type and details	Evaluation design/ methods	Setting/ geographic location	Population and sample character-istics	Outcomes	Key Factors	Quality of Evi-dence
Couzos (1998)	Augmentation of Pap smear screening of high risk Aboriginal women: use of a computerised process tool within the Broome Aboriginal Medical Service	PR	Cervical screening	*AHW clinics and computerised recall system* – 4 hour/week AHW-run pap smear; outstation remote screening; reminder letters and active recall by AHWs through computer-generated work lists; Health planner software to augment opportunistic pap screening; 4 months	Mixed method	AMS/ Broome region, WA	121 Aboriginal women aged 20–69 yrs	78% increase in pap smear screening during intervention period; significant increase in smears from older and remote women; in 4 months, 21–30% of Aboriginal women eligible for Pap smears in these high risk categories including those with abnormal smear were screened; Smears taken by AHW staff were of high quality	AHW involvement	IV
Merrison (2011)	Persistence pays off – healthy lives more than just a dream to La Perouse!	PR (non-research)	Breast screening	*Mobile breast screen clinic* – Community member driven; local Aboriginal organisation support; opportunistic men's group while women being screened; partnerships and collaboration with area health service to undertake screenings; healthy lunch provided; 10 days	Descriptive	Mobile breast screen van/Sydney, NSW	Up to 300 Aboriginal women from La Perouse	South Eastern Sydney Division of General Practice and Sutherland Division of General Practice collaborated to bring in a range of health professionals both from private practice and from within the local hospital network to offer health info & education; while the local women visited the BreastScreen	Community member driven; integrated with other health initiatives including men's health	IV

First author (Year)	Title	Peer-review /grey	Target behaviour	Intervention type and details	Evaluation design/ methods	Setting/ geographic location	Population and sample character-istics	Outcomes	Key Factors	Quality of Evi-dence
								NSW mobile van, the men took some time to sit down and yarn up about men's health issues (informal session on diabetes, CVD and cancers e.g. prostate and testicular)		
Latham (2010)	Wadeye women visit BreastScreen NT	PR (non-research)	Breast screening	*Organised trip for breast screening* – organised bus trips for mammograms is Darwin; use of a culturally appropriate pamphlet; 1 day trip	Descriptive	Darwin region, NT	19 Aboriginal women	19 women had breast screen for each of two years program has been running	Culturally-appropriate resources; transport provided	IV
Christou (2010)	How could the National Bowel Cancer Screening Program for Aboriginal people in Western Australia be improved?	Grey	Bowel screening	*National Bowel Screening Program* – WA Aboriginal Bowel Cancer Flipchart and education session; Aboriginal person implemented questionnaires, info on bowel, risk factors, symptoms, screening and follow-up procedures	Pre-/post-questionnaire; focus groups	AMS and NTP; /Geraldton, Kalgoorlie, Perth, WA	Flipchart recipients included WA health service providers; participants in the educational intervention were Aboriginal men and women community members and health workers	Increased knowledge, but no change to attitudes and intentions to screen; perceived susceptibility to bowel cancer was quite low from the baseline surveys; a relationship existed between greater knowledge on bowel cancer and intention to take up bowel cancer screening	Aboriginal person involved in study implementation; tailored resources	IV

First author (Year)	Title	Peer-review /grey	Target behaviour	Intervention type and details	Evaluation design/ methods	Setting/ geographic location	Population and sample character-istics	Outcomes	Key Factors	Quality of Evi-dence
Reath (1998); Reath (2008)	Improving cervical screening in a remote Aboriginal community; Breast and cervical cancer in Indigenous women: overcoming barriers to early detection	PR	Breast and cervical screening	*Community based participatory cervical screening intervention* – in three sites a female indigenous worker and female GP developed and implemented local plans aimed to improve service coordination and access, GP knowledge, recall systems, and health promotion; AHW; locally appropriate health resources; appropriate settings; awareness raising awareness amongst local Indigenous women of the need for breast and cervical screening; 15 months	Community participation model – mixed methods; interviews, consultations, community forum, literature review; analysis of qualitative and quantitative data; pre-/post	AMS; 3 pilot sites; rural, urban and regional had partnership between local DivGP and ACCHS/ Anangu Pitjantjatjara Lands, SA (remote north west)	Aboriginal women/ services (12 female AHWs)/GPs	Increased cervical screening was documented in one site and a trend toward increased breast and cervical screening in another. Outcomes varied between sites, all sited reported an improvement in service communication and co-operation, links between GPs and ACCHS were strengthened; two sites showed a change in awareness and attitude; engaged in health promotion activities and reported improvements in participation. All sites had issues around recall and reminder systems	Collaboration between service providers, community participation in planning and delivery, an indigenous health worker raising awareness in both the women and GPs, and a female GP providing a holistic service	IV

First author (Year)	Title	Peer-review /grey	Target behaviour	Intervention type and details	Evaluation design/ methods	Setting/ geographic location	Population and sample character-istics	Outcomes	Key Factors	Quality of Evi-dence
AFP/Coonamble AMS	Coonamble Project	Grey	Cervical screening	*Health promotion and clinical training and education program* – involved designing and implementing a community education program on importance of regular Pap tests; increase skills of AMS staff, and provide an environment in which Aboriginal women were comfortable to undergo cervical screening; Women's Wellness Day resource bag provided to women attending; 7 months	Descriptive evaluation; pre- and post-training questionnaires, interviews	AMS, rural/Coonamble, NSW	Aboriginal women in Coonamble	Began to build partnership with new AMS, increased Pap smear rates amongst the Aboriginal women of Coonamble (2%), health promotion training for AHWs, community awareness events and activities, media advertising campaign	Partnership approach with AMS in design and imple-mentation of project	IV
Costley (2008)	Aboriginal Women's Breast Screening Project	Grey	Breast screening	Women's gatherings/yarning; Training and discussions on breast cancer and breast cancer screening; 5 months.	Focus groups and questionnaires	South-western Sydney (urban)	66 women pre-intervention; 23 women participated in post-intervention focus group evaluations; aged 37–72 yrs	Aboriginal project officer established relationships with a range of communities; increased understanding of screening and benefit (from 30% to 93%); screening concern decreased including fear of machines and cultural inappropriateness of facilities	Culturally appropriate support and information were important to the women; AHW-coordinated; methods relevant to indigenous ways of knowing	IV

Appendix E: Cancer control programs and activities1

Aboriginal and Torres Strait Islander cancer control programs and activities

Organisation	Title	Major topic/issue	Cancer specific	Key area of cancer journey	Target
NATIONAL					
AIHW & Department of Health and Ageing	Indigenous pilot programs for the national bowel cancer screening program	bowel cancer screening	✓	prevention; screening; diagnosis	consumers
Australian General Practice Network; Royal College of Nursing Australia; Bachelor Institute of Indigenous Tertiary Education	E-learning training package to support Medicare item 10997	chronic disease management		education and training	practice nurses and AHWs
Department of Health and Ageing	Health for life	chronic disease management and prevention		education; prevention	primary health care services
Rural Health Education Foundation	Education services	all health conditions including cancer	✓	education; prevention	consumers, Aboriginal and non-Aboriginal health pro-fessionals
The National Palliative Care program, funded by the Department of Health and Ageing	Program of experience in the palliative approach (PEPA) for Aboriginal and Torres Strait Islander health workers	palliative care		education and training	AHWs
NEW SOUTH WALES					
Aboriginal Medical Service of Western Sydney (AMSWS)	Butt busters	tobacco control/smoking cessation		prevention	consumers
Aboriginal Health College	Cancer awareness skills set	cancer education and awareness	✓	education and training	AHWs
BreastScreen NSW	Training on breast cancer and breast screening for Aboriginal health workers on the North Coast – Lismore	breast cancer knowledge and screening	✓	education and training, prevention; screening	AHWs
Cancer Council NSW	Aboriginal health worker training	cancer education and awareness	✓	education and training	AHWs

[1] This table was adapted from Miller J, Knott V et al. (2010). Aboriginal and Torres Strait Islander Cancer Control Research Project. South Australia, Cancer Service Networks National Demonstration Program, Cancer Australia, Cancer Council SA.

Organisation	Title	Major topic/issue	Cancer specific	Key area of cancer journey	Target
Cancer Council NSW	Environmental tobacco smoke and children project	tobacco control/smoking cessation		education and training; prevention	consumers
Cancer Council NSW; Aboriginal Health and Medical Research Council of NSW	Aboriginal stories of cancer journeys project	cancer education and awareness	✓	education	consumers, Aboriginal and non-Aboriginal health prof-essionals
Cancer Institute of New South Wales	Aboriginal cancer care coordinator	coordination of care	✓	diagnosis; treatment and services	n/a
Department of Health and Ageing	No smokes North Coast: a comprehensive Koori quit campaign	tobacco control/smoking cessation		education; prevention	consumers
Healthy Cities Illawarra; The Cancer Council NSW; National Heart Foundation Australia; 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		education; prevention	consumers
Hunter New England Area Health Service; Awabakal Aboriginal Medical Service; Hunter New England Aboriginal Health Unit	Hunter New England Area Health Service, Awabakal Aboriginal Medical Service, Hunter New England Aboriginal Health Unit breast screening project	breast cancer screening	✓	screening; diagnosis	
Mid North Coast Division of General Practice; Galambila AHS; UNSW Rural Clinical School	Give up the smokes	tobacco control/smoking cessation		education; prevention	consumers
National Heart Foundation Australia (NSW Division); Biripi Aboriginal Medical Corporation; SIDS and Kids NSW (Hunter region); Cancer Council NSW (Mid-North Coast region); NSW Ministry of Health	*SmokeCheck*	tobacco control/smoking cessation		education; prevention	consumers

Organisation	Title	Major topic/issue	Cancer specific	Key area of cancer journey	Target
South Coast Aboriginal Medical Service; Illawarra Aboriginal Medical Service; Illawarra Health; National Heart Foundation of Australia (NSW Division)	Koori tobacco cessation project	tobacco control/smoking cessation		education; prevention	consumers
South Coast Medical Service Aboriginal Corp; Illawarra Aboriginal Medical Service; Katungal Aboriginal Corporation	Clean air dreaming project	tobacco control/smoking cessation		education; prevention	consumers
SSWAHS Health Promotion Service; Aboriginal Metropolitan Council; Australian Indigenous Doctors' Association; Aboriginal Medical Service Redfern	Environmental tobacco smoke (ETS) and harm of tobacco smoke while breast feeding	tobacco control/smoking cessation		education; prevention	consumers
The Australian Centre for Health Promotion, University of Sydney, NSW Health, Cancer Institute of NSW	*SmokeCheck,* NSW	tobacco control/smoking cessation		education; prevention	consumers
NORTHERN TERRITORY					
Aboriginal Resource and Development Service	Audio education programs	all health topics		education; prevention	consumers
Aboriginal Resource and Development Service	Community education sessions	all health topics, including	✓	education; prevention	consumers
Cooperative Research Centre for Aboriginal and Tropical Health Department of Health and Families	Tobacco action project	tobacco control/smoking cessation		education; prevention	consumers
School of Public Health, Tropical Medicine and Rehabilitation Sciences, James Cook University, Cairns	Top End tobacco project	tobacco control/smoking cessation		education; prevention	consumers
NT Department of Health	Gynaecology outreach service (GOS)			prevention; screening	consumers
NT Department of Health	Well women's screening program (WWSP)	breast cancer and cervical cancer screening	✓	prevention; screening	consumers
Wurli Wurlinjang Health Service	Chronic disease program	chronic disease		education; prevention; screening; diagnosis; treatment	consumers

Organisation	Title	Major topic/issue	Cancer specific	Key area of cancer journey	Target
Wurli Wurlinjang Health Service	Sexual health program	sexual health		education; prevention; screening; diagnosis; treatment	consumers
QUEENSLAND					
Queensland Cervical Screening Program	Healthy women's initiative (HWI)	cervical cancer screening	✓	prevention; screening	consumers
Cancer Council Queensland	Pilot program - Cancer care course for Aboriginal Health Workers	coordination of care	✓	education and training; screening; diagnosis; treatment	AHWs
Cancer Council Queensland	Speakers Program	cancer education and training	✓	education; prevention	consumers
Queensland Health	Mobile Women's Health Service (MWHS)	women's health		education; prevention; screening	consumers
Queensland Health (Tropical Public Health Unit Network, Cairns); James Cook University (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		education; prevention	consumers
Queensland Health; University of Queensland; James Cook University, Tropical Public Health Unit	*SmokeCheck*, Queensland	tobacco control/smoking cessation		education; prevention	consumers
SOUTH AUSTRALIA					
Aboriginal Health Council of South Australia (AHCSA)	Aboriginal Health Council of South Australia (AHCSA) tobacco control project	tobacco control/smoking cessation		education; prevention	consumers
Aboriginal Health Council, SA Government, Cancer Council of SA, Heart Foundation	Quit SA – quit skills training program	tobacco control/smoking cessation		education; prevention	health professionals and community workers
BreastScreen SA	BreastScreen SA	breast cancer screening	✓	prevention; screening	consumers

Organisation	Title	Major topic/issue	Cancer specific	Key area of cancer journey	Target
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 Message*s Aboriginal and Torres Strait Islander cancer information	cancer education and training	✓	education and training; prevention; screening; diagnosis; treatment	Aboriginal and non-Aboriginal health professionals and community workers
Cancer Voices SA	Pilot study of cancer conversations in Aboriginal communities, South Australia	cancer experiences	✓	education and training; prevention; screening; diagnosis; treatment	Aboriginal and non-Aboriginal health professionals and community workers
The Second Story; Kumangka Aboriginal Youth Service; AHCSA; South Australian Film Corporation	Nunga kids don't need Puiya	tobacco control/smoking cessation		education; prevention	consumers
ACT					
Winnunga Nimmityjah Aboriginal Health Service; QUIT ACT (Cancer Council ACT)	No more Bundah	tobacco control/smoking cessation		education; prevention	consumers
WESTERN AUSTRALIA					
Cancer Council WA	Make smoking history: fresh start program	tobacco control/smoking cessation		education; prevention	consumers
Geraldton Regional Aboriginal Medical Service	Midwest Indigenous women's cancer support group	cancer support	✓	diagnosis; treatment; supportive services	consumers
Cancer Council WA	Cancer education for Aboriginal health workers	cancer education and training	✓	education and training	AHWs
Combined Universities Centre for Rural Health	Smoke free kids	tobacco control/smoking cessation		education; prevention	consumers
East Metropolitan Population Health Unit	Say no to smokes	tobacco control/smoking cessation		education; prevention	consumers
Heart Foundation	Smarter than smoking				
Kimberly Aboriginal Medical Services Council (KAMSC); Aboriginal Health Council of Western Australia (AHCWA)	Beyond the Big Smoke	tobacco control/smoking cessation		education; prevention	consumers

Organisation	Title	Major topic/issue	Cancer specific	Key area of cancer journey	Target
Smoking and Health Program, Health Department of Western Australia	The Western Australian Aboriginal smoking project	tobacco control/smoking cessation		education; prevention	consumers
Women's Health Care Association	Aboriginal women's project	women's health		education; prevention	consumers
VICTORIA					
Cancer Council VIC	Tobacco control program	tobacco control/smoking cessation		education; prevention	consumers
Cancer Council VIC	Pap screening program	cervical cancer screening	✓	education; screening; prevention	Aboriginal health services and organi-sations
Cancer Council VIC	Aboriginal health worker education	cancer education and training	✓	education and training	AHWs
Department of Health Victoria	Victorian Aboriginal palliative care program	palliative care		education; access to services; supportive services	consumers; AHWs; Aboriginal health services
Rumbalara Aboriginal Health Service	No more Dhonga	tobacco control/smoking cessation		education; prevention	consumers

Appendix F: Ongoing cancer control activities and programs

Organisation	Title	Description
Menzies School of Health Research	Talking About the Smokes	The project aims to improve our understanding of the impacts of national, local and regional tobacco control policies and programs on smoking and quitting, and the factors mediating this, in Aboriginal communities in Australia. The project will involve working closely with Aboriginal and Torres Strait Islander community–controlled health services throughout Australia to collect data over two years
Tharawal Aboriginal Corporation	Djurali Program	The program aims to raise awareness about the positive health benefits of eating healthy food, getting physically active, and quitting smoking. The Djurali Program is also offering specific activities to the community to help them make these positive lifestyle changes
Cultural and Indigenous Research Centre (CIRCA)	QuitLine Aboriginal Enhance-ment Project	The Quitline provides an evidence-based smoking cessation service for smokers seeking to quit. The Aboriginal Quitline Enhancement Project has been funded to provide a Quitline service for Aboriginal people who smoke in NSW and ACT that is culturally appropriate and accessible. The project is underpinned by a partnership between key agencies including the Aboriginal Health & Medical Research Council, Cancer Institute NSW, Quitline, NSW Health, ACT Health and the SmokeCheck Project
Aboriginal Health and Medical Research Centre (AH&MRC)	Kick the Habit	The program is a small social marketing campaign that aims to reduce the number of Aboriginal people smoking within NSW. Its goal is to promote awareness of quit smoking options, denormalise smoking, and essentially help Aboriginal people through their journey in giving cigarettes
Illawarra and Shoalhaven Health Promotion Service	It's now Your Choice NOW	The 'It's now Your Choice NOW' project is in partnership with Barnardo's and Beyond Empathy, we engaged youth from a housing estate to discuss issues around smoking. The focus was to identify young people's own strengths though group work, production/filming as well as general monitoring. The end result was an ad, "It's Your Choice NOW!" that highlights the issues of choice, resilience, consequences and financial implications of smoking
Waltja Tjutangku Palyapayi	Healthy Community Healthy Life	The project aims to encourage physical activity, good nutrition and the importance of regular health checks, whilst facilitating the retention and transfer of traditional and contemporary systems of knowledge about good health practices between community elders and younger generations in Western Desert communities. This project constitutes a series of community walks, culminating in members of all communities undertaking a long walk, a week of camping and walking following traditional Tjukurrpa routes. In addition to providing participants with the necessary gear to undertake these activities, the project will deliver healthy community cook ups, recipe books and kitchen cooks to improve community nutrition

Organisation	Title	Description
Uncle Jimmy Thumbs Up! Limited	The Good Tucker Long Life program	The program will work with schools, traditional owners, local stores, men's and women's groups and other community members and groups to encourage healthy eating. Activities will include providing store signage indicating healthy foods, healthy recipe promotions, nutrition education and health lifestyle workshops for children, and a media campaign including targeted editorial and new media strategies
Awabakal Newcastle Aboriginal Medical Service	The Lost and Found in the Smoke	The project will develop, produce and present an interactive play, engaging 12-14 year old students. Focusing on the health, social and financial consequences of smoking, the play will promote healthy choices and lifestyles and the benefits these deliver for individuals, families and communities. The play will be developed in partnership with Ngarrama Productions and will be piloted for 15 performances before audience feedback is used to refine the production for a further 35 performances
Coomealla Health Aboriginal Corporation	The Get Active Coomealla project	The project aims to increase the capacity of Wentworth Shire community members to manage their health and fitness and reduce the incidence of overweight and obesity. The project will make gym equipment and exercise instruction available to community members in the Dareton area and will involve a community member training as a personal trainer. In addition, health checks will be arranged for community members who use the gym facilities, and advertising and print materials will promote the services and the messages about avoiding or managing chronic disease.
South Coast Women's Health & Welfare Service Corporation	Waminda Aboriginal Women's Health and Wellbeing Program	The program will include brief interventions and early interventions to assess and support women interested in behaviour modification, a comprehensive and intensive tobacco cessation program, healthy wellbeing camps, support for the community garden, and localised health promotion and health education days
Tharawal Aboriginal Corporation	Good Tucker All Round project	The project will develop a food distribution network to purchase fresh fruit and vegetables from the Sydney Markets on a daily basis. The network will then distribute different sized bags of produce at a subsidised cost to community members in South West Sydney. Participants will be given health checks and Tharawal's Community Kitchen will also be used to educate community members about healthy preparation of the produce. Recipe cards and other health information will also be provided and community service announcements will be developed
Tharawal Aboriginal Corporation	The Get Active, Anytime, Anywhere project	The project involves expanding an existing community exercise program. The funding will be used to provide equipment and professional instructors, as well as resources such as exercise charts, exercise and nutrition diaries and a dedicated space on the Tharawal website for participants to share their experiences.

Organisation	Title	Description
Murray Plains Division of GPs Inc.	Aunty Jean's Project	This project will extend the Aunty Jean's Project, an early intervention/preventative health education program, to clients in Deniliquin and Moama over the next two years. This program focuses on smoking, chronic disease management, and mental and cultural health. Activities include gentle exercise sessions, health education sessions, health checks and healthy lunches
Ramahyuck District Aboriginal Corporation (RDAC)	The Eating Strong project	The project will deliver a series of Gippsland based Koori Healthy Eating education and skills attainment programs tor expectant mothers, babies, children and families. The project activities will include healthy cooking demonstrations, health checks and workshops where smoking cessation and chronic disease prevention and management will be discussed
Mungabareena Aboriginal Corporation	The Keep Healthy, Keep Moving project	The project will deliver community activity days to share resources and information to develop healthy family gardens, cooking classes and healthy eating sessions, and physical activity sessions at the local gym and pool. The project is aimed at enhancing the spiritual and emotional wellbeing of individuals and families within the Albury/Wodonga community. Healthy record diaries and information resources will help reinforce the messages and encourage engagement with local health services
Charles Darwin University / Yalu Marnggithinyaraw	Sharing the Full and True Story About Chronic Disease	The project aims to revive positive traditional knowledge and practices related to health whilst also improving access to Western health information. Using community workshops and education sessions, and resources translated into the traditional Yolngu language. The project will promote informed decision-making, lifestyle changes and the use of health services
Gap Youth Centre Aboriginal Corporation	GYC4 Life Campaign	The project has four main elements: Active, Food, Culture and Media. As part of the project, the GYC gym will be upgraded and promoted, healthy cooking activities will be run in an upgraded kitchen, cultural activities including 'Storywalks' and 'Yarn sessions' will be used to encourage chronic diseases prevention, and local media organisations will be involved in documenting and promoting the activities and messages about healthy lifestyles.
Hoops 4 Health Aboriginal Corporation	The Hoops 4 Health Challenge	The project aims to raise awareness of the lack of understanding of risk factors that contribute to chronic disease through a series of 'Live Longer' basketball challenges in remote communities leading up to a major basketball tournament to be held in Darwin. The tournament will invite schools from all over the NT and promote physical activity, having health checks, drinking water and healthy eating as important factors in reducing chronic disease. This will be reinforced by radio advertising
Skinnyfish Music	Digital Health Stories Project	The project aims to involve young people aged 12-18 in creating a series of themed digital stories (three to five minutes in length) from each seven remote NT communities. The digital stories will be developed around the themes of nutrition, physical activity, smoking, health

Organisation	Title	Description
		checks and chronic disease issues. The stories will then be uploaded to the internet to be shared
Tiwi Education Board Inc. (TiwiCollege)	The Taste It, Do It, Live It project	The project will engage Tiwi Islanders to improve their diets, exercise more and access primary health care. The main focus of the activity is the training of TiwiCollege students in safe and nutritious food preparation and service, the collection and hunting of traditional bush tucker, and learning health assessment skills. This campaign will extend to the broader community through holistic health days and will be supported by promotional messages from the Essendon Football Club and local Tiwi Bombers team
Western Desert Nganampa Waltja Palyantjaku Tjutaku Aboriginal Corporation	The PALYA! Project	The project will provide holistic care and education, working with people to keep active and engaged. It focuses on issues relating to nutrition and hydration to both prevent and manage chronic disease. Activities a will include healthy food preparation (in a renovated kitchen) and nutrition advice, local language resources, exercise sessions, bush trips and art activities
Apunipima CapeYork Health Council	The Go Physical Live Longer project	The project aims to reducing risk factors for chronic disease in the communities of Mapoon and Coen. The project will include a physical activity program delivered through improvements to gyms in each community, as well as fishing competitions, healthy food cook ups and regular check-ups for participants. The campaign will extend messages about smoking cessation, nutrition and the importance of accessing primary health care through radio and community engagement activities
Brisbane Indigenous Media Association Incorporated	The Move project	The project aims to raise awareness of the benefits of physical activity among Aboriginal and Torres Strait Islander peoples aged 18 and over in the greater Brisbane region through regular on air messaging, a website and community comedy events. The project will encourage healthy lifestyle choices and regular access to appropriate health services and programs to prevent and/or manage chronic disease. Community members will participate in the campaign directly and receive media training
North Coast Aboriginal Corporation for Community Health	The Lifestyle Modificatio n Program	The program will run four times over a period of two years. Participants will be involved in regular physical activity and workshops about healthy shopping and cooking, the importance of physical activity and underlying issues including self-esteem and mental health. Monthly health screenings will also be conducted, with incentives of fresh fruit and vegetables given to participants
The EON Foundation	EON Thriving Com-munities Program	The program will be delivered to six remote Indigenous communities in the Kimberley region of WA. The program aims to promote healthy lifestyle choices to reduce chronic disease and will include activities such as the creation and maintenance of local community gardens, education about nutrition and food hygiene, and the teaching of skills in home repair and maintenance skills for good hygiene

Organisation	Title	Description
Nindilingarri Cultural Health Services	The Skutta Girls program	The program will extend a pilot program targeting at-risk young women aged 12-18 years in the Fitzroy Crossing region and provide a safe space where participants can become engaged in fun activities and receive important health education information. These weekly sessions, which will be community developed and implemented, will focus on nutrition, sexual health, chronic disease management and prevention, and involve some light exercise
Greater Southern Area Health Service (GSAHS)	Aboriginal Health and Cancer Services – Working Together	The project aims to improve Aboriginal men's health literacy and in particular, their understanding of cancer. An e-learning cultural awareness training package for staff in cancer services working with Aboriginal communities in development.
Hunter New England Area Health Service (HNEAHS)	Cancer Screening and Prevention in an Aboriginal Community Project	The project aims to improve awareness of cancer within Aboriginal communities and provide access to culturally appropriate prevention, screening, treatment and care. This project is a core component of CanNET 2 and will specifically encourage Aboriginal women to promote disease prevention and health improvement within their communities

Appendix G: Levels of evidence

National Health and Medical Research Council levels of evidence scale

Rating	Evidence
I	Evidence obtained from a systematic review of all relevant randomised controlled trials
II	Evidence obtained from at least one properly designed randomised controlled trial
III-1	Evidence obtained from well-designed pseudo-randomised controlled trials (alternate allocation or some other method)
III-2	Evidence obtained from comparative studies with concurrent controls and allocation not randomised (cohort studies), case control studies, or interrupted time series with a control group
III-3	Evidence obtained from comparative studies with historical control, two or more single-arm studies, or interrupted time series without a parallel control group
IV	Evidence obtained from case series, either post-test or pre-test and post-test

Appendix H: Key prevention and risk modification reviews

Author Year	Title	Purpose of the paper/hypothesis
Carson KV et al (2012)	Interventions for smoking cessation in Indigenous populations. The Cochrane Library	To evaluate the effectiveness of smoking cessation interventions in Indigenous populations and to summarise these approaches for future cessation programmes and research
Clifford A et al (2011)	Smoking, nutrition, alcohol and physical activity interventions targeting Indigenous Australians: Rigorous evaluations and new directions needed	This paper has two aims: to critique the methodological and contextual aspects of evaluations of Indigenous-specific SNAP intervention studies; and to examine the effect of these studies on reducing SNAP related harm in Indigenous Australian communities
Clifford A et al (2009)	Disseminating best-evidence health-care to Indigenous health-care settings and programs in Australia: Identifying the gaps	This study systematically identifies and reviews published Indigenous-specific dissemination studies targeting SNAP interventions (smoking, poor nutrition, alcohol misuse and physical inactivity)
Ivers RG (2003)	A review of tobacco interventions for indigenous Australians	To conduct a review of interventions to reduce the harm resulting from tobacco use among Indigenous Australians and to discuss the likely effect of a range of tobacco interventions if conducted in this population
DiGiacomo M et al (2011)	Smoking Cessation in Indigenous Populations of Australia, New Zealand, Canada, and the United States: Elements of Effective Interventions	To identify and discuss the key elements of individual-level smoking cessation interventions in indigenous people worldwide
Power J et al (2010)	Tobacco interventions for Indigenous Australians: A review of current evidence	To review effective interventions for increasing smoking cessation among Indigenous Australians and identified gaps in evidence regarding smoking cessation interventions for Indigenous Australians