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Evidence Check

Support along the cancer pathway for Aboriginal and Torres Strait Islander peoples

An Evidence Check rapid review brokered by the Sax Institute
for the Cancer Institute NSW—November 2021

NSW GOVERNMENT

Cancer Institute NSW

An Evidence Check rapid review brokered by the Sax Institute for the Cancer Institute NSW. November 2021.

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Disclaimer:

This Evidence Check review was produced using the Evidence Check methodology in response to specific questions from the commissioning agency.

It is not necessarily a comprehensive review of all literature relating to the topic area. It was current at the time of production (but not necessarily at the time of publication). It is reproduced for general information and third parties rely upon it at their own risk.

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Abbreviations

ABS	Australian Bureau of Statistics
ACCHS	Aboriginal Community Controlled Health Services
CanDAD	Cancer Data and Aboriginal Disparities
CQI	Continuous Quality Improvement
ED	Emergency department
HPV	Human papillomavirus
ICUs	Intensive care units
NBCSP	National Bowel Cancer Screening Program
NSW	New South Wales
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analysis
SCNAT-IP	Supportive Care Needs Assessment Tool for Indigenous Patients
WA	Western Australia

Definitions

Evidence Check review

An Evidence Check is a rapid review of existing evidence tailored to the individual needs of an agency. Evidence Check reviews answer specific policy or program questions and are presented as a report in a policy friendly format. Reviewers may be asked to identify gaps in the evidence but do not undertake new research to fill these gaps.

Evidence Check rapid reviews follow a systematic process and are conducted in three-to-four months instead of the 12–24 months required for a systematic review and there are some limitations to the included studies (usually 10 years of publication), languages and databases and some steps may be modified or omitted. These limitations are negotiated with the agency at the start of the process.

Indigenous populations

Aboriginal and Torres Strait Islander peoples are the original inhabitants of Australia, and we have used ‘Aboriginal and Torres Strait Islander Australians / peoples’ to refer to Indigenous peoples of Australia. The term ‘Indigenous’ is used to refer to common features that are identified across Canadian Aboriginal peoples, Māori peoples of New Zealand and Aboriginal and Torres Strait Islander Australians.

Cultural awareness, competency, safety and security

Formal definitions of these concepts:

1. **Cultural awareness**: An awareness of different cultural groups, including identification of own cultural values, practices and identity.
2. **Cultural competency**: Behaviours, attitudes and policies that together create effective cross-cultural working relationships. The enactment of culturally respectful practices.
3. **Cultural safety**: Cultural safety is an environment that is safe for people and where there is no assault, challenge or denial of their identity, of who they are and what they need. It is about shared respect, shared meaning, shared knowledge and experience, of learning together with dignity, and truly listening.[1]
4. **Cultural security**: Cultural security involves an overall commitment to ensure cultural safety within an organisation. Examples of steps that can demonstrate an organisation's commitment include community engagement in organisational decision-making processes such as appointment of staff; training; job descriptions; and appropriate protocols and policies.[2]

Executive summary

Background

Cancer is a major contributor to the health burden in Australia[3], and Aboriginal and Torres Strait Islander peoples with cancer face worse outcomes.[3–5] Across all cancers, overall survival at five years is only 50% in Aboriginal and Torres Strait Islander peoples compared with 65% in Australians of non-Aboriginal background.[4]

The Cancer Institute NSW has commissioned this Evidence Check rapid review to identify and evaluate current and emerging national and international evidence for improving cancer care access and outcomes for Indigenous peoples. The review will inform decisions regarding the feasibility of implementing solutions to address barriers in access to cancer care and support for Aboriginal peoples with cancer in NSW. In particular, it will assist in the development of evidence-based policy and consideration of coordination of care models for Aboriginal and Torres Strait Islander Australians with cancer.

The Evidence Check addresses the following two questions:

Question 1: What are the main barriers to accessing screening, diagnosis, treatment and management services for Aboriginal and Torres Strait Islander peoples and Indigenous peoples?

Question 2: What approaches or interventions have been effective in improving access to and coordination of healthcare for Aboriginal and Torres Strait Islander peoples and for Indigenous peoples?

Summary of methods

To answer these questions, the research team undertook a rapid review of peer-reviewed articles, conference abstracts and grey literature using a search strategy designed with input from an experienced research librarian. As stipulated by the Cancer Institute NSW, the search included only English-language work published in the past five years (2015–21) relating to Aboriginal and Torres Strait Islander peoples in Australia, Māori peoples from New Zealand, and First Nations peoples from Canada. We identified a total of 1279 records of which 105 were included after removal of duplicates and screening of both abstracts and full texts. We assigned a level of evidence (‘strong’, ‘considerable’ or ‘low’) to each article using Daly’s Hierarchy of Evidence for qualitative studies and the National Health and Medical Research Council (NHMRC) evidence hierarchy for quantitative studies.

Evidence Check findings

Question 1

What are the main barriers to accessing screening, diagnosis, treatment and management services for Aboriginal and Torres Strait Islander peoples and Indigenous peoples?

Fifty-two articles addressed barriers to various aspects of cancer care: screening, diagnosis, and treatment. We organised them under three broad categories of contextual, health service-related and patient-related barriers. The key barriers we identified were:

Contextual barriers

- A mistrust and fear of Western institutions stemming from racism, colonisation and past mistreatment of Indigenous peoples within the health system hinders Indigenous peoples from accessing services[6–15]
- The availability of and inequitable access to healthcare in rural and remote areas directly affects provisions for screening and diagnosis in primary healthcare settings, treatment and overall cancer care, and associated costs for travel, accommodation and food needs[16, 17, 9, 18–23]
- Lack of accurate and complete Indigenous-specific cancer screening data and identification of Indigenous status in medical records limit equitable delivery of services, including regular monitoring and evaluation of progress against targets, and the process of identification of effective resources and interventions.[24]

Health service-related barriers

- Some studies found that limitations in the knowledge of health professionals about cancer and the importance of cancer screening, especially in rural and remote primary healthcare settings, have affected Aboriginal and Torres Strait Islander Australians' participation in cancer screening[6, 8, 9, 25]
- Fragmented care in primary, tertiary and specialist care settings, including a lack of coordination between health professionals in these three settings, has a negative impact on the care quality, continuity of cancer care and, ultimately, the cancer outcomes for Aboriginal and Torres Strait Islander peoples[5, 26, 27]
- Several health system factors affect Indigenous patients' acceptance of healthcare facilities and influence clients' choices and decision-making. Some of these include underrepresentation and high turnover of Aboriginal and Torres Strait Islander health professionals[28]; health professionals dealing with multiple clinical priorities and tasks concurrently due to a shortage of facilities and staff, which affects the quality of service delivery[29]; a shortage of female practitioners[8, 20, 29]; lack of flexibility within the system[29];

clinical staff turnover[29]; lack of well-maintained and efficient clinical information systems for notifying, recalling and reminding women (especially sending letters) of their screening due date or appointments[29]

- Health professionals' lack of education and knowledge about Indigenous cultural beliefs, rituals and needs in general is a barrier to cancer screening and care. This requires capacity building through cultural competency training to promote engagement and enhance the quality of communication and interpersonal relationships between health professionals and Indigenous patients[6, 13, 14, 29]
- Western non-Indigenous health professionals often do not understand the importance of involving families in decision-making processes. This makes communication and relationship-building harder[18, 30–33] and can lead to poor communication between patients, their families and health professionals.

Patient-related barriers

- A number of studies identified a lack of knowledge and low community awareness[12, 13, 20, 34] of different aspects of cancer, including screening options; the risk, harm and prevalence of cancer treatment; and the availability of other supportive care as an important barrier to Indigenous participation in cancer screening and care. An absence of culturally appropriate health literacy programs for community members is also responsible for this lack of awareness, knowledge and education among Indigenous patients and families
- Pre-existing and differing cultural beliefs about a cancer diagnosis, including fatalistic attitudes, fear, stigma, shame and embarrassment, may impede participation in cancer screening and overall cancer care for Indigenous peoples[6, 9, 12–14, 20, 23, 25, 29, 34]
- Indigenous patients often deal with multiple and complex personal and familial crises overlaying the cancer diagnosis, including other seriously ill family members and looking after other family members, including children and grandchildren.[31, 33, 35, 36] Many patients expressed concerns about family members' health and wellbeing arising from their illnesses—it was among the most highly ranked unmet needs.[37, 38] This hinders many Indigenous patients from accessing cancer treatment, care and support services.
- Gendered dimensions of cancer experiences in Indigenous communities[10, 18, 30, 39] showed Indigenous men generally avoid seeking help for health matters, preferring to ignore or put up with the physical symptoms of illness, leading to late diagnosis of cancer. This highlights a need for better engagement and support for Aboriginal men within the healthcare system so cancer care is appropriate and timely for Aboriginal and Torres Strait Islander men.[39]

Many of these barriers are especially significant for Indigenous peoples living outside major metropolitan areas. These barriers to cancer care are outlined further in Tables 3, 4 and 5.

Question 2

What approaches or interventions have been effective in improving access to and coordination of healthcare for Aboriginal and Torres Strait Islander peoples in Australia and for Indigenous peoples internationally?

This Evidence Check identified a number of initiatives, approaches and interventions or models of care supporting Indigenous peoples through the cancer journey in a further 53 articles. Thirty-six articles were specific to cancer and 17 were about other chronic diseases; 10 of the 36 articles specific to cancer involved different strategies for care coordination as a significant focus.

Key care coordination strategies include:

- Cancer care can be improved by the **employment of Aboriginal and Torres Strait Islander cancer care coordinators**, as has been demonstrated by the Cancer Data and Aboriginal Disparities survey in South Australia.[5]
- A **whole-of-service approach** where staff at every level of the services were engaged in the implementation of culturally safe cancer care, as outlined in Taylor et al. (2018 and 2020), resulted in sustainable improvement in cancer care for Aboriginal and Torres Strait Islander peoples[40–42]
- Cancer care has also been improved by implementing **the navigator models**, such as the Indigenous Patient Navigator model in Queensland[43] and Champlain Indigenous Cancer Program in Ontario, Canada[44, 45]
- A **women's cancer support group** was trialled, evaluated and shown to create a positive feeling among Aboriginal and Torres Strait Islander patients with cancer in WA. However, this initiative failed to continue because of a lack of funding commitment and also due to several unresolved tensions between mainstream health professionals and Aboriginal and Torres Strait Islander support people.[46, 47]

Outside of the care coordination strategies, other approaches aiming to improve access to cancer care for Indigenous peoples include:

- High-level evidence-based strategies across the cancer care continuum include the **use of 'co-design' principles**, with early and continuous engagement of Indigenous representatives and leadership groups[48–52]
- **Continuous quality improvement** cycles for incremental beneficial change; and highly involved executive leadership with regards to Indigenous peoples' needs at the forefront of a service's values.[53]
- Screening approaches with at least considerable supporting evidence include patient reminders about upcoming screening or health check-up dates[54–57], self-taken vaginal human papillomavirus (HPV) sampling[8, 9, 15, 22, 24, 58–61], and opportunistic screening of Indigenous peoples accessing healthcare for other reasons.[19] This Evidence Check found a low level of evidence for the mobile cancer screening model; however, this strategy has the potential to improve screening outcomes, especially in remote and isolated communities[62, 63]
- Actions to improve diagnosis and treatment of cancer include **increasing the number of Indigenous health service providers**[40, 42, 64, 65], **targeted cultural safety workshops for**

health workers[66], and culturally safe assessment tools such as the **Supportive Care Needs Assessment Tool for Indigenous Patients** (SCNAT-IP).[67]

Tables 6, 7 and 8 provide more detailed descriptions of these and other strategies; Table 9 is a succinct list of all strategies and models identified for cancer and chronic disease care.

Key messages

This Evidence Check review showed clearly that holistic cancer care needs to be developed by, and in partnership with, local Indigenous communities and stakeholders to ensure the improvement of cancer outcomes for Indigenous peoples. A summary of other key considerations and principles that should be at the forefront of all efforts, policies and initiatives to improve cancer outcomes for Aboriginal and Torres Strait Islander Australians includes:

- Aboriginal and Torres Strait Islander patients' and families need to feel safe, confident and cared for in the healthcare system. Relationships between Aboriginal and Torres Strait Islander communities and the treating medical teams must be based on the principles of respect, reciprocity and responsibility. Trust-building takes time and involves mutual understanding and communication between both parties, especially in the context of past injustices experienced by the Indigenous populations. Thus, a **long-term funding commitment** is required for any initiative to be successful
- Health services need to acknowledge and implement strategies to accommodate differing cultural values, beliefs and approaches at the system level to allow for sustainable and meaningful partnerships and engagements with Indigenous patients, families and communities. These include opportunities for Indigenous leaders to advise, lead and represent required system changes, and opportunities for mutual learning. This requires **commitments at the health system level**
- The issues of communication, education and information provision must be considered within a local socio-cultural and economic context. Meaningful Indigenous and non-Indigenous partnership is vital; and **Indigenous leadership** should be at the centre of such initiatives
- The continuation and expansion of **care coordination** should be a priority area for action, alongside further initiatives to improve the provision of supportive care to Indigenous peoples with cancer and their families. Care coordination is one of the core dimensions of patient-centred care, alongside treating patients with dignity and respect; communication of appropriate information about their clinical condition and treatment options; and encouraging patient participation in decision-making. **Patient-centred care** is one of the key pillars of quality healthcare
- The need to understand patients' experiences within the health system so as to know whether the care provided is meeting **appropriate standards of clinical safety and effectiveness** has been prioritised internationally. **Further research with more locally appropriate approaches and methodologies** regarding the experience of Aboriginal and Torres Strait Islander Australians dealing with cancer will contribute to better understanding of the multiple barriers of care currently affecting these patients
- **Complete and accurate data collection and reporting using continuous quality improvement (CQI)** should be ensured at all levels of service delivery. This includes staff training to identify and record Aboriginal and Torres Strait Islander status through

appropriate questions and ethnicity-specific data collection protocols; financial investment in information systems that can transfer information both locally and in organised programs; and the development and capacity building of cancer registries. High quality data collection and reporting enables ongoing monitoring and evaluation, measures progress against benchmarks, identifies where resources are most needed, and measures which interventions work best.

- **Family and cultural connections** are important supports for Indigenous peoples. Thus, Indigenous leadership encompasses family collectives, language groups, tribes, Elders and knowledge holders, as well as Indigenous health professionals. **Aboriginal and Torres Strait Islander leadership must be central** to directing where to focus efforts, planning, policy, monitoring and evaluation; intervention design and implementation; and supporting the program and Aboriginal and Torres Strait Islander community initiatives.

Background

Cancer among Aboriginal and Torres Strait Islander peoples in Australia

Cancer is one of the greatest contributors to the health burden in Australia.[3] Aboriginal and Torres Strait Islander Australians suffer disproportionately from a range of diseases, including cancer. Aboriginal and Torres Strait Islander peoples are the original inhabitants of Australia, and we have used this term to refer to Indigenous peoples of Australia. The term 'Indigenous' is used to refer to common features that are identified across Canadian Aboriginal peoples, Māori peoples of New Zealand and Aboriginal and Torres Strait Islander Australians.

Aboriginal and Torres Strait Islander peoples with cancer have substantially lower five-year crude survival rates across all age groups compared with non-Aboriginal peoples: 50% versus 65% between 2007 and 2014.[4] Previously, cancer had been thought to be less prevalent among Aboriginal and Torres Strait Islander Australians; however, a recent survey has shown cancer prevalence among Aboriginal and Torres Strait Islander Australians has been steadily increasing over the past 10 years and, in fact, is slightly higher when compared with non-Aboriginal Australians among people living in non-remote areas.[4] Cancer has now become the leading cause of death in Aboriginal and Torres Strait Islander communities.[68] Between 2009 and 2013, Aboriginal and Torres Strait Islander Australians were 1.1 times more likely to be diagnosed with cancer than non-Indigenous Australians.[4] The quality and reliability of figures on Aboriginal and Torres Strait Islander Australian status still vary by jurisdiction and year of collection. It is not known how many Aboriginal and Torres Strait Islander Australians are misclassified as 'non-Indigenous' or of 'unknown' status. The most recent Australian Institute of Health and Welfare (AIHW) report states the statistics presented in that report are likely to be underestimates.[4]

Cancer death is more common for Aboriginal and Torres Strait Islander peoples than non-Aboriginal Australians, and the most common cancers diagnosed among Aboriginal and Torres Strait Islander peoples are lung, breast (female), bowel and prostate (male) cancers.[4, 69] Lung cancer had the lowest rate of survival in the period 2010–14 and the rate of death was 1.8 times higher for Aboriginal and Torres Strait Islander peoples than for non-Aboriginal Australians.[4] Lung cancer is the fourth leading cause of all deaths for Aboriginal and Torres Strait Islander peoples, followed by cancers of the liver, head and neck and unknown primary sites.[4] Aboriginal and Torres Strait Islander Australians were 2.4 times as likely to be diagnosed and 2.4 times as likely to die from liver cancer compared with non-Aboriginal people.[4, 69] The age-standardised incidence rate for liver cancer ranged from 6.6 per 100,000 to 24 per 100,000 across remote areas. The age-standardised mortality rate for liver cancer ranged from 5.8 per 100,000 to 24 per 100,000 across remote areas.[4]

While mortality from bowel cancer in the general population has declined in recent years, these improvements are not seen in Aboriginal and Torres Strait Islander Australians, which is consistent with Aboriginal and Torres Strait Islander Australians' outcomes from cancer overall.[70] Bowel cancer, the third most common cancer after lung and breast in Aboriginal and Torres Strait Islander women and after lung and prostate in Aboriginal and Torres Strait Islander men, accounts for about 10% and 9% of all cancers, respectively.[3, 4] Aboriginal and Torres Strait Islander Australians with bowel cancer also experience significantly lower survival rates compared with non-Aboriginal people.[4]

A key driver of poor cancer prognosis within Aboriginal communities is the often late stage of diagnosis.[4, 71] In Australia, three national population-based screening programs for breast, bowel and cervical cancers are available, all of which contribute to reducing mortality and morbidity from cancers through early diagnosis. However, Aboriginal and Torres Strait Islander Australian participation in all three screening programs is well below that of non-Aboriginal Australians.[4, 69] In 2014–15, participation of Aboriginal and Torres Strait Islander women in the BreastScreen program was 37% compared with 53% for non-Aboriginal women.[69, 72] The lower survival rate for breast cancer among Aboriginal and Torres Strait Islander women can be explained in part by lower participation in the BreastScreen Australia early detection program.[69, 72, 73] For the National Bowel Cancer Screening Program, it was estimated that the participation rate for Aboriginal and Torres Strait Islander people in 2015–16 was 20%, whereas the estimated participation rate for non-Aboriginal people was 43%.[74] While the participation of Aboriginal and Torres Strait Islander women in the cervical screening program is not collected in registry data nationally[75], available data suggests they are under-screened compared with non-Aboriginal women; for example, 42% versus 58%, as observed in the Northern Territory.[76] Correspondingly, the rate of deaths from cervical cancer in 2013–17 was 3.5 times as high for Aboriginal and Torres Strait Islander women as for non-Aboriginal women.[69] Findings from studies of the first National Cervical Screening Program suggest the participation gap between Aboriginal and Torres Strait Islander and non-Aboriginal women stands between 20% and 30%.[69, 77]

Growing evidence shows patterns of cancer care differ between Aboriginal and Torres Strait Islander and non-Aboriginal Australians, with Aboriginal and Torres Strait Islander patients often receiving less optimal treatment.[78, 79] As per the clinical guidelines of the cancer continuum in Australia, access to and engagement with cancer care for Aboriginal and Torres Strait Islander Australians is lower at all stages of cancer, including screening, diagnosis, continuity of care, adherence to follow-up and treatment, and survivorship.[4, 69, 78] In 2016–17, age-adjusted hospitalisation rates for cancer were lower for Aboriginal and Torres Strait Islander peoples than for non-Aboriginal Australians, but the length of stay was longer.[80] All of these contribute to poorer cancer outcomes for this cohort of population.

Purpose of this Evidence Check

In this context, The Cancer Institute NSW (the Cancer Institute) commissioned an Evidence Check of the current research into healthcare models that support Aboriginal and Torres Strait Islander people through chronic disease pathways, with a focus on cancer. The primary focus is on *evaluated* approaches or initiatives. However, we have also included promising initiatives or approaches.

The Institute wanted to identify the initiatives, approaches, interventions or models and evaluate the effectiveness of those initiatives in supporting Indigenous peoples through the cancer journey that includes:

- Accessing screening
- Timely cancer diagnosis
- Coordinating the journey from cancer diagnosis to treatment completion.

The Institute is guided by the NSW Cancer Plan, where equity is a central theme, ensuring that Aboriginal and Torres Strait Islander Australians and Culturally and Linguistically Diverse (CALD) population groups with poorer outcomes have the same access to cancer services and outcomes as the rest of the population.

Aboriginal and Torres Strait Islander peoples and communities are a priority population. There is growing recognition that there is a large and complex health system surrounding cancer, and that it could be improved to support coordinated care for Aboriginal and Torres Strait Islander populations. Coordination of care could be achieved through a range of solutions. Understanding which solutions could have the biggest impact is an important piece of work. Any solution to improve cancer care and support for Aboriginal and Torres Strait Islander peoples should focus on the social determinants of health and how these factors influence timely access to diagnosis, treatment, culturally safe services and a culturally competent workforce.

The Cancer Institute commissioned this Evidence Check rapid review of the current national and international evidence in relation to improving cancer care access and outcomes for Indigenous peoples. The outcomes of the review will guide future programs and policy planning for Aboriginal peoples with cancer in NSW.

Evidence Check questions

The Evidence Check will answer the following questions:

Question 1: What are the main barriers to accessing screening, diagnosis, treatment and management services for Aboriginal and Torres Strait Islander peoples and Indigenous peoples?

Scope includes

- Barriers to screening, diagnosis, treatment and management of chronic disease and cancer
- High quality studies and/or systematic reviews from the past five years looking at barriers.

Question 2: What approaches or initiatives have been effective in improving access to and coordination of healthcare for Aboriginal and Torres Strait Islander peoples and for Indigenous peoples?

Scope includes

- Approaches or initiatives for chronic disease and cancer
- Approaches or initiatives that are aimed to improve access to and coordination throughout a cancer or chronic disease journey, including screening, early detection, diagnosis, treatment and management

- Approaches or initiatives may include those related to:
  a. Workforce
  b. Service delivery mode
  c. Culturally appropriate information and service delivery
  d. Care coordination
  e. Health literacy
  f. Support to attend appointments.

Exclusions

- Prevention (e.g. health promotion activities, social marketing campaigns / activities, availability of healthy foods, support for improving physical activity) is outside the scope of this Evidence Check.

Methods

An Evidence Check is a rapid review of existing evidence tailored to the individual needs of an agency. Evidence Check reviews answer specific policy or program questions and are presented as a report in a policy friendly format. Reviewers may be asked to identify gaps in the evidence but do not undertake new research to fill these gaps.

Evidence Check rapid reviews follow a systematic process and are conducted in three to four months instead of the 12–24 months required for a systematic review and there are some limitations to the included studies (usually 10 years of publication), languages and databases and some steps may be modified. These limitations are negotiated with the agency at the start of the process.

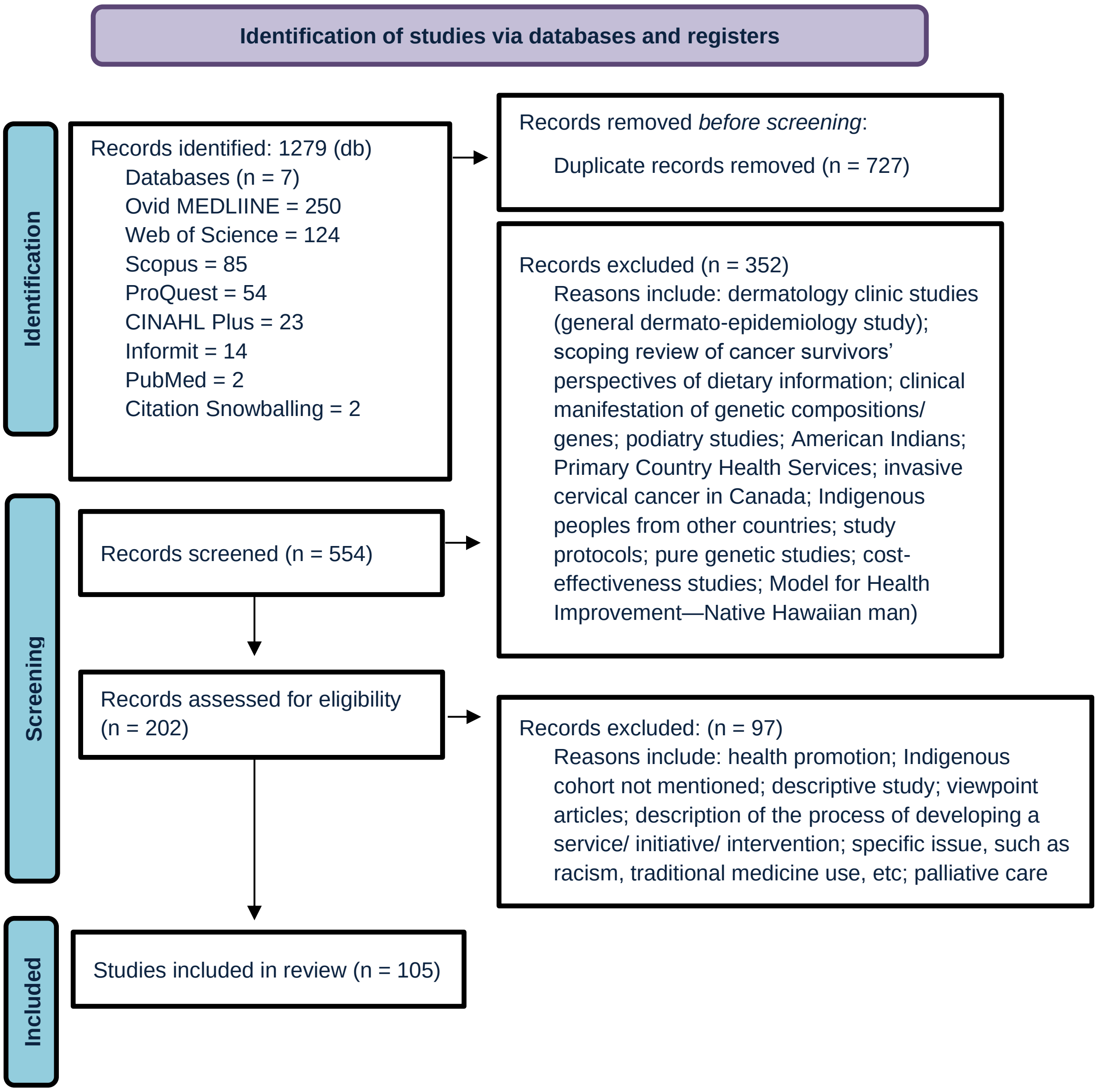
The authors of this Evidence Check followed the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA)[81] guidelines to minimise the methodological bias and to ensure the search strategy and reporting were consistent. We conducted a multi-database search for peer-reviewed journal articles with terms (subject heading, title, abstract and/or keywords) pertinent to Aboriginal and Torres Strait Islander Australians, Māori peoples from New Zealand, Canadian Aboriginal populations, cancer, health services access and patient-reported outcome measures. An experienced librarian conducted the search. The search syntax was modified (as were subject headings, if applicable) according to the requirements of each electronic database. The generic structure of the search strategy is outlined below.

Table 1—Search strategy (STARLITE principles)[82]

STARLITE principles	
S—Sampling strategy	Guiding research questions sought to identify key barriers and effective approaches/ models/ initiatives/ interventions in improving access to and coordination of healthcare for Aboriginal and Torres Strait Islander peoples in Australia and for Indigenous peoples in Canada and New Zealand
T—Type of literature	Any kind of study: Qualitative and/or quantitative studies, case studies, systematic reviews, rapid reviews, peer reviewed conference abstracts, grey literature
A—approaches	Database searching, citation searching, grey literature
R—range of years	2015–21
L—limits	English

STARLITE principles	
I—inclusions and exclusions	Inclusion Articles discussing barriers to cancer screening, diagnosis, treatment and management Articles discussing different models/ initiatives/ activities/ approaches in relation to cancer and chronic disease Exclusion Palliative care; health promotion; general epidemiology in relation to cancer screening, diagnosis, treatment and management; articles from places other than Australia, Canada and NZ
T—terms used	Cancer [and related] cancer OR cancers OR cancer* OR malignancy OR malignancies OR tumor* OR tumour* OR neoplas*OR carcinom* OR sarcom* OR lymphom* OR leukem* OR leukaem* OR melanoma* OR mesothelioma* Indigenous [and related] indigenous OR indigene* OR aborigin* OR “torres strait islander*” OR maori* OR polynesian* OR “pacific people*” OR “first nation*” OR inuit* OR eskimo* OR “native canadian*” OR metis Health service factors [and related] “health services access*” OR “health equity” OR “culturally competent care” OR “health access” OR “health care disparit*” OR “supportive care” OR “patient satisfaction” OR “patient reported outcome measures” We undertook a Google Scholar supplementary search to identify any other peer-reviewed articles that had been overlooked in the electronic database searches. Moreover, the Google database was searched for grey literature using phrases, such as, ‘Barriers to Cancer Care among Aboriginal Communities’, ‘Maori Cancer Care Model in New Zealand’, ‘Best Practice for Aboriginal Cancer Care’
E—Electronic sources	PubMed, ProQuest, Ovid databases, Scopus, Informit, Global Health (Ovid), EBSCOhost, Web of Science

Figure 1—A flowchart of the article selection process (PRISMA diagram)



From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

The seven databases retrieved a total of 7092 references (Ovid MEDLINE = 1415; Scopus = 1420; ProQuest = 953; Web of Science = 1417; CINAHL = 552; PubMed = 1335; Informit = 35). SS then identified and discarded 'clearly non-relevant' articles on review of titles/abstracts. That screening reduced the number of articles to 1279. Retrieved references were stored in a reference library (EndNote® Version X8). We identified and discarded duplicates after we imported the references into the EndNote library using the 'Finding Duplicates' option, supplemented with a manual check. We removed 727 articles as duplicates, which left 554 for us to review as a team. Two other articles were included through citation snowballing. Three team members (SS, BL and JH) reviewed these articles (Ovid MEDLIINE = 250, Web of Science = 124, Scopus = 85, ProQuest = 54, CINAHL Plus = 23, Informit = 14, PubMed = 2, Citation Snowballing = 2), and discarded a further 352 articles. We divided the articles among the three team members (SS, JH, BL) who independently screened titles and abstracts of the publications identified in the search using the predetermined inclusion criteria. Then we met in pairs to review the included abstracts and finalise the inclusion process. Articles were excluded because they were: dermatology clinic studies; a general dermato-epidemiology study; scoping review of cancer survivors' perspectives of dietary information; clinical manifestation of genetic compositions/ genes; podiatry studies; American Indians; primary country health services; invasive cervical cancer in Canada; Indigenous peoples from other countries; study protocols; pure genetic studies; cost-effectiveness studies; Model for Health Improvement—Native Hawaiian man.

After cleaning up the RIS (.txt) files, 202 full texts of these references were imported into EndNote, either automatically or manually when auto-import did not work. We reviewed all remaining articles' full texts (n = 202). Those containing evidence of barriers to cancer care and effectiveness of cancer screening, treatment, management or in general, cancer care services/ initiatives/ models/ approaches within the community and/or tertiary care setting for Indigenous populations were read more carefully. A further 97 articles were discarded in this process for the following reasons: health promotion; Indigenous cohort not mentioned; descriptive study; viewpoint articles; description of the process of developing a service/ initiative/ intervention; Specific issue such as racism, traditional medicine use; palliative care.

We identified (n = 36) articles describing models, initiatives and approaches that addressed the second research question of this Evidence Check. These articles were also scrutinised and critically appraised, and a brief description of their key initiatives has been included in this report. Pre-specified characteristics of these articles have been entered into a spreadsheet. The first research question was addressed by another set of articles (n = 52) that included information about barriers to cancer screening, diagnosis, treatment and management. We also looked at a further 17 articles on successful chronic disease models within Indigenous communities, and included a brief description of these models in Appendix 1. As we did not systematically search strategies and models addressing chronic disease, we did not use these articles in the main analysis, but included them as additional information.

Quality of evidence assessment through grading

We graded 33 studies (35 articles) that described and explored different models of cancer care, initiatives and approaches. Although the use of such grading tools helps to assess the quality of evidence, it was difficult to grade the included published studies using one classification for levels of evidence and, more importantly, the NHMRC evidence hierarchy, which is a more traditional one and focuses on clinical and quantitative studies.[83] Therefore, we assessed the methodological quality of the selected publications using Daly's hierarchy of evidence-for-practice[84] for qualitative research; the NHMRC evidence hierarchy was used to score quantitative studies by two researchers.

Daly's hierarchy of evidence categories are:

- **Level I—**Generalisable studies: Sampling focused by theory and the literature, extended as a result of analysis to capture diversity of experience. The analytic procedure is comprehensive and clear. Located in the literature to assess relevance to other settings

- Level II—Conceptual studies: Theoretical concepts guide sample selection based on analysis of the literature. May be limited to one group about which little is known or a number of important subgroups. Conceptual analysis recognises diversity in participants' views
- Level III—Descriptive studies: The sample is selected to illustrate practical rather than theoretical issues. It records a range of illustrative quotes including themes from the accounts of 'many', 'most' or 'some' study participants
- Level IV—Single case study: Provides rich data on the views or experiences of one person. Can provide insights in unexplored contexts.[84]

NHMRC evidence hierarchy categories are:

- Level I—Systematic review of Level II studies
- Level II—Randomised controlled trial
- Level III-1—Pseudorandomised controlled trial
- Level III-2—Comparative study with concurrent controls (non-randomised experimental trial; cohort study; case-control study; interrupted time-series study with a control group)
- Level III-3—Comparative study without concurrent controls (historical control study; two or more single arm studies; interrupted time-series study without a parallel control group)
- Level IV—Case series with either post-test or pre-test/post-test outcomes.[85]

Table 2—Level of evidence

Types of quantitative studies	NHMRC evidence hierarchy for quantitative studies[85]	Types of qualitative and/or mixed-methods studies	Daly's hierarchy of evidence for qualitative studies[84]
Randomised controlled studies (cluster and parallel group RCT) [N = 2]	Level II (N = 2)		
Cross-sectional and/or cohort studies (retrospective cohort study) [N = 4]	Level III-3 (N = 3) Level IV (N = 1)		
		Before–after studies (quasi-experimental design, interrupted time-series analysis, mixed-methods pilot study) [N = 3]	Level II (N = 2) Level III (N = 1)
		Qualitative studies [N = 18]	Level I (N = 1) Level II (N = 4) Level III (N = 10) Level IV (N = 3)
		Questionnaire survey (nationwide postal survey; community based survey) [N = 4]	Level I (N = 4)

		Review articles [N = 4]	Level I (N = 4)
	N = 6		N = 29
Total [N = 35]*			

*Two articles described one initiative (one was a poster abstract and the other one was a single case study)

Six of the 35 included articles that had focused on models of care/ strategies/ initiatives were found to have used quantitative study design while 29 articles used different types of qualitative and/or mixed-methods study designs. Ten of the qualitative publications were descriptive studies (evidence Level III) as per Daly's hierarchy of evidence-for-practice. The heterogeneity in data collection and reporting of findings made it difficult to rate the articles. A number of articles reported findings from project evaluations, in-practice experiences and retrospective patient data analysis. A participatory action research approach was used in designing and developing some research projects and/or community programs. The reporting of findings in these articles was very different from a standard research project, as they had included detailed descriptions of their research processes and, in some instances, research data were obtained at different stages. We did not exclude any articles that failed to meet a quality standard as our focus was to review papers relevant to the topic rather than particular study types that met strict methodological standards.[86]

Findings

Question 1

What are the main barriers to accessing screening, diagnosis, treatment and management services for Aboriginal and Torres Strait Islander peoples and Indigenous peoples?

Fifty-two peer-reviewed articles described barriers to cancer screening, diagnosis, treatment and management (cancer care) among Indigenous populations in Australia, Canada and New Zealand. We divided key barriers into three sections; barriers to cancer screening, barriers to early diagnosis of cancer and barriers to cancer care are discussed below.

1.1 Barriers to cancer screening

Screening programs and services can detect cancer early and increase people's awareness of cancer symptoms.[24, 69, 77] Early detection helps a person to seek treatment sooner, which may improve cancer outcomes. In Australia, there are three government-funded screening programs for cervical, colorectal and breast cancer detection. Low participation rates for Aboriginal and Torres Strait Islander Australians in these screening programs have been consistent for a number of years and widely reported.[69, 87] Cancer screening programs have been criticised for failing to address the particular cultural needs of Aboriginal and Torres Strait Islander Australians[69] and many service providers have identified the need for flexibility in the delivery of screening programs.[24, 88] The drivers of cancer inequities need to be addressed, especially the barriers to screening.[69]

We found 13 papers that discussed barriers for Indigenous peoples in accessing cancer screening services in Australia, Canada and New Zealand, seven looking at cervical cancer, three at colorectal cancer, one at breast cancer and two at general cancer screening. Additionally, we included one systematic review of colorectal cancer screening[6] and one systematic review of cervical cancer screening.[24] The findings in Table 3 are summarised below under three broad categories: contextual, health service-related and patient-related barriers.

Contextual barriers

Colonisation, racism and its aftermath

- Internationally within the Indigenous health context, access to healthcare is greatly affected by the historical and social contexts in which Indigenous peoples have been living.[11, 89] The ongoing impact of colonisation, oppression, racist policies, maltreatment and racism against Indigenous peoples has created distrust among this population group that limits Indigenous peoples' access to many services, including cancer screening.[6, 9, 12,

[13] This has been identified as a key barrier in a number of studies.[6, 8, 12, 13, 23, 24] Historically, government institutions and authorities in all three of the countries included in this Evidence Check controlled health services in a paternalistic manner that silenced Indigenous peoples and excluded and disconnected them from decisions about their own health and wellbeing.[12, 90, 91] Distrust of healthcare provided by government-controlled institutions and mistrust of Western medicine stemming from this historical context requires closer attention by policy makers. In the context of cancer screening, previous negative experiences with formal or government health services, fear of being sexually abused within institutions (as had been the experience of many Indigenous peoples in the past)[8, 12–14, 21], negative body perception[12] and concerns about confidentiality and privacy in the management of personal health information[6, 8, 12–14] will continue to be barriers for many Indigenous peoples unless they are addressed.

Geographical Isolation

- Inequitable access to healthcare in rural and remote Australia is widely acknowledged.[16, 17 9, 18, 19] This, along with unevenly distributed resources in a geographical location or across levels of care, has been noted as another key barrier in access to cancer screening, particularly for Australian Aboriginal and Torres Strait Islander peoples and for Canadian Aboriginal peoples.[20–23] For example, Mi'kmaq women in Eastern Canada reported a lack of availability of Pap screening services, timely appointments, transportation and interpreters as their accessibility issue.[8] Limited transport options, transportation costs, availability of screening services, limited clinic opening hours and appointment times in rural and remote areas have been highlighted in a number of other studies.[20, 24, 58] Although cancer screening is free for eligible men and women in Australia, costs related to transport to screening facilities[8, 9, 13, 14, 25, 34, 92] and parking[8, 9, 20] can be a burden for people from lower socioeconomic backgrounds. Participants in a study by Butler et al. 2020[20] suggested making screening services available outside working hours and reducing waiting times by having a nurse complete screening rather than a doctor
- Low rates of Medicare registration containing an up-to-date address may have been an influence in precluding Aboriginal and Torres Strait Islander Australians from receiving a Faecal Occult Blood Test (FOBT) kit in the mail.[34] On the basis of the 2011 Australian Bureau of Statistics (ABS) census population data and Medicare billing data, there has been an increase in the uptake of the *Health Assessment for Aboriginal and Torres Strait Islander People* (Medicare Benefits Schedule item number 715 [MBS-715]) nationally from 14.3% in 2011–12 to 21.3% in 2013–14. However, the rates are still low, and there is great variability across rural areas and the types of primary healthcare services.[93]

Limitations of the national health information systems

- National cervical screening rates for Aboriginal and Torres Strait Islander women are not available in Australia, as Aboriginal and Torres Strait Islander Australian status information is not collected on pathology forms in all jurisdictions.[75] Therefore, regular monitoring of screening rates is not possible for some jurisdictions. This is a major issue of the national health information systems, which must be addressed by including Aboriginal and Torres Strait Islander Australians in cancer research, as participants and in leadership and governance roles.[24] High quality data collection and regular reporting enables *"ongoing monitoring and evaluation, measures progress against elimination targets, identifies where resources are most needed, and measures which inventions work and do not work".*[24]

Health service-related barriers

Lack of knowledge and confidence of health professionals

- A number of studies in all three countries—Australia, New Zealand and Canada—have found health professionals have limited knowledge about cancer and the importance of cancer screening, especially in rural and remote locations.[6, 8, 9, 25] This is true for knowledge of colorectal cancer screening. It has been reported in a systematic review that health professionals, including general practitioners, lack knowledge of the risk of colorectal cancer and the importance of screening for it. This often results in their failure to recommend screening for this disease to patients, which has influenced Aboriginal and Torres Strait Islander Australians' participation.[6] Health professionals working within Aboriginal and Torres Strait Islander communities do not frequently raise or discuss early detection of bowel cancer during appointments.[6] While there is general awareness of the National Bowel Cancer Screening Program (NBCSP) in some communities, there is little discussion to raise awareness of it.[34] This can be attributed to shame, embarrassment and fear, combined with the low priority given to participation in the NBCSP both by health professionals and Indigenous community members.[6, 34] A mixed-method study from Australia included in the same systematic review identified that health professionals working with Aboriginal and Torres Strait Islander clients did not feel confident to discuss the topic and required upskilling and training with respect to colorectal cancer and colorectal cancer screening.[70] High complexity associated with the bowel cancer screening kit and accompanying instructions is also associated with low uptake of this screening. Complexities identified in the literature include faecal immunochemical test (*FIT*) initiation; scheduling; capacity and no-shows; screening capacity; multiple disconnected patient charts.[34]

Lack of availability of appropriate practitioners

- There is evidence that having female practitioners and trained Aboriginal health workers to advocate for and perform screening tests for eligible women leads to increased breast and cervical screening participation for Aboriginal and Torres Strait Islander Australians and Aboriginal Canadians.[8, 20] A strong and trusting relationship with health professionals is critical for Indigenous patients and families to feel comfortable within health services.[6, 12–14, 20] Butler et al. (2020), in Australia, also reported that Aboriginal and Torres Strait Islander participants in their study were more comfortable with one '*of our own mob*' conducting cervical screening because most women viewed cervical screening as 'women's business'. A shortage of female and/or appropriate and Aboriginal and Torres Strait Islander health professionals has been widely reported in the literature.[8, 9]

Logistical barriers

- Seven studies identified several health system factors that may affect Indigenous patients' acceptance of healthcare facilities for cancer screening and influence their choices and decision-making. For example, underrepresentation and high turnover of Aboriginal and Torres Strait Islander health professionals[28]; health professionals dealing with multiple clinical priorities and tasks simultaneously because of shortages of facilities and staff, which affects the quality of service delivery[29]; a shortage of female practitioners[9]; lack of flexibility within the system[29]; clinical staff turnover[29]; absence of well-maintained and efficient clinical information systems for notifying, recalling and reminding women (especially sending letters) of their screening due date or appointments.[29]

Cultural inappropriateness

- Some other barriers identified from the literature included the experience of medical discrimination and/or negative experiences with health professionals or health services[8, 12, 13, 21] and culturally incompetent health services and staff.[6, 13] Three qualitative studies reported that health professionals lacked education and knowledge about Indigenous cultural beliefs, rituals and needs in general. They require capacity building through cultural competency training to promote engagement and enhance the quality of communication and interpersonal relationships between health professionals and Indigenous patients.[6, 13, 14, 29] Many studies also reported a lack of culturally relevant and acceptable information and resources.[6, 20–22, 34]

Patient-related barriers

Patients' health literacy and low community awareness

- Most studies identified a lack of knowledge and low community awareness[12, 13, 20, 34] about different cancers and screening, especially the risk, harm and prevalence of colorectal cancer, as an important barrier to Indigenous participation in cancer screening. Fear of cancer[6, 8, 13, 14, 20, 25, 34], stress over the results[25] and fear of the procedure[6, 9, 13, 14, 29] were some of the patient-related factors that negatively influenced Indigenous peoples' approach to cancer screening in all three countries.

Differing cultural beliefs

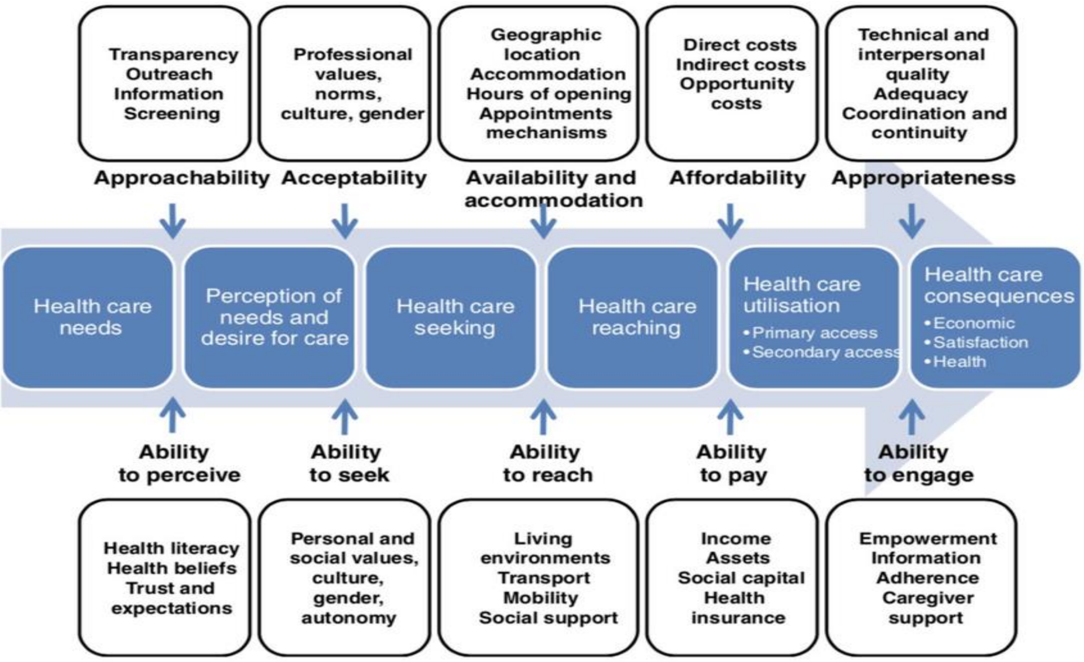
- Differing cultural beliefs about a cancer diagnosis including fatalism, fear, stigma, shame and embarrassment may thwart participation.[6, 9, 12–14, 20, 23, 25, 29, 34] A number of studies have reported shame and stigma related to sexuality and sexually transmitted infections, negative stereotypes of the body image of Indigenous women and body shyness[12] and sensitivities about sexual health[12, 21]; women, therefore, can decline a Pap smear test to protect themselves against sexual abuse and violation.[8, 9, 12, 24] Strategies identified to address such misconceptions and information gaps focused on a need for culturally tailored education and promotion, ideally featuring and delivered by local Indigenous people.[6, 24, 25] Indigenous patient navigators, educators and/or Aboriginal health workers have been able to address several of the barriers, as they can promote screening, provide culturally sensitive information about screening, assist patients to complete screening and navigate complex health systems.[43]

Initially, we organised the key barriers to cancer screening, diagnosis, treatment and management as service and patient-level barriers in the five Levesque[94] dimensions of access to healthcare that are included in Tables 3, 4 and 5. Levesque et al. (2013) derived five broad dimensions and determinants of access that integrate the demand and supply-side factors of the process of obtaining care and benefiting from the services.[94] As shown in Figure 2, the five dimensions of service accessibility (approachability, acceptability, availability and accommodation, affordability and appropriateness) are represented in the upper part of the diagram, whereas five corresponding consumer factors interacting with the accessibility (ability to perceive, ability to seek, ability to reach, ability to pay and ability to engage) are described in the lower part.

According to Levesque et al.:

- **Approachability** relates to people with health needs being able to identify relevant services and approach them
- **Acceptability** relates to cultural and social factors, and the judged appropriateness for people to seek care
- **Availability and accommodation** relates to the physical existence of services and facilities. It also results from “characteristics of facilities (e.g. density, concentration, distribution, building accessibility), of urban contexts (e.g. decentralisation, urban spread, and transportation system) and of individuals (e.g. duration and flexibility of working hours). It also relates to characteristics of providers (e.g. presence of the health professional, qualification) and modes of provision of services (e.g. contact procedure and the possibility of virtual consultations)” [94]
- **Affordability** relates to the economic capacity of people to access to health services
- **Appropriateness** is a complex concept with various dimensions and definitions, which may differ between populations and geographical locations. Appropriateness, according to Levesque et al., denotes “the fit between services and clients’ need, its timeliness, the amount of care… the technical and interpersonal quality of the services provided.” [94]

Figure 2—Levesque et al.’s model of access to healthcare[94]



The following table summarises the key barriers to cancer screening for Indigenous peoples.

Table 3—Barriers to accessing cancer-screening services for Indigenous peoples in Australia, Canada and NZ according to Levesque's model of access to healthcare

Approachability	
Service approachability factors	**Patient factors (ability to perceive)**
Ongoing impact of colonisation and oppression including racist policies leading to distrust of healthcare services[24]; lack of trust, respectful relationship with health professionals[13] **Jurisdictional ambiguity, such as in Canada[12]** **Social & popular media that reduces boundaries/ privacy (e.g. Facebook)[21];** **Previous negative experiences with health professionals or health services (painful pelvic exams, inappropriate actions/ comments by health professionals)[19]** **Low community awareness[95]; limited promotion of the program in community languages[12]** **Missing vaccination data.[24]**	**Systemic mistrust**[6, 12–14, 33]; **lack of confidence** in government and institutions[95] **Mistrust of medicine**[14] such as in the medical knowledge of doctors to diagnose or treat cancer[24], in the scientific procedures in laboratories to test the FOBT[13, 14]; and the overall efficacy of the iFOBT[13, 14] **Patient history, including personal history of sexual abuse**[9, 12, 21], social determinants of health[24]; experiences with residential schooling and abuse[9, 21]: an extension of colonisation and the pain and suffering from sexual abuse[9, 21] **Fear of cancer**[6, 9, 13, 14, 20, 25, 34]; experiencing stress over the results received[25]; fear of the procedure[6, 9, 13, 14, 29] **Low individual awareness** levels about screening and benefits of prevention[19]; (screening was only necessary if they experienced symptoms)[6, 13, 14]; Seeking healthcare when symptomatic[23]; concomitant futility (pointless) of undertaking screening[13, 14]; perceived invasiveness of a pelvic examination[12, 22] **Lack of health literacy** about HPV and cervical cancer[13, 14] **Not knowing which health professionals to see**[30] **Negative body perception** (shame and the female body)[12] **Shame related to sexuality and sexually transmitted infections**[12, 21]; sensitivities regarding sexual health promotion[21]; not accessing Pap smear was a way to protect against sexual abuse and violation[58] **Embarrassment**[58]**, stigma and fear**, shame.[12–14, 20, 29]

Acceptability	
Service acceptability	**Patient factors (ability to seek)**
Competing clinical priorities[29]; **chronic conditions consuming consultation time**[24] **Shortage of female practitioners**[88, 96] **Health system challenges**[54]; mainstream health services were not aligned with Indigenous peoples' needs **Lack of flexibility** within the system[29] Lack of endorsement by GPs (colorectal)[95] Difficulties following up with patients because of inconsistencies in the way results are entered into patient health records.[95]	**Beliefs about cancer** including **fatalistic views and stigma**[6, 9, 12, 20, 34] Exposing body compromises sacredness of women's bodies[12] **Differing cultural beliefs** about a cancer diagnosis, including fatalism, fear, stigma and shame, may thwart participation[6, 9, 12–14, 20, 23, 25] Embarrassment[6, 13, 14, 20, 29, 34]; **cultural beliefs about cancer in general** and breast cancer in particular[54;] remain a responsibility of women[62] Unpleasant nature of the test[6, 34]; **Pap smears made them feel violated**[9] **Strong beliefs in traditional medicines** or other alternative therapies[6] Disrupted relationships to nature & spirituality.[21]
Availability (and accommodation)	
Health service factors	**Patient factors (ability to reach)**
Service infrastructure gap[62] **Lack of recall systems**, especially when opportunistic screening programs rely on primary healthcare providers to remind women to screen[95] **Limited clinic opening hours and appointment times**, especially for women who are working and/or have caring responsibilities[95]; **structural barriers**[9, 20] **Limited access to primary healthcare**[95] Inequitable healthcare access and poor patient outcomes[90, 97]; multiple disconnected patient charts[97, 98]; screening capacity[97, 98]; fewer services[62] **The use of the postal service** in remote areas with a lack of privacy[13, 14]; delays in receipt of mailed correspondence due to potentially having an on-reserve address and an urban residence[23] Never received a kit.[34]	**Forgetting**[95]; not having time[58]; **desire for bodily autonomy** (retaining privacy, control over one's body)[58]; poor physical and mental health[22] **Competing life priorities**[25]; working outside the home, attending school, keeping house, or having community and childcare responsibilities[9] Negative coping strategies for life adversities[62] **Other health issues**[9] **Psychological factors**[34]; substance misuse & reduced inhibitions[21] Broken family relationships / loss of connectedness[21] Move away from monogamous relationships.[21]

Affordability

Service affordability	Patient factors (ability to pay)
Transport (cost of travel to hub communities, fewer transport options)[62]; poor road conditions[62]; **transport**[9, 13, 14, 20, 25]; **financial**[22]; hidden cost (transport, parking, childcare, accommodation, etc.).[62]	**Poverty**[21]; low socioeconomic condition[9, 21] (being poor, lack of money for transportation or childcare; lacking education, being a young, single parent, being economically dependent on the govt.[13]; overcrowding[21], hunger[21] **Absence of Medicare registration.**[34]

Appropriateness

Service inappropriateness	Patient factor (ability to engage)
Unavailability of national participation data for Indigenous women; under-ascertainment of Indigenous status[24]; challenges in identifying patients who are overdue for screening[95]; **Lack of culturally relevant and acceptable information and resources**[6, 21, 22]; **inappropriate promotional materials**[6, 20]; complex, difficult to understand test kit instructions[6] Reduced elder involvement in education[21] **Health professionals not educated about cultural beliefs, rituals and needs**[6, 14, 29]; Culturally incompetent staff[6] **Health professionals' lack of knowledge about the risk of colorectal cancers,** the **importance of** colorectal cancer screening, and options for this[6] Lack of appropriate/ empathetic services[9]; Inadequacies in cultural awareness in the screening program.[25]	Means of communication between the healthcare provider and the patient[12, 99]; Language difficulties[14] **Fear of confidentiality and privacy** breaches[6, 9, 12–14, 29] **Gender of practitioners.**[9, 20]

1.2 Barriers to early diagnosis, treatment and management of cancer

Thirty-nine of the articles included in this Evidence Check discussed barriers related to early diagnosis, treatment and management of cancers. Only four articles explicitly talked about barriers and enablers to early presentation and diagnosis; two of these are systematic reviews.[10, 30] Two articles focused on lung cancer[18, 30]; one on colorectal cancer[100]; and one on cancer in general.[10] Five articles discussed diagnosis as part of the treatment process.[31, 97, 98, 101, 102] As above, we grouped the key barriers we identified under the five dimensions of accessibility as specified by Levesque et al. in Tables 4 and 5. However, they have been thematically grouped under three broad categories of contextual, health service-related and patient-related barriers, below, for discussion:

Contextual barriers

Geographical isolation, infrastructure and logistical barriers

Arising from the long history of mistreatment, institutional racism and discrimination[5, 7, 12–14, 32, 90, 98], many Indigenous peoples live in poor socioeconomic conditions and/or rural or remote locations[7, 8, 21, 33, 53, 90] where health and education services are limited.[30, 31, 33, 41, 50, 102, 103] This directly influences the availability and quality of care and the significant direct and indirect costs of care that can accrue. This includes long waiting times for specialist appointments for public patients, a shortage of medical doctors[104, 105], high staff turnover among rural GPs[10, 18, 30], travel for medical appointments or diagnostic tests, diagnostic delays in the primary healthcare setting and long waiting times for specialist care[10, 31, 98, 100], delays in treatment and overall cancer care, and associated accommodation and food needs.[5, 10, 30, 31, 102] These different logistical barriers have made the cancer journey fragmented for many Indigenous people.[5, 7, 10, 31, 36, 40, 90, 106] Galloway et al. (2020), for example, reported in their study that communities living in northern Canada were required to travel considerably more for medical services than were southern Canadians, and the distances require complicated and expensive flight paths involving multiple transfers and overnight stays en route.[31] Lack of accessibility to public transport is reported in a study conducted in Queensland.[102]

Taylor et al. (2021) in Australia and Chan et al. (2019) in Canada reported there were significant access barriers to specialist cancer care for many communities. Three-quarters of the Aboriginal and Torres Strait Islander participants affected by cancer in the Taylor et al. study reported difficulties in reaching the cancer service.

“Time between them first experiencing symptoms and reaching either the urban or regional cancer services was ‘confusing’, ‘stressful’, and marked by medical delays, misdiagnosis and poor communication from health service providers.” [41]

Chan et al. (2019) reported:

“With no road access in most regions, providing health services to small and scattered populations across a vast geographical area is one of the most challenging issues faced by health-care providers in the Arctic. The only option for travelling is by flight, which might only depart from a community twice per week.” [103]

While there are efforts to address these barriers, ongoing monitoring will be required to ensure they result in the desired changes for Indigenous peoples with cancer. The issue of being away from one’s own country to receive treatment can be especially devastating for many Indigenous peoples, *“not only because of logistical barriers, but also due to the loss of emotional and cultural support networks and the loss of spiritual and other benefits of connection to Country during a stressful and traumatic time.”* [32]

Identification of Indigenous status

- Within some communities, historical legacies have also resulted in Indigenous peoples being unwilling to disclose their identity because of fear of discrimination and discomfort about 'Aboriginality'[32] and a lack of trust in Western medicine; this has had a negative impact on health-related communication.[33, 44, 45, 106–111]

Health service-related barriers

Differences in professional values and practices between Indigenous and non-Indigenous staff and a shortage in the Indigenous workforce

- Mainstream health system professional values and practices may be different from Indigenous social and cultural values and this can affect how comfortable Indigenous patients and families feel when they are accessing health services.[33, 64, 97] Five qualitative papers have highlighted how these differences can affect communication between health professionals and patients, as they generate different kinds of expectations from each other. This can lead health professionals to feel uncertain about how best to handle and respond to Indigenous peoples' needs.[38, 49, 66, 106] An Indigenous workforce can, in many different ways, minimise the negative effects on, and experiences of Indigenous patients by overcoming key cultural and communication barriers.[112] For example, there is evidence that Aboriginal and Torres Strait Islander health workers help to improve attendance at appointments and acceptance of treatment[113], reduce discharge against medical advice, increase patient contact time, enhance patient referral linkages and improve patient follow-up practices.[114] Indigenous health professionals also support non-Indigenous health professionals to deliver culturally appropriate care through providing cultural, social and community mentorship and education, acting as cultural brokers, helping to increase patient trust towards the health system and therefore improving care and health outcomes.[28, 112–114] However, studies have reported that little is being done to increase, support and retain this workforce[112], and due to low numbers, Aboriginal and Torres Strait Islander staff often carry a heavy workload and hence are more prone to mental exhaustion.[33, 97]

Culturally inappropriate service delivery and communication barriers

- Increasing the number of Aboriginal and Torres Strait Islander health professionals is an utmost need, but it is also true that delivering culturally safe care within a culturally safe environment is everyone's responsibility, not just that of Indigenous workforce.[53] There is evidence that the care of Indigenous people with cancer is rife with interpersonal communication issues between patients and health professionals that include use of medical jargon, language barriers (with some reporting reluctance to use interpreters because of the associated shame of the diagnosis)[32, 33, 36, 38, 101, 103, 107, 115], poor or inappropriate communication[5, 7, 31, 32, 49, 66, 98], and health professionals' lack of respect for traditional cultural practices and healing.[106, 107, 111] Therefore, there is a need for all health professionals providing cancer care for Indigenous peoples to attend to compulsory cultural safety training so they learn to acknowledge and accept differing cultural views and practices as valid, and to be trained in interpersonal skills that foster empathetic and respectful communication, leading to the development of therapeutic relationships with their patients.[36, 66, 106] Organisations must also ensure they implement and meet standards in cultural safety and security so staff feel supported to practise culturally safe care.[116] Attention is needed to promote cultural safety within the health system.[5, 7, 36, 98, 107, 109, 117]

- The literature included in this Evidence Check highlighted several other quality factors with regard to health services. These include inflexible appointments[64]; poor coordination in the appointment process[52]; poor care coordination[10, 18, 30]; lack of respectful care[90]; insensitive or disrespectful hospital staff[109]; cancer information provided in a manner that does not demonstrate cultural responsiveness.[7]

Lack of appreciation of the role of family and communities in patient care

- Most Indigenous cultures adhere to collective cultural practices.[115] An appropriate cancer service for Indigenous people must recognise the important role the family and communities play in providing support to Indigenous patients with cancer and their families.[32, 107, 115] This was mentioned, with a broad range of support types highlighted, such as emotional, spiritual, practical, advocacy, home care, assistance in decision-making about treatment options, information provision, moral support and gatekeeping.[18, 30–33] Western non-Indigenous health professionals often do not understand the importance of involving families in decision-making processes; that can make communication and relationship-building more difficult.[18, 30–33] Patients and families have reported feeling disconnected and unhappy about their treatment and cancer care experience, which then spread through their communities, reinforcing mistrust of the health system in general.[10, 36] Little things such as this can jeopardise the cancer journey for many Indigenous people. A continuing relationship between health professionals, patients and extended family members is crucial to ensure understandable information flows to both parties.[35] Studies have found that shared decision-making between the cancer patient, family, staff and community members enabled better access, care planning and continuity of care.[53]

Patient-related barriers

Patients’ health literacy, health beliefs, language and communication

- A predominant barrier to cancer diagnosis and treatment relates to patient perceptions and understanding of cancer and its symptoms[10, 18, 30, 33, 39, 100–102]; this barrier starts prior to any healthcare contact but can continue to influence treatment along the patient journey. This relates to self-appraisal and self-management of initial presentation of symptoms[10, 18, 30, 33, 39, 100] and perceptions of cancer including shame and embarrassment[10, 18, 30, 100, 101], such as for cancers arising from the prostate, breast and cervix. Targeted and appropriately written information and resources need to be developed.[50] This can include individual support plans, financial information, transport options, accommodation support information and other general health literacy information.[53]
- Some studies reported that there was no word for cancer[38, 48] in Indigenous languages. Furthermore, Indigenous patients have been reported to have unrealistically high expectations of Western medicine and often there is an expectation that doctors are going to fix everything.[91, 101, 108] Once the outcomes are poor, this belief reinforces the distrust Indigenous peoples already have towards the health system from past negative experiences and racism within the system.[91, 101, 108]

Personal, social and cultural values and other competing priorities

- A number of studies reported that Indigenous patients often must deal with personal and familial crises overlaying the cancer diagnosis, including managing other seriously ill family members and looking after family, including children and grandchildren.[31, 33, 35, 36] Many patients expressed concerns about how family members would be affected by their illnesses; this was among the most highly ranked unmet needs.[38] Chan et al. (2019), in their study, found some Inuit patients in Canada delayed or declined their treatments during subsistence seasons to enable them to stay at home and provide food for their families.[103] Cancer treatments often require patients to stay at or near hospital for long periods of time and it is often hard for support people to stay away from home for that long due to financial restrictions and other commitments at home.[64, 103, 107] Patient Assisted Travel Schemes, available in most states in Australia, only provide assistance for one companion to travel with a patient, and the patient often feels lonely and isolated if that support person needs to return home.[38] A review by Micklem et al. (2015) reported many patients referred to the hospital environment as cold, impersonal and intimidating.[38] The importance of Indigenous patients being supported by their family members needs to be acknowledged and addressed at the system level.[38, 43, 53, 103, 107] Indigenous 'patient navigators' have been found to fill these gaps for Indigenous patients with cancer[43] where the hospital Indigenous liaison officers could not provide the necessary support.
- A universal message across different studies was that Indigenous peoples are diverse and need to be treated as individuals.[11] It is now widely accepted that a person's life circumstances and background do significantly influence their engagement with treatment and their need for support, and these should be considered by health services.[32]

Gendered dimensions of cancer care

- A few studies reported on the gendered dimensions of cancer experiences in Indigenous communities.[10, 18, 30, 39] Newman et al. (2017) identified seven recurrent beliefs of Aboriginal and Torres Strait Islander men in Australia that highlighted that these men avoid seeking help for health matters, preferring to ignore or put up with the physical symptoms of illness. The implication of this is a late diagnosis of cancer. They also reported that after a cancer diagnosis, Aboriginal and Torres Strait Islander men preferred not to talk about it and a preferred response to cancer diagnosis among Aboriginal and Torres Strait Islander men was also to just 'get on with it' rather than dwelling on the emotional implications of the disease. Many Aboriginal and Torres Strait Islander men just wanted to protect their cultural roles throughout cancer care and treatment. Their findings confirm the need for better engagement and support for Aboriginal men within the healthcare system so that cancer care is appropriate and timely for Aboriginal and Torres Strait Islander men.[39]

Barriers to early diagnosis of cancer and treatment and management of cancer among Indigenous peoples in Australia, Canada and New Zealand are summarised in Tables 4 and 5.

Table 4—Barriers to early diagnosis of cancer among Indigenous peoples in Australia, Canada and NZ according to Levesque's model of access to health services

Approachability	
Service approachability factors	**Patient factors (ability to perceive)**
GP misdiagnosis of cancer[10, 30, 33, 41] **GPs lacked knowledge to interpret symptoms**[30]; health professionals' appraisal led to an inaccurate re-evaluation of self-diagnosed symptoms (e.g. symptoms of lung cancer being diagnosed as asthma)[30] **Limited access to healthcare** (provider and services)[30, 31, 102] **Racism and institutional rules and expectations**[10, 98] **Past negative experience within health services**[5] **Poor care coordination**, especially across different areas of the system, i.e. primary and hospital care, rural/ regional and metropolitan, different health professionals and hospitals.[30, 41] **Policy-related factors (Canada):** • Limited availability of care in several First Nations communities; and • Federal medical transportation policy that does not subsidise transportation for preventive and diagnostic purposes.	**Lack of knowledge of cancer:**[30, 101, 102] **Comorbidities**[10]; **Misattribution of symptoms**, especially when mismatched to public messaging about cancer symptoms as for lung cancer[18, 30], and/or hidden by pre-existing conditions or attributed to benign causes[10, 100]; self-management of symptoms delay presentation[10, 30, 100] **Denial or stoicism about symptoms**[30, 33, 39] **Severity of symptoms:** reluctance to present to the GP when cancer symptoms first occur[106, 117]; symptoms had to be severe before patients sought assistance[100] **Symptoms of lung cancer**[18] **Distrust of health system**: discomfort with one's Aboriginality[5]; systemic distrust limits health-related communication[5]; fear of the whole system.[10]
Acceptability	
Service acceptability	**Patient factors (ability to seek)**
Shortage of Aboriginal health professionals[10] **Competing demands for time:**[10, 30, 102] In Australia, an **increased societal awareness of lung cancer as being smoking-related and therefore the 'fault of the individual'**; increased stigma related to the condition and smoking, thus serving as a barrier to seeking help[30]	**Fear of leaving home** for treatment[10] **Reluctance to attend GP**[106, 117]; low health-seeking behaviour[102] **Shame and embarrassment**: often organ-specific, such as breast, prostate, and cervix cancer[10, 101]; related to desire for privacy and reluctance to reveal illness[100, 117]; perception that they will be reprimanded about health behaviours, especially smoking[30]

Waiting times for specialist care.[10, 31, 98, 100]	**Perceptions of cancer** (often from cultural beliefs): cancer as fatalistic ‘death sentence’[18, 30, 97], as **‘payback’ for past wrong-doings** with associated **blame and guilt**[10, 30, 117] **Gender-specific patient beliefs** (male): losing ‘pride as men’[10, 39]; value placed on masculinity over needs as a person with cancer[39] **Bush medicine and traditional healing**[10] **Time for self-care is not prioritised, especially among women.**[10]
Availability (and accommodation)	
Health service factors	**Patient factors (ability to reach)**
Under-resourcing for rural healthcare: waiting times, less access to diagnostic tests[10, 18, 33, 102], diagnostic services not provided to First Nations communities[7] **Shortage of doctors** in remote communities[105] **Timely access to primary care**: rural doctor shortages[105] and high turnover of rural GPs[10, 18, 30], GP as important advocate for patients.[98, 100]	**Transport needs**: generally[7] and for specialist care[5, 30, 102], reluctance or fear to leave home.[10, 41]
Affordability	
Service affordability	**Patient factors (ability to pay)**
Direct costs: out-of-pocket costs of healthcare including costs of insurance[5, 30, 102, 117] **Indirect costs:** lack of subsidised transport for preventive care or diagnostics (versus providing treatment).	**Impact of medical travel**[31]; Ongoing stressors **Extensive medical travel imposed significant burdens on families and communities** in the forms of childcare, missing paid work, time away from family, and the financial costs of travel.[31]
Appropriateness	
Service inappropriateness	**Patient factor (ability to engage)**
Lack of **culturally appropriate resources** (pictorial, easily read, or use of traditional dance or song or art)[102]	Involvement of **family and caregivers**[18]: support role of Whanau or family members is crucial[7, 98]

Poor care coordination: especially across different areas of the system, i.e. primary and hospital care, rural/ regional and metropolitan, different health professionals and hospitals[30, 41] **Lack of cultural safety**: lack of respect for other worldviews[10, 18], not understanding 'Māori way of speaking'[18, 101]; judgmental or racist and blame-based view of Māori[18] Other **communication issues**: language barrier[18], jargon[98], poor communication delivery or quality[18, 41, 102] **Patients with no or limited symptoms are low priorities**[10] **Inadequate information delivery.**[18]	**Other life stressors**, including multiple healthcare issues[30, 117]; Differences in **understanding the treatment terminologies.**[98]

Table 5—Barriers to cancer treatment and management (cancer care) according to Levesque et al.'s model of access to health services

Approachability	
Service approachability factors	**Patient factors (ability to perceive)**
History and policy **Policy challenges related to the fragmented context of care** that requires First Nations peoples to 'cross' jurisdictional boundaries repeatedly to access care.[97] **Effect of Stolen Generation and the legacy of colonial history**[32]; **history of trauma/abuse**[7] *Institutional and interpersonal racism* **Institutional racism and discrimination**[5, 32, 90, 98] **Negative experiences** with local health clinics, other hospitals and non-cancer wards[41]; **previous experiences with health services**; hospitals were usually associated with death and dying, not recovery[115] Health professionals' judgmental or **racist blame-based** view of Māori [101,10,18,90,41]; racialised clinical judgments about their health needs[90]	*Trust* **Mistrust of services**[5, 33, 90, 107–109, 115] **Distrust of conventional medicine**[109, 118, 119]; **of diagnosis and Western treatment after cancer therapy**[108] *Expectations* **Unrealistic expectations of Western medicine**[101]**:** 'doctor knows best'—patients in the more remote areas of northern Saskatchewan tended to trust the physician expertise[108] *Health literacy* **Patients ill-prepared and poorly informed** about cancer, cancer care and treatment options[107, 7, 53, 105, 103, 32, 33, 120]; **available services**[33]; significant **gaps in knowledge** about HPV transmission, prognosis, protective health behaviour and treatment[106]**;** **Fear**[108] **and cumulative grief of losing loved ones** to cancer[90,119,50, 52]; cancer is **a death sentence**[36, 49,38]; **silence about cancer**[115,51,90,36] relating to **stigma, other**

Cancer support groups less appropriate for Indigenous peoples[107]; support groups uninviting and spaces where only white women could go[90,36] ***Lack of transparency*** Issues with **delayed diagnosis or referral leading to mistrust.**[33, 52]	**stressors**[32, 51, 35, 119, 7, 36, 38, 48, 50]; cancer is a hidden disease ***Health beliefs*** **Belief cancer is contagious**[38] **No word for cancer—a foreign concept**[38, 48] **Reluctance in accessing cancer services** (not reporting cancer symptoms[64]; Fear of seeking clarification from a hospital specialist about their cancer condition[64]); **denial or not wanting to know about diagnosis and prognosis**[119]; **not interested in follow-up information as they concentrated on negative aspects of cancer recovery**[52] Historically in Canada, the word for cancer **in Inuktitut is 'cannot be fixed or healed'**, which has resulted in fear, and might discourage Inuit community members from discussing such topics openly and from actively seeking treatment.[103]
Acceptability	
Service acceptability	**Patient factors (ability to seek)**
Professional values and practices **Aboriginal liaison officers and navigators have heavy workload and busy** schedule[64,97,33] **Tertiary follow-up appointments time-consuming**[52] Displays of **impatience** with people[90] **Stereotypical evaluations of patients' life circumstances**[90, 41, 33] Patients are not always granted an accompanying person for their medical travel and appointments[103] **GPs do not have time** to discuss cancer screening[7] **Inflexible appointments**[7,64], poor coordination of appointments and inflexibility in the appointment process[52] **Lack of respectful care** for First Nations patients[90]; hospital staff insensitive or disrespectful of patients' feelings[37, 109]	***Personal and social values*** **Physical symptoms of disease**, functional impairments of disease, side effects of treatment (hair loss, disfigurement from surgical intervention)[38]; **highly visible effects of cancer**[90]; being burdened with complex and distressing physical symptoms (the majority living with advanced disease) [53] **Fear of gossip**[101, 48, 35, 6] **Collective decision-making** within the community[36, 103]; **family contribution to treatment decisions (both positives and negatives)**[36, 109]; being strong for family, family support[119] **Managing competing needs** in addition to own health issues[53 107]; caregiving traditions, i.e. family/community look after patient[103, 64]; concerns about the worries of those close to you and need for family to also receive practical and emotional support[38, 37]; patients were less likely to accept treatment in winter months; some patients (Inuit in Canada) delay, interrupt or forego treatment during subsistence seasons

Provided cancer **information not culturally responsive** or not in the right language[7] **Incongruity between Western medical framework and Indigenous views of health and illness**[49,38,90]; different expectations between the health professionals and patient led to health professionals feeling uncertain and lacking confidence about how best to respond[66]; **value mismatch** between staff and patients[107] ***Staff shortage*** **Lack of Indigenous staff**[32, 107]; difficulty finding female health professionals (gynae cancer)[7, 36]; Gender-specific health providers[33] **Identification of Indigenous status** within the health system influenced by history and racism[32] High staff turnover and poor staff retention in remote areas[7] Health professionals’ misjudgement and lack of awareness.[101, 33]	to enable them to stay at home and provide food for families[103] ***Culture*** Spirituality and connection to place; **Indigenous women ‘out of country’ can become quiet and withdrawn**[101,48]; cultural shock of relocation[103] Role of the land in healing[31, 32, 36] Concept of ‘chosen’, ‘bad spirits’, fatalism; sacredness of the body[36] **Preference for traditional medicine** ‘rongoa Māori’[109, 118, 108, 121]; beliefs in healing power of cultural ceremony[108] **Cultural significance of removing hair and body parts**[101] **Shyness and embarrassment**[109]; shame Cultural concerns about **blame and payback** can also influence pain management[38,36]; cultural barriers in accessing specialist care[40]; **shyness ‘whakama’** talking about medical situation in public setting, e.g. reception[109] Delays or interruptions to treatment due to cultural practices, e.g. sorry business or going bush[107] ***Gender*** **Being male**[10, 39]; **fear of losing their ‘pride as men’**[10, 39]; preferring to ignore or put up with the physical symptoms of illness[39]; stoicism among men, where patients did not wish to complain, instead putting on a brave face[30]; female ‘stoicism’ as well[33]; do not talk about their experience[39]; old men are ashamed of admitting that they are unwell[10]; **protect cultural roles for men** throughout cancer care and treatment—prioritise the value they placed on masculinity over their potential needs as a person with cancer.[39]
Availability (and accommodation)	
Health service factors	**Patient factors (ability to reach)**
Simply ‘getting here’ was a barrier (specialist cancer centre)[41]; with no road access in most regions, the only option for travelling is by flight, which might only	**Transport to medical appointments**, locally or in the metropolitan area[5, 32, 41, 64, 103, 107, 115, 50]

depart from a community twice a week[103]; geographical (poor road infrastructure, travel burden)[103, 50, 33] **Lack of availability of** • **Treatment and supportive care** within or close to the community[36, 90, 97, 7] • **Doctors in rural and remote settings**[10, 40, 48, 48,1 03] • **Public transport** in rural areas[115] • **Palliative care** in some provinces[7] • **Culturally appropriate cancer clinics**[10, 36] • **Radiation therapy services** [103] • **Beds** • **Allied health professionals** • **Explicit follow-up processes for returning patients**[101] • **Accommodation** facilities[107, 64]; housing while receiving outpatient treatment • **Proper funds to community clinics** to provide sufficient care and support for cancer survivors[90] • **Primary and tertiary health support** and navigation[50, 7] • **Social support** (family, childcare).[7, 37]	**Difficulties associated with extensive medical travel**[31, 33] **Patients need to be transferred to metro**[10, 31] **Dislocation from social support**[107]; **dislocation from home**[107] **Comorbidities**[52] **Emotional strain of cancer diagnosis and treatment**[33]; hard to cope with treatment demand[33] with other family members going through other serious health conditions[33]; psychosocial issues[5] and **stress** related to housing insecurity, financial issues, relocation[33] Treatment affected and challenged family relationships and roles.[35, 31, 36]
Affordability	
Service affordability	**Patient factors (ability to pay)**
Hidden costs, i.e. travel/ accommodation/ food[7, 32, 33, 48–50, 96, 97, 103, 107, 117] **Bureaucratic complexities** of claims for financial reimbursement of expenses.[33]	**Costs for hospital parking, overnight accommodation and meals** left families with significant out-of-pocket expense[115, 33] **Uncertainty and lack of knowledge about financial support** available to patients[107, 33] **Socioeconomic factors** (housing, food insecurity, family violence) and transport for themselves or family due to poverty[7, 53, 90, 33]; **difficulty with housing**[53] **Costs of medication after discharge from the hospital**[52] **Loss of income and its impact on family.**[50, 53, 64, 90, 103, 107]

Appropriateness

Service inappropriateness	**Patient factor (ability to engage)**
Staff inadequacy (quantity and quality) **High staff turnover,** i.e. hard to have culturally sensitive care[107] **Limited experience with Indigenous patients**[49] **Lack of cultural safety**[5, 36, 98, 109, 7, 107, 117] **Health professionals have limited understanding**[98] **and knowledge of different cultural practices, including traditional medicine and healing**/ health professionals lack understanding of traditional beliefs and values[118, 101, 10, 111, 32]; **Lack of understanding of complex nature of travel arrangements**[105] and living conditions[33] *Lack of appropriate information, resources and training* **Lack of availability of culturally appropriate cancer information and resources** for Indigenous patients (text-heavy educational resources dominate)[49, 48, 90, 50, 33]; resources not comprehensive (e.g. no screening coverage)[7] **Lack of sufficient and appropriate information** about treatment plans, appointments, side-effects and support leading to feeling stressed and bewildered[33]; **confusion about medications, little understanding about what the medication** was for and unsure what the side effects or benefits of the medication were[52] **Lack of adequate training for health professionals** in rural and remote areas[49]; health services provided on-reserve are limited to prevention and public health, delivered by community health nurses and paraprofessionals[97] *Communication* **Language barrier**[101, 107, 32, 38, 115, 103, 50, 36, 33]	*Disempowering and isolating experience* **Stress related to culturally alienated** hospital environment[33] Feeling very alone at discharge, not knowing what to expect in terms of follow-up appointments, access to medications, potential side effects, and overall follow-up care[52] **Not feeling safe** within the system[32] **Negative and stressful experiences** with the specialist[98] *Communication* **Inconclusive communication between staff and patients and their families** was seen as problematic[115, 109, 31, 105] Difficult c**ommunication about traditional and complementary medicine** with HCPs[110]; traditional healing practices tended not to be shared with HSPs because of previous stigmatisation[108] *Engagement and relationship* **Shared decision-making** was hard[105]; no explanations were provided[105]; **family and community were not considered** during the decision-making process[105, 121] **Disjointed relationships with care providers**[107, 105] **Lack of knowledge** about cancer care limits involvement to engage in decision-making[105] *Intimidating environment* **Cultural insensitivity** (gender matters)[90 33] Feeling of intimidation or 'cold' interactions with medical culture and associated distrust[32] Indigenous patients **felt overwhelmed, confused and vulnerable** accessing cancer-related services and treatment[64]; the **medical culture was found to be challenging** with significant disconnection[35] **Fear, intimidation and disorientation** when attempting to navigate the system and hospital buildings, and feelings of loneliness and worry

Poor, inappropriate communication[7, 66, 31, 50, 5, 32, 98]; poor communication with the GP[49]; communication inhibited by **inaccessible medical jargon**[90, 52, 103, 31, 101, 3] Interpreters can have unique challenges in discussing sensitive topics such as cancer or death[103]; **unqualified translators/ interpreters**[31, 109, 101, 33] Health professionals' **lack of respect** towards traditional medicine and healing that hindered patient–provider communication[118, 110, 11] **GPs who lacked communication skills or cancer-related knowledge**, meaning patients waited for tertiary follow-up appointments to have their questions and concerns addressed[52] ***Engagement and relationship*** **Family or whanau not involved**[18, 5, 32, 31]; HSPs did not seek family assistance to communicate information to patients who had literacy issues.[115, 31, 33]	when having to leave family and community behind to attend appointments[109, 36]; **overwhelming experience** when coming from rural/ remote locations[36] Not being supported effectively due to varying expectations for interactions with healthcare practitioners[35]; **navigating the systems**[33]; number of cancer and/or cancer treatment-related side effects requiring ongoing maintenance or medication.[52]

Overall summary of findings for Question 1

Key barriers to cancer screening, early diagnosis, treatment and management

Contextual barriers

- Mistrust and fear of Western institutions, stemming from racism, colonisation and mistreatment of Indigenous peoples within the health system, hinder Indigenous peoples from accessing services
- Socioeconomic conditions of Indigenous peoples
- Direct and indirect costs of care including transport, accommodation and disruption to day-to-day life
- Availability of care in the areas where Indigenous people live that has a direct impact on diagnostic delays in the primary healthcare setting, treatment and overall cancer care, and associated travel, accommodation and food needs.

Health service-related barriers

- Fragmented care and lack of coordination among and between health professionals in primary, tertiary and specialist care settings
- Lack of Indigenous representation among healthcare staff
- Poor communication quality between patients, their families and health professionals
- Lack of availability of locally developed, Indigenous-led culturally appropriate resources.

Patient-related barriers

- Absence of culturally appropriate health literacy programs leads to lack of awareness, knowledge and education among Indigenous patients and families
- Pre-existing and differing health beliefs, misconceptions and attitudes towards cancer among Indigenous peoples lead to fatalistic views and stigma about cancer
- Indigenous people often have competing social and cultural commitments
- Comorbidity and other competing life priorities affect individuals and families seeking available services.

Question 2

What approaches or initiatives have been effective in improving access to and coordination of healthcare for Aboriginal and Torres Strait Islander peoples and for Indigenous peoples?

We identified a number of approaches and initiatives that have been effective in improving access to and coordination of healthcare for Indigenous peoples in Australia, Canada and New Zealand in a further 53 articles in this Evidence Check. Of these, 36 were specific to cancer and 17 related to other chronic diseases. Sixteen of the 36 articles focused on cancer screening; while 20 focused on cancer care, treatment and management. Ten of these 20 articles involved care coordination as a significant focus. Table 6 provides a detailed description of the screening strategies that have been effective in improving rates of Indigenous cancer screening in Australia, Canada and New Zealand. Table 7 describes the strategies to improve cancer care coordination for Indigenous peoples, while Table 8 provides a detailed overview of the strategies and initiatives that have been effective or have the potential to become effective in making cancer care culturally safe and accessible for Indigenous communities in the three countries included in this Evidence Check. Table 9 is a succinct list of all the strategies and models identified for cancer and chronic disease care.

2.1 Approaches and initiatives to improve access to cancer screening

Screening approaches with strong supporting evidence include patient reminders about upcoming screening or health check-up dates[54–57, 122], self-taken vaginal human papillomavirus (HPV) sampling[8, 9, 22, 58–60], and opportunistic screening of Indigenous peoples accessing healthcare for other reasons.[19] Strategies that have insufficient evidence but have the potential to positively influence screening uptake include: culturally appropriate media campaigns[95] and mobile screening services taken to the communities.[15, 61, 62] A detailed description of each of these approaches is described below by level of evidence followed by two summary tables (Table 6 and Appendix 2):

Strategies that have strong evidence of success

Patient reminders (telephone message and/or text message and GP prompting)

Effective interventions using client reminders have been implemented in the US, Canada, New Zealand and Australia, in populations of low to mixed or middle-class background for promoting breast, cervical and colorectal screening, and have had strong evidence of effectiveness in increasing screening uptake. A recent rapid review of cancer screening interventions in Indigenous populations included one study from the US that used a two-arm randomised controlled trial to increase colorectal cancer screening among unscreened Alaskan Natives and American Indian peoples.[55] In the intervention group, the study reported a 30% statistically significant increase in screening when all age groups were combined, a 42% non-significant trend towards increased screening in those aged 50–75, and a 24% non-significant trend towards increased screening in those aged 40–49.[55, 54]

In New Zealand, a parallel group randomised controlled trial was conducted with bowel cancer screening invitees from Māori, Pacific or Asian background who did not return a test kit within four weeks of postage. Non-returners were randomly allocated either to active follow-up or the control group. There was a statistically significant increase in screening participation among Māori (5.2% absolute increase; 95% CI = 1.8–8.5%) and people of Pacific background (3.6% absolute increase; CI = 0.7–6.4%), but not among Asian individuals.

Sending reminders via text messaging is an inexpensive and sustainable way to increase screening participation.[54, 56, 57] However, other factors, for example, consultation with tribal leaders and community members, adopting culturally appropriate strategies, and developing and delivering appropriate messages are pivotal to achieve success.[54, 55]

HPV self-sampling

An increasing number of studies in the past 10 years have been trialling self-taken vaginal HPV samples as an alternative to attending a healthcare provider. We identified eight articles on this topic: two studies from New Zealand (three articles), two studies in Australia (one in NSW and another in Victoria; two articles), one study from Canada (one article) and two systematic reviews.

The strongest evidence came from the study conducted by Adcock et al. (2019)[58] and MacDonald et al. (2021)[9] in Northland, New Zealand, where 931 under-screened or never-screened 25–69-year-old Māori women were included in a cluster randomised controlled trial between March 2018 and August 2019. After this successful trial, primary care providers incorporated the offer of this test into their routine work, suggesting that introducing self-testing into the National Cervical Screening Program should be sustainable for primary care in New Zealand. In Australia, Dutton and colleagues (2020)[60] conducted a pilot study that used a culturally appropriate community-based HPV self-sampling service model to recruit never-screened and under-screened Aboriginal women for cervical cancer screening. Aboriginal women aged 25–69 years from eight rural and remote communities in NSW were recruited to participate in HPV self-sampling. The project distributed HPV self-sampling kits from September 2016 to June 2018 (21 months). Participation was the highest among women aged 25–29 years. McLachlan and colleagues (2018) implemented a pilot project in Victoria that had a participation rate of 80%, demonstrating the acceptability of self-collection among under-screened women.[22]

There was overwhelming agreement that self-screening for cervical cancer is appropriate for Indigenous women as it ensures respect for Indigenous women's business.[24, 58, 59] MacDonald and colleagues (2021) concluded that offering HPV self-testing might decrease the number of under-screened or never-screened Māori women by half. These results may be generalisable to Indigenous peoples with similar barriers in other high-income countries.[8, 9, 58, 59]

Strategies that have considerable evidence of success

Opportunistic cancer screening pilot program

Chow et al. (2020)[19] implemented a pilot project, the Wequedong Lodge Cancer Screening Program, in Northwestern Ontario from October 2013 to November 2016. Wequedong Lodge provides accommodation in Thunder Bay, Ontario, Canada, for approximately 9500 First Nations adults each year who require medical services. The Wequedong Lodge Cancer Screening Program provided cancer-screening education followed by opportunistic breast, cervical and colorectal cancer screening to consenting participants among those staying at the lodge. Uptake in age-appropriate screening was 32% (106/333) for colorectal cancer, 22% (60/275) for breast cancer and 8% (45/554) for cervical cancer. Even though organised population-based screening programs are superior to opportunistic screening, the program removed some of the geographical, transportation and cultural barriers by providing accessible, convenient and culturally sensitive cancer screening services to under- or never-screened individuals who would not usually participate in an organised population-based program.[19]

Translational research and continuous quality improvement

Continuous quality improvement is an appropriate and effective intervention within Aboriginal and Torres Strait Islander community settings.[92, 123] In Australia, Dorrington and colleagues[122] led an intervention targeting Aboriginal and Torres Strait Islander women within the urban Aboriginal Community Controlled Health Service where they combined Rapid Plan-Do-Study-Act cycles of continuous quality improvement with translational research to improve Pap smear rates by addressing local barriers and facilitators. Five Rapid Plan-Do-Study-Act cycles, each lasting 4–5 weeks, led to a 40% significant increase in cervical screening (n = 217) compared with the average of the previous three years (mean = 170; s.d. = 33.2; p = 0.002). This increase was sustained for 10 months of follow-up. The research combined community and service collaboration and knowledge acquisition from Aboriginal Community Controlled Health Service clients, staff, internal research and data.[122]

Diaz et al. (2019)[88] analysed 3801 clinical audit records for primary healthcare clients aged 20–64 years from 135 Indigenous primary healthcare centres participating in the Audit for Best Practice in Chronic Disease Continuous Quality Improvement program across five Australian states/ territories between 2005 and 2014. Indigenous primary healthcare centres enrolled in the continuous quality improvement program for a longer period performed better compared with centres that only participated in the baseline audit. Ongoing involvement in continuous quality improvement has also been associated with improved best-practice care related to other chronic diseases, and general preventive care.[124] This offers access to service-level data, and the tools required to assess and reflect on this data, to inform locally relevant strategies for service delivery improvements.[88, 124]

Strategies that have insufficient evidence of success

Media campaigns

In order to increase public awareness of bowel cancer screening, Cancer Council Victoria ran a public health television-led campaign and several other targeted approaches for specific population groups, including Aboriginal and Torres Strait Islander Australians. Lotfi-Jam et al. (2019)[95] described three screening interventions in Victoria, Australia, one of which was a mass media public health campaign. There was a significant increase in the return of bowel cancer screening kits during and soon after the campaign was aired, compared with baseline return rates. Furthermore, the campaign showed increased awareness in pre- and post-intervention population surveys: 80% of 1700 respondents were aware of at least one campaign element and 40% discussed the message with someone else.[95]

Humour is one of the key modes of communication within the Aboriginal and Torres Strait Islander communities. Lotfi-Jam et al. (2019)[95] mentioned a comedy show about bowel cancer screening that was delivered to several Aboriginal audiences in Victoria. A sample of 43 attendees completed evaluation surveys before and after the show, with 76% reporting they had a good or very good understanding of bowel screening after the show, compared with 30% prior. Further, 96% reported that they were confident to use the test and 88% of eligible participants intended to screen within the next 12 months. Despite the small sample and self-reported nature of its screening outcome, the show provides a promising example of how health information can be delivered through non-traditional mechanisms in order to be more acceptable to hard-to-reach community groups.[95]

Mobile screening mammography service (hub and spoke model and enhanced access to cervical and colorectal cancer screening)

Byers et al. (2018)[62] described a successful remote outreach mobile screening mammography service in Australia that operated out of large remote communities, inviting smaller, more remote communities to participate in a so-called ‘hub and spoke’ model. In collaboration with community members, remote outreach nurses coordinated and delivered information sessions about breast health and senior Aboriginal women became informed ‘ambassadors’ for the promotion of mammography screening and women's health. Aboriginal health practitioners facilitated cross-cultural communication and understanding for non-Aboriginal clinicians. Traditional Aboriginal ceremonies and activities took place on the days when the mobile services were there; 50% of eligible women from three very remote communities in Central Australia undertook mammography screening and some participated in cervical screening as well.[62]

A similar initiative was reported in rural and remote communities of northern Alberta in Canada.[63] The Enhanced Access to Cervical and Colorectal Cancer Screening (EACS) intervention invited women aged between 50 and 74 years to take part in Screen Test, an established mobile mammogram program. A pilot intervention combining Screen Test and EACS to screen for the three cancers was introduced to selected communities, with a particular focus on hard-to-reach women living in First Nations, Métis and Hutterite (Anabaptist) communities. A total of 8390 and 1312 women participated in Screen Test and Screen Test–EACS, respectively. Screen Test–EACS significantly increased the uptake of cervical (10.1% v. 27.5%) and colorectal (10.9% v. 22.5%) cancer screening. This enhanced mobile program provided a client-centred ‘one-stop shop’ for breast, cervical and colorectal cancer screening services.[63]

Table 6—Strategies and models used/ trialled to make cancer screening accessible to Indigenous communities in Australia, NZ and Canada

Models/ approaches/ strategies/ interventions in the literature	**Description of strategies to make cancer screening accessible to Indigenous communities**	**Level of evidence of effectiveness**
Client reminder (telephone message and/or text message/ GP prompting) and active follow-up with non-participant groups.[54–57]	Mail-based, using printed materials, letters, postcards, etc., or non-mail-based strategies using interactive tools, telephone, text messages for follow-up.	Strong
Self-taken vaginal HPV sample [8, 9, 15, 22, 24, 58–61]	Several studies (two randomised controlled trials[8, 9], two pilot[22, 63], two systematic reviews[24, 54]) using various strategies, such as a community-based service model in NSW[8, 9, 60, 122], a multi-agency group and partnerships among multidisciplinary teams[60], have offered self-testing to Indigenous women and explored acceptability and preferences. These studies have consistently found self-testing to be highly acceptable, feasible and effective at overcoming multiple barriers to clinician-collected samples via a pelvic examination.	Strong
Opportunistic screening[19]	Individuals staying in a lodge in Northwestern Ontario were offered cancer screening education and opportunistic breast, cervical and colorectal screening.	Moderate evidence (pilot study)

Translational research and/or continuous quality improvement (CQI)[88, 122]	Translational research and continuous quality improvement (CQI) processes used to identify and address barriers and facilitators to Pap smear screening within an urban ACCHS.[122] Rapid Plan-Do-Study-Act (PDSA) cycles were conducted, informed by client surveys, a data collection tool, focus groups and internal research.[122] There was a statistically significant increase in Pap smear numbers during PDSA cycles, continuing at 10 months follow-up. The use of translational research with continuous quality improvement appears to be an effective and acceptable way to offer Pap smear screening.	Moderate evidence (pilot study)
Mobile screening (breast and cervical)[62, 63]	Mobile screening mammography service that adopted a 'hub and spoke' model, operating out of larger remote communities and inviting participation from smaller, more remote communities within the geographical hub. In another study, women in rural and remote communities access breast cancer screening through a mobile mammogram program (Screen Test). That mobile service integrated cervical and colorectal cancer screening in a project called Enhanced Access to Cervical and Colorectal Cancer Screening (EACS) for a two-year pilot program.	Low level of evidence
Mass media campaign[95]	At the population level, Cancer Council Victoria has delivered television-led mass media campaigns to motivate age-eligible individuals to complete and return their NBCSP kit. A significant increase in screening kit return rates was observed.	Low level of evidence

2.2 Approaches and initiatives to improve cancer care coordination

Lack of coordination of care has been identified as a key contributor to the poorer cancer outcomes among Indigenous peoples.[5] Coordinating cancer care is challenging across the board because of the complex and multi-layered treatment options for cancers that involves multimodal therapies, treatment of other chronic conditions at multiple organisational levels, health services, providers and sites of care.[27] Although the clinical aspects of cancer care are universally challenging for everyone, ensuring that the pathway is culturally safe and responsive is vital to address the disparities in outcomes for Aboriginal and Torres Strait Islander peoples with cancer.[79] The complexity is exacerbated by the service delivery system itself that is not integrated and organised.[27]

Several models made an attempt to coordinate cancer care by employing and engaging Aboriginal and Torres Strait Islander care coordinators, as happened at the Alan Walker Cancer Centre in the Northern Territory, and in Queensland[40, 64], or as evaluated by the Cancer Data and Aboriginal Disparities survey in South Australia.[5] Navigator models, such as the Indigenous patient navigator model in Queensland[43] and Champlain Indigenous Cancer Program in Ontario, Canada[44, 45], have also been effective. While 'Optimal Care Pathways for Aboriginal and Torres Strait Islander peoples with cancer' in Australia has not been fully implemented yet, this policy document has identified care coordination as a key component for improved cancer care for Aboriginal and Torres Strait Islander Australians.[79] These models are described below, followed by two summary tables (Table 7 and Appendix 3).

We looked at a further 17 articles describing successful chronic disease models within Indigenous communities, and a brief description of these is included in Appendix 1. As we did not systematically search for strategies and models addressing chronic disease, these articles were not part of the main analysis but have been included as additional information.

Strategies that have strong evidence in the literature

Culturally sensitive service model

The Alan Walker Cancer Centre, the only radiation therapy centre in the NT, incorporated and administered several culturally tailored strategies to improve service delivery for Aboriginal and Torres Strait Islander Australians. Carruthers et al. (2019)[40] analysed patient records from the first five years of the centre's operation to observe improvements and changes in clinical attendance. Attendance during radiation therapy significantly improved for Aboriginal and Torres Strait Islander patients from 70.6% to 81.6% (P=.038).

De Witt et al. (2018)[64] reported that Aboriginal and Torres Strait Islander health professionals significantly contributed to the provision of culturally competent cancer care. *"It's just their presence"* that can change the dynamic in the relationship between Aboriginal and Torres Strait Islander patients and health professionals. Their qualitative study identified several roles of Aboriginal and Torres Strait Islander health professionals as enablers to support the needs of Aboriginal and Torres Strait Islander cancer patients.[64] Slater and colleagues (2016)[65] conducted a similar study, but with a national approach, in New Zealand and administered a nationwide postal survey to all Māori health professionals in 2011. The aim was to explore the role of Māori health professionals within cancer care and prevention. This study identified the various roles provided by Māori health professionals in New Zealand, and highlighted the wide-ranging cancer services they provide, and what they would continue to do more if their positions were adequately funded.[65]

Comprehensive cancer care

Four papers[41, 42, 125, 126] have been published from a series of studies conducted by a team of researchers in WA that identified culturally appropriate steps that the Australian cancer services have taken to address the needs of Aboriginal and Torres Strait Islander patients and families.

Some of the cancer services:

- Trained their workforce with effective communication skills (12 out of 14 services made it compulsory, and training ranged from a two-hour webinar to a one-day face-to-face workshop)
- Increased flexibility in their clinical practice
- Offered outdoor consultations
- Provided shorter treatment programs
- Provided access to clinical staff of the appropriate gender
- Grouped Indigenous patients' appointments together
- Changed the physical environment (planned or completed) that improved the cultural safety of the treatment centre (e.g. flying the Aboriginal flag, installing artwork by local Indigenous artists, displaying a welcome statement in the entrance in local language and consulting the local Indigenous community when planning a new cancer centre or renovating an existing centre)
- Incorporated suggested features into the structure of the building (e.g. outdoor waiting areas, efforts to *"bring the outside in"* by installing windows with views of nature, a colour scheme that represented the local landscape, fish tanks to represent the local waterways, installing a light box above the radiotherapy machine)
- Put processes or positions in place to support Indigenous patients throughout their cancer journey (not just while undergoing treatment)
- Employed Indigenous cancer care coordinators
- Developed an Indigenous Cancer Patients Pathway that incorporated cultural needs at each stage along the treatment continuum
- Ensured family involvement by holding one or more family meetings (in person or via video conferencing) before starting treatment and sometimes during treatment (two services)
- Developed a formalised survivorship program (one remote service)
- Worked with local health networks when striving to deliver best practice care
- Formed an Aboriginal Cancer Network that worked on different projects in relation to prevention, screening, treatment, survivorship and palliative care (one regional service)
- Offered an outreach service in efforts to improve care
- Formalised telemedicine or tele-oncology services.

There were several other initiatives to improve knowledge, attitudes and understanding of cancer among Aboriginal and Torres Strait Islander communities; to promote prevention and screening programs and also to enhance the capacity to deliver quality services to Aboriginal and Torres Strait Islander peoples.[41, 42, 125, 126]

The same WA team conducted two case studies on two high-performing cancer services, reporting the more nuanced approaches these two cancer centres took to improve their service delivery for Aboriginal and Torres Strait Islander patients.[41, 42] This study identified eight key themes about the way the two services supported their Aboriginal and Torres Strait Islander workforce: strong executive leadership, a proactive employment strategy, the Indigenous Health Unit, the Indigenous liaison officer, multidisciplinary team inclusion, professional development, the work environment and a culture of respect.[41, 42] Participants reported several positive outcomes related to patients' health outcomes and also staff satisfaction and retention.[41, 42]

Strategies that have considerable evidence in the literature

Navigator model: Supporting patients in the community and facilitating access to health services

The US and Canada pioneered the patient navigator model as an attempt to reduce cancer disparities by addressing barriers to appropriate supportive care. Navigator programs not only inform patients about cancer and coordinate care through a variety of services, but can also address barriers to screening, diagnosis and treatment through outreach via community health care workers. Two US programs, the Native Sisters Program[127] and Walking Forward[128], have demonstrated improvement in outcomes for cancer patients, such as increasing adherence to breast screening and reducing delays in treatment.

In Australia, a collaboration between researchers, clinicians and allied health professionals developed and implemented a pilot study of the Indigenous patient navigator model in Queensland. The model combines patient navigation, cancer education and communication coaching to improve outcomes of Aboriginal and Torres Strait Islander patients with cancer. Health workers with experience in patient navigation were trained as Indigenous patient navigators to assess, educate and support patients to take on a more active role in seeking support for their cancer. An individualised action plan was formulated for each patient to address unmet needs or concerns identified by the Patient-Reported Outcome Measures—Supportive Care Needs Assessment Tool for Indigenous People and the Distress Thermometer. The pilot study aimed to deliver Indigenous patient navigator assessment at baseline and two months. Most respondents who took part in the study were “extremely satisfied” with the model, singling out in particular communication, responsiveness to requests for support and advice, provision of information (cancer pamphlets), and assistance with managing appointments and writing down questions to be used at future doctors’ appointments. Participants valued having the navigator as someone to talk to and show compassion as the greatest contribution to the patient experience.[43]

The Champlain Indigenous Cancer Program is a similar program in Canada established to help improve the cancer care experience of Indigenous peoples. Between the first six months and final six months of the implementation period (through 2017–18), there was a four-fold increase in patient encounters with the nurse navigator, with increased referrals from clinicians. Clinicians reported increased awareness and understanding of the unique context of Indigenous patients and families.[44, 45] Notably, patient navigators play a significant role in supporting patients while they access hospital services in urban centres for treatment, and many of them helped with coordinating flights, scheduling appointments, interpreters, and finalising follow-up and discharge plans.[103]

Strategies that have insufficient evidence in the literature

Aboriginal Women’s Cancer Support Network

It is evident that cancer support groups have positive effects on people affected by cancer[129]; however, there is limited information about the role and outcome of peer-support programs for Indigenous peoples. An Aboriginal Women’s Cancer Support Network was established in a regional town in WA in 2007–08. The evaluation results documented that the network:

- Provided emotional and informational support to the patients and families
- Became ‘community navigators’ or ‘cancer navigators’ within the local area
- Bridged the gap in cancer service delivery
- Acted as a ‘cultural broker’ by providing a culturally safe space for women
- Provided instrumental and practical support to its clients
- Engaged in culturally safe health promotion and education initiatives
- Fostered social interaction
- Fostered discussion about cultural and upbringing experiences within the network
- Actively engaged in grassroots health promotion and education.

However, the network faced numerous challenges and could not sustain itself and continue.[46]

Optimal Care Pathway

The Optimal Care Pathway was an initiative of Cancer Australia as part of the National Cancer Work Plan of the National Cancer Expert Reference Group. Established by the Council of Australian Governments in 2011, this group brought together jurisdictional representatives with cancer experts and consumers to take forward key initiatives that address disparities in cancer outcomes across different groups. An iterative methodology was used over a two-year period, and more than 70 organisations and individuals from diverse cultural, geographic and sectoral backgrounds provided input into this pathway. Cancer Australia reviewed experiences of care and the evidence base and undertook national public consultation with the Aboriginal and Torres Strait Islander health sector and community, health professionals and professional colleges. The leadership of Aboriginal and Torres Strait Islander health experts and consumers was critical to the Optimal Care Pathways development. This model has not been implemented and evaluated yet; however, it will definitely be at the forefront of future delivery of high-quality culturally appropriate and evidence-based cancer care in Australia.[79]

Table 7—Approaches and initiatives to improve cancer care coordination for Indigenous communities in Australia, NZ and Canada

Models/ approaches/ strategies/ interventions	Description of strategies to improve cancer care coordination	Evidence of effectiveness
Cancer care		
Culturally sensitive services/ cafe and quality care/ care coordination (service model)[5, 40, 64]	The Alan Walker Cancer Centre in Darwin, NT, provides culturally responsive cancer care via multiple patient-centred initiatives: • Indigenous liaison officer, working through cultural barriers and providing appropriate supportive care needs • Ongoing efforts to improve treatment logistics, including provision of suitable accommodation and daily transportation	Strong

Models/ approaches/ strategies/ interventions	Description of strategies to improve cancer care coordination	Evidence of effectiveness
	• Coordination of timely access to psychosocial, social welfare and other allied health services during the course of treatment • A cultural security policy introduced • Personnel are trained to maintain a high level of cultural competency • Individual patient-centred effort is made[40] De Witt et al. (2018) highlighted how the presence of Indigenous staff within a health service can make patients comfortable, and make the services culturally competent and responsive.[64] Lessons from the Cancer Data and Aboriginal Disparities narratives have been reported by Reilly, et al. (2018)[5]; the research team tried to understand how care coordination influences Aboriginal and Torres Strait Islander peoples' experiences of cancer treatment. Care coordinators addressed the needs of Aboriginal patients in four main areas: **Navigating the health system** • Adherence and engagement • Travel and accommodation • Access to supplies and resources **Information and communication** • Care coordinators provided information about cancer and treatment • Interpreters • Care coordinators ensured information reached patients' PHC services and assisted with planning return visits for follow-up **Things to manage at home** • Housing • Financial resources • Family needs **Cultural safety** • Some care coordinators communicated cultural needs to doctors and other health staff • Care coordinators also provided education to families so they were not afraid to have their family member with cancer return home, and assisted people to return to country at the end of life.[5]	

Models/ approaches/ strategies/ interventions	**Description of strategies to improve cancer care coordination**	**Evidence of effectiveness**
Indigenous patient navigator model[43–45]	The Indigenous patient navigator model combined patient navigation, cancer education and communication coaching to improve outcomes for Indigenous patients with cancer. A guidebook for training Indigenous patient navigators was developed to link patients with support networks and cancer services, thus improving quality of life and decreasing unmet care needs. Patient navigators completed training, including an individualised learning plan through one-on-one sessions, and their action plans focused on treatment and recovery phases of the cancer care continuum. Similarly, the Champlain Indigenous Cancer Program team developed a patient-centred culturally appropriate land-based approach to support First Nations, Inuit and Métis patients with cancer. Nurse navigators developed therapeutic trusting relationships with Inuit patients and families "on the land", outside the hospital office, based on the observation that Inuit peoples often felt most comfortable in this setting. A greater than four-fold increase in patient encounters was observed over 2017–18.	Considerable
Aboriginal Women's Cancer Support Network[46, 47]	The Aboriginal Women's Cancer Support Network was established in a regional town in WA during in 2007–08. This initiative combined characteristics of peer-support programs, and performed the role of connecting and linking people and services. This role had four distinct domains: i. Facilitating access to cancer services ii. Fostering social interaction iii. Providing a culturally safe space iv. Building relationships with other agencies.	Low level of evidence
Optimal Care Pathway [79]	The key principles and steps of the theoretical model of Optimal Care Pathway are: • Patient-centred care (contextualisation of the principle of patient-centred care within holistic health and wellbeing)	Low level of evidence because it has not been implemented and evaluated yet

Models/ approaches/ strategies/ interventions	Description of strategies to improve cancer care coordination	Evidence of effectiveness
	• Safe and quality care (relationship-building with local community, optimisation of health literacy, recognition of men's and women's business) • Multidisciplinary care • Supportive care (including the support of family and carers using culturally appropriate supportive care needs assessment and provision) • Care coordination • Improvement in cross-cultural communication • Research and clinical trials.	

Approaches and initiatives to make cancer care culturally safe and accessible

Once diagnosed with cancer, Indigenous peoples face numerous challenges within the health system, including poor and culturally inappropriate communication, racism, poor interagency coordination, cultural misunderstandings, emotional and physical stress from long-distance travel, financial issues, alienation and isolation within the system. These factors make the experiences of receiving cancer treatment for Indigenous peoples emotionally traumatising, distressing, inefficient and potentially dangerous.[5, 39, 52, 101] A number of approaches and initiatives to improve experiences of cancer care for Indigenous populations have been described in the literature. Examples include 'co-designing' with Indigenous representatives and leadership groups; continuous quality improvement cycles for incremental beneficial change; targeted cultural safety workshops for health workers[66], and culturally safe assessment tools such as the Supportive Care Needs Assessment Tool for Indigenous Patients.[53, 67] These models/ initiatives/ approaches are described below by level of evidence first, followed by a summary of each one of them in Table 8 and Appendix 3.

Strategies that have strong evidence in the literature

Supportive cancer care (Supportive Care Needs Assessment Tool for Indigenous People—SCNAT-IP)

Two large tertiary cancer treatment centres and two regional oncology clinics participated in the descriptive study that evaluated the clinical implementation of the SCNAT-IP in routine care in Queensland.[67] The SCNAT-IP is a 27-item measure of unmet supportive care needs for Aboriginal and Torres Strait Islander Australians, which is verbally administered and consists of four domains (physical and psychological, hospital care, information and communication, and practical and cultural).[130] The majority of Aboriginal and Torres Strait Islander cancer patients liked being asked about unmet supportive care needs as they found the process empowering.

The questions and format of the SCNAT-IP were acceptable. Screening for unmet needs and distress improved communication between patients and clinicians and enhanced psychosocial referrals.[67] Thewes et al. (2016)[131] also assessed the feasibility and acceptability of the SCNAT-IP qualitatively and found it beneficial and easy to understand. The participants felt valued and heard. They found the tool comprehensive and systematic. There were also intercultural benefits, with a positive and bi-directional exchange of information and cultural knowledge reported when using SCNAT-IP.[131]

Strategies that have considerable evidence in the literature

Community engagement and co-designing

Christie et al. (2021)[48] conducted a systematic review to assess the evidence as to whether cultural safety affects breast cancer outcomes in high-income countries. They included 15 studies. Two concepts stood out as important for programs that improved outcomes:

- Community participation, with the community being the investigators of their own health concerns
- Incorporation of culture in research design, including in methods of recruitment and data collection.

Overwhelmingly, the literature found culture made a real difference to the breast cancer journey of Indigenous women. Many studies found women fared better when culture was incorporated into the screening, diagnosis, treatment and follow-up care. No studies claimed there was no relationship between culture and health.[48]

Meiklejohn et al. (2019, 2018, 2017) reported results of a qualitative study where the community was engaged by involving community champions. The community conceptualised the project and a consensus decision-making approach guided the selection of resources or activities to represent community perceptions of cancer and raise cancer awareness. The community chose to prepare a community quilt that was displayed in the local primary health clinic to spread messages about cancer. The quilt represented community perceptions about cancer as well as important messages about cancer prevention and the disease itself, thereby acting as a message medium. Participants, primary healthcare professionals and community champions viewed the overall project as valuable for facilitating and improving the conversation about cancer with family and friends, the broader community and among health professionals.[49–52]

In order to deliver culturally safe and appropriate services, one Aboriginal Community Controlled Health Service in NSW implemented and evaluated a model called the Cancer Care Team. This initiative enhanced the acceptability and accessibility of cancer care services that included availability of home visits, transport and accompaniment to tertiary settings. The service was viewed as ‘culturally safe’ by the patients and their families. Cancer Care Team members visited homes, were present during the initial stage of cancer care, amended appointments with clients and had knowledge of and facilitated access to both primary and secondary care. They explained medical terminologies and also provided counselling services to relieve depression, stress, anxiety, anger and loneliness.[132]

Social workers and Aboriginal liaison officers in St Vincent’s Hospital in Melbourne, Victoria, partnered with Aboriginal and Torres Strait Islander organisations to develop, implement and evaluate a culturally informed model of supportive cancer care. Engaging with Aboriginal and

Torres Strait Islander stakeholders and drawing on continuous quality improvement and the Aboriginal and Torres Strait Islander Quality Improvement Framework and Toolkit for Hospital Staff (AQIFTHS, 2015), they co-designed and developed strategies to address the social and cultural determinants of health across the cancer journey. The model of care guided social workers and other health professionals to collaborate with stakeholders to promote health equity, and to improve supportive cancer care in accordance with optimal care guidelines and national quality standards. These processes and the model of care worked well because the whole organisation worked together with the health services and the Aboriginal and Torres Strait Islander community with a strong commitment to co-learning.[53]

Strategies that have insufficient evidence in the literature

Cultural safety training of health service professionals

A single two-hour workshop in WA co-delivered by an Aboriginal and a non-Aboriginal presenter to educate health professionals about the needs of Aboriginal and Torres Strait Islander patients was attended by 59 radiation oncology professionals. The workshop was evaluated to see whether participating in it improved the confidence of the health professionals in their knowledge, communication and ability to offer culturally safe healthcare to Aboriginal and Torres Strait Islander Australians with cancer. The study demonstrated that attendance at this one workshop not only increased health professionals' confidence in applying culturally safe practices, but also appeared to translate knowledge into better care for Aboriginal and Torres Strait Islander patients with cancer. Relationships, communication and awareness all improved after the workshop and persisted for up to two months.[66]

Shared decision-making strategy

Shared decision-making is a strategy where health professionals and patients make healthcare decisions together. A shared decision-making framework was developed in southern Canada. Leaders at three urban organisations providing support or healthcare to Inuit people were trained to implement the shared decision-making strategy. Five urban-based Inuit cancer care workers were recruited and trained to use this decision-making framework and help finalise the strategy (including training and a booklet) by providing their feedback. This strategy was used early in the cancer care journey. Participants felt the booklet made it easy to talk about what was important to them and it helped the case workers to engage with the patients. An approach in shared decision-making called 'decision coaching' occurs when trained health professionals provide nondirective support to people, preparing them to make healthcare decisions consistent with their own values and beliefs.[104]

Table 8—Approaches and initiatives to make cancer care culturally safe and accessible to Indigenous communities in Australia, NZ and Canada

Models/ approaches/ strategies/ interventions	Description of strategies to make cancer care culturally safe and accessible	Evidence of effectiveness
Cancer Care		
Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP) and continuous quality improvement[53, 67]	The SCNAT-IP is a 27-item measure of unmet supportive care needs for Aboriginal and Torres Strait Islander Australians, which is verbally administered and consists of four needs domains (physical and psychological; hospital care; information and communication; and practical and cultural). The SCNAT-IP takes approximately 15 minutes to complete. Full scoring can be completed in less than five minutes; however, in clinical applications, results can be very quickly scanned to identify moderate- to high-need items requiring further exploration and possible follow-up. The SCNAT-IP has been demonstrated to have good construct and face validity as well as internal consistency.	Strong level of evidence
Principles of co-design, including community engagement, community governance and capacity building[48–52]	Strong Indigenous community leadership and governance at all stages of the research including the design is an imperative for improved breast cancer outcomes for Indigenous women. Aboriginal and Torres Strait Islander cancer survivors' perspectives of cancer survivorship were explored through a community co-designed study in Queensland. Participants emphasised key action areas and recommendations to enhance cancer survivorship: establishing a community cancer advocate and peer support program; availability and use of a cancer-specific Indigenous primary healthcare worker; and hospital-based Indigenous patient navigators, as well as adoption of question prompt lists and cancer survivorship care plans.[49–52]	Considerable level of evidence
Targeted cultural safety workshop for HSPs[66]	Two-hour workshop included theory, case studies and group discussions to explore barriers and facilitating factors to delivering culturally safe care to Aboriginal and Torres Strait Islander peoples with cancer.	Considerable level of evidence

Shared decision-making strategy[104]	Health professionals and patients make healthcare decisions together. The shared decision-making strategy (training and booklet) was developed and finalised based on feedback from five urban-based Inuit cancer care workers who were recruited and trained in using the strategy. Leaders at three urban organisations that provide support or healthcare to Inuit people were trained to implement the field test of the shared decision-making strategy. Five crews were trained and matched to eight community member volunteers, and formed cancer support worker – community member pairs. Each pair was observed to read and understand the booklet; to engage in discussion prompted by the booklet; to use the booklet in both Inuktitut and English, with some pairs (*n* = 3) using the booklet exclusively in Inuktitut; and to have sufficient space to make notes in the booklet. Further work is needed to test the shared decision-making strategy.	Low level of evidence

Table 9—An overall summary of Question 2: Key strategies, models and initiatives that have been trialled to promote and increase cancer screening, and improve cancer care coordination for Aboriginal and Torres Strait Islander peoples and Indigenous peoples in Canada and NZ

What works/ what is needed	Identified models/ strategies
Indigenous leadership	i. Aboriginal Women's Cancer Support Network[46, 47]* ii. Targeted cultural safety workshop for HSPs[66]* iii. Self-taken vaginal HPV sample[8, 9, 22, 24, 58, 60]***
Community initiated	i. Co-designing[48–52]** ii. Nurse-practitioner-led approach[133]* iii. He Pikinga Waiora (HPW) Implementation Framework[134–136] iv. Community initiated health service partnership[134] v. The Indigenous Chronic Disease Package (ICDP)[133]
Culturally responsive care	i. Indigenous patient navigator (IPN) model[43–45]** ii. The Champlain Indigenous Cancer Program (CICP) team[45]*** iii. Two cancer centres in NT and Victoria[41, 42]*** iv. Employment and presence of Indigenous staff[65, 109]*** v. Optimal Care Pathways[79]* vi. Targeted cultural safety workshop for health professionals[66]

	vii. Supportive Care Needs Assessment Tool (SCNAT-IP)[67, 88]*** viii. Nurse-practitioner-led approach[133]* ix. He Pikinga Waiora (HPW) Implementation Framework[134–136] x. Self-taken vaginal HPV sample[8, 9, 22, 24, 58, 60]***
Care coordination between multidisciplinary teams and within different levels of health services	i. Indigenous patient navigator (IPN) model[43–45]** ii. Aboriginal Women's Cancer Support Network iii. Optimal Care Pathways[79]* iv. Nurse-practitioner-led approach[133]* v. Client reminder[54, 56, 57]*** vi. Opportunistic screening[19]** vii. Digital health technology[137, 138] viii. One Stop Liver Shop[139] ix. Models of care incorporating district hospitals[140] x. The Indigenous Chronic Disease Package (ICDP)[133]
Services close to home	i. Mobile screening (breast and cervical)[62, 63, 141]* ii. Home-based, outreach case management of chronic disease Exploratory (HOME)[142, 143]** iii. Digital health technology[137] iv. Models of care incorporating district hospitals[140]
Family and community inclusivity	i. Aboriginal Women's Cancer Support Network[46, 47]* ii. Supportive Care Assessment Needs Tool (SCNAT-IP)[67, 88]*** iii. Shared decision-making strategy (SDM)[104]* iv. Day respite facility[144, 145]* v. Opportunistic screening[19]**
Continuous monitoring and quality improvement	i. Translational research and/or continuous quality improvement[88, 122, 124]**
Mass media campaign	i. Mass media campaign[95]*

*Low level of evidence

**Moderate level of evidence

***Strong level of evidence

Discussion and conclusion

Cancer is the leading cause of death for Aboriginal and Torres Strait Islander Australians.[68] Despite major breakthroughs in cancer research, screening, diagnosis, treatment and management, leading to Australia's cancer outcomes being among the best in the world, the burden of cancer continues to weigh heavily on Aboriginal and Torres Strait Islander peoples.[146] Aboriginal and Torres Strait Islander peoples experience poorer cancer outcomes, with a 40% increased likelihood of death compared with non-Aboriginal Australians with cancer.[69]

These disparities in cancer care are significantly influenced by the socioeconomic and cultural determinants of health. This includes low socioeconomic background, access to education, unemployment and job insecurity, poor housing and living conditions, early childhood trauma, health literacy, availability of culturally safe services, racism, access to affordable and appropriate health services.[78, 79, 147, 148] Differing world views and Indigenous peoples' holistic perspectives on health and spiritual connection to land, culture, community and identity are widely acknowledged[10, 13, 14, 36, 101], but are often not well-reflected in how medicine is practised. Healthcare initiatives, including cancer care, designed to recognise and protect these core cultural aspects have generated improved health outcomes.[148]

This Evidence Check rapid review of national and international literature relating to cancer care access and outcomes for Indigenous peoples has identified several key barriers that are well aligned with the social and cultural determinants of health. These barriers to cancer screening, diagnosis, treatment and management from three countries—Australia, Canada and New Zealand—have been synthesised here. Consistent with prior literature, many cross-cultural issues related to cancer care have been mentioned repeatedly. Contextual barriers include difficulties in establishing trust between health professionals and Indigenous patients; lack of availability of appropriate services; and direct and indirect costs of care associated with long-distance medical travel. Key health service barriers include fragmented care and lack of coordination among and between health professionals at different care settings; shortage of Indigenous and also general staff and associated turnover; communication barriers; the intimidating and often culturally alien nature of the health system; and health professionals who lack understanding of cultural issues.[32] While issues related to care coordination affect *all* cancer patients, rural and remote communities are disproportionately affected by long waiting times for tests and specialist care; long-distance travel to tertiary metropolitan hospitals for diagnosis and treatment; poor communication with primary healthcare centres post-treatment; under-resourced rural healthcare facilities; lack of support services; and transport and accommodation issues.[5] Other patient-related barriers include a lack of awareness, knowledge and education among Indigenous patients and families about cancer due to the absence of culturally appropriate and targeted health literacy programs; different health beliefs and other competing social and cultural priorities.

This Evidence Check aims to assist the development of evidence-based policy to address barriers in access to cancer care and thus the gap in outcomes between people with cancer of Indigenous and non-Indigenous background. This future policy will exist on the background of the National Aboriginal and Torres Strait Islander Cancer Framework (the Framework)[147] and the Optimal Care Pathway for Aboriginal and Torres Strait Islander People.[78] The Framework provides direction for individuals, communities, health organisations and governments to improve service delivery for Aboriginal and Torres Strait Islander peoples. Within this, the Framework covers all aspects of the cancer journey including prevention, screening and early detection, diagnosis and treatment, palliative care and survivorship. The Framework also outlines policies, research and infrastructure surrounding those service areas. Locally fostered policies, strategy and actions are key to working with Aboriginal and Torres Strait Islander Australians.[147]

The Optimal Care Pathway for Aboriginal and Torres Strait Islander peoples with cancer includes practical examples of how health professionals can deliver culturally safe and responsive cancer care to meet the needs of Aboriginal and Torres Strait Islander peoples, a complement to the tumour-specific Optimal Care Pathways that promote best practice cancer care and patient experience for different cancer types.[78] Key considerations have been provided for understanding patients' background, philosophies, socioeconomic conditions, language and communication and practical considerations while in medical consultations. A series of resources for Aboriginal patients with cancer has also been developed and outlines what patients can expect while they are undergoing the cancer journey.[78]

The Evidence Check identified several successful Indigenous-specific initiatives, strategies, programs and health services in the three countries under consideration. Sending reminders to clients about their upcoming screenings has been found to be an inexpensive and sustainable way to increase screening participation.[54–57]

The cost of attending a clinic, the perceived invasiveness of the pelvic examination, embarrassment, hygiene fears and lack of time are among the barriers to cervical screening.[8, 9, 24, 58] To minimise some of these barriers, self-collected vaginal specimens (self-testing or self-sampling) are being used for HPV screening. Recent evidence suggests vaginal self-obtained samples provide sensitivity and specificity equal to clinician-collected specimens for detecting high-risk HPV type diseases.[8, 9, 58] Studies of acceptability, feasibility and satisfaction in Indigenous and ethnic minority women using HPV self-testing found this was preferred to healthcare provider-collected cervical cytology, and potentially eliminates numerous barriers to cervical screening.[58]

Most of the available literature agreed that even if it is challenging and requires dedication, time and resources, engaging with local Indigenous communities in the planning and delivery of cancer care is an important way to empower Indigenous peoples to access and engage with cancer services.

"Effective governance with genuine leadership and co-design by Aboriginal people is essential to improve Aboriginal cancer outcomes and experience. Aboriginal leadership and co-design must be embedded at all levels of planning, from state to local activities." [149]

Community engagement, participation, accountability and ownership are intrinsically linked to effective governance approaches and service use for Indigenous health programs and services.[48, 50, 149] Dutton et al. (2020) reported on a well-designed community based model that respected Aboriginal women's business and developed culturally appropriate strategies while at the same time maintaining high clinical governance and professionalism within the program, and still effectively recruited hard-to-reach under-screened and never-screened Aboriginal women to complete cervical cancer screening.[60]

Nevertheless, much work is still to be done in developing and maintaining partnerships with Indigenous organisations. The National Aboriginal and Torres Strait Islander Cancer Framework in Australia[147], for example, should facilitate learning and collaboration at a local, regional, jurisdictional and national level. Key principles of effective engagement and partnerships identified in the literature include context-specific strategies, long-term mutually beneficial partnerships, relationships and engagement with Aboriginal and Torres Strait Islander communities, genuineness, accessible and ongoing communication and information, appropriate time frames, capacity building through participatory governance, and Aboriginal-led monitoring and evaluation.[7, 123, 139, 146, 148, 150]

Having a trained workforce with effective communication skills is critical when endeavouring to deliver culturally appropriate cancer care to Indigenous peoples. Three articles in this Evidence Check have demonstrated how the presence of Indigenous health workers changes the dynamic of the relationship between patients and providers.[40, 64, 65] However, in this current infrastructure and considering the ratio of Indigenous patients and health professionals, it would be unrealistic to expect that all Indigenous patients would be treated by Indigenous staff.[80] Indeed, everyone should take responsibility to deliver culturally safe care to all patients.[80] Attitudes of some ‘culturally blind’ health professionals who believe that ‘by treating everybody the same, they are promoting equality’ need to be altered by regular monitoring and updating their knowledge and skills.[91, 126]

Taylor et al. (2018) proposed a restructure of the Australian tertiary health curriculum so Aboriginal Community Controlled Health Services could be involved in the clinical placements for non-Aboriginal students.[126, 151] Mandatory cultural awareness training, cultural mentoring by Aboriginal and Torres Strait Islander mentors, navigators and ongoing monitoring of service performance using cultural security tools[2] are some of the other ways culturally safe workforces and workplaces can be developed. Workplaces must include ongoing cultural safety training to health professionals at all levels, the completion of which should be recorded in their performance management.[152] This training needs to be revisited on a regular basis. Training programs must ensure health staff understand the importance of acknowledging and working with local people and within local cultural protocols. They must recognise the wide range of beliefs and practices that Aboriginal and Torres Strait Islander peoples have, and how these might affect peoples’ care-seeking behaviours and their communication styles.[91, 153, 154] The literature also strongly emphasised tailoring services to an individual patient’s needs, background and preferences (person-centred care), and the involvement of a patient’s family wherever possible and appropriate.[41–43, 64, 96, 125, 126]

However, most importantly of all, the health service as a whole needs strong leadership and policies to support the Aboriginal and Torres Strait Islander workforce. Taylor et al. (2020) observed in their study that changes *“start from the top”*, and should be coordinated and mandated by the whole organisation, not just a few staff. The commitment to Aboriginal and Torres Strait Islander peoples’ health needs should be at the forefront of the service’s values or mission statement.[41, 42, 126]

Another key issue and barrier to cancer care for many patients and families, including Aboriginal and Torres Strait Islander peoples, is the current fragmented nature of cancer care, which can perpetuate barriers to access and service use and can lead to increased distrust, mistrust towards the system, and reduced effectiveness and efficiency.[149] To combat this issue, care coordination is critical. Coordination, as Weaver et al. (2018) defined, means *“synthesising care goals and decisions across the multiple groups involved in patient care, as well as* *mutually aligning, timing, and adapting key care tasks among different care teams or team members over time."*[155] Gorin et al. (2017) conducted a systematic review and meta-analysis to synthesise the findings of studies addressing cancer care coordination. Although not Indigenous-specific, their review included different types of care coordination interventions. Patient navigation (generally by trained community members) was the most frequent intervention (N = 5), followed by home telehealth (with an automated message delivery by an interactive telehealth informatics infrastructure and a care coordinator) (N = 3) and then nurse care management (N = 3).[27] Cancer care coordination approaches led to improvements in 81% of outcomes, including screening, measures of patient experience with care and quality of end-of-life care. If implemented, care coordination brings positive outcomes and, although progress has been made, recent data emphasise that these are not easy tasks in the characteristically complex healthcare delivery system.[155] Care coordination plays a critical role in addressing the social, cultural and logistical barriers to effective participation in the healthcare system that disproportionately burdens Aboriginal people. In our Evidence Check, we only found two studies that trialled the patient navigation model (one in Australia and one in Canada). Patient satisfaction was recorded. More innovative initiatives need to be trialled and evaluated to come up with a holistic, culturally safe, patient-centred model of care for Aboriginal and Torres Strait Islander patients. The Framework[147] defines quality cancer care for Aboriginal and Torres Strait Islander peoples as care that:

- Is ***person centred*** so that the whole person (including their family and cultural role) is considered, and the psychosocial, cultural and supportive care needs and preferences of Aboriginal and Torres Strait Islander peoples are addressed across the continuum of care
- Is ***multidisciplinary and integrated across health sectors (primary, secondary, tertiary care)*** and into the community (including referral pathways to primary care, allied health and other relevant community services)
- Includes ***strong involvement and leadership from Aboriginal and Torres Strait Islander peoples*** (including those affected by cancer) to ensure care is effective and appropriate to the patient and their family needs and preferences.

Some other key points reiterated in many of the articles included in this Evidence Check are mentioned below. To improve cancer outcomes for Aboriginal and Torres Strait Islander Australians, the following considerations should be borne in mind at the system level:

- Understanding and comprehensive support from the services improved the quality of engagement and relationship of Indigenous patients, families and staff. A supportive workplace for Indigenous staff is the responsibility of the service as a whole, which will have a positive effect on patient and staff outcomes[41, 42, 126]
- Aboriginal and Torres Strait Islander leadership is essential to increase Aboriginal and Torres Strait Islander participation in screening programs for cervical, colorectal and breast cancer. This requires a public health commitment[88], something that is also important for the overall development and sustainability of any programs targeting Aboriginal and Torres Strait Islander health and wellbeing[156]
- Complete, accurate data collection and reporting using continuous quality improvement should be ensured at all levels of service delivery. This includes staff training to identify and record Aboriginal and Torres Strait Islander status through appropriate questions, ethnicity-specific data collection protocols; financial investment in information systems that can transfer information both locally and in organised programs; and the development and capacity building of cancer registries. High-quality data collection and reporting enables ongoing monitoring and evaluation, measures progress against benchmarks, identifies

where resources are most needed, and measures which interventions work best.[24, 80, 88] One simple question—“Are you of Aboriginal or Torres Strait Islander origin?”—would identify Aboriginal and Torres Strait Islander peoples accessing services that would in turn improve national health and welfare data. This, in turn, would help ‘close the gap’ in outcomes between Aboriginal and Torres Strait Islander and non-Aboriginal Australians and help Aboriginal and Torres Strait Islander people access Aboriginal-specific health measures designed to overcome their poorer health outcomes[157]

- Increased education delivered by locally respected Indigenous Elders; culturally appropriate education and promotion through locally appropriate and engaged education resources; and the provision of care and support from other people—for instance, Elders have enhanced knowledge of screening and cancer care and their input has increased participation in their communities[25]
- Making screening programs more accessible to Aboriginal and Torres Strait Islander peoples by bringing them closer to home through mobile screening services or providing more dedicated, sustainably funded cancer screening services through local district hospitals, Aboriginal Community Controlled Health Services or other outreach services can address the current disparity between the screening participation rates of Aboriginal and non-Aboriginal men and women[25]; the higher participation rates in breast screening for Aboriginal women in WA compared with nationally demonstrate the success of the strategies put in place by BreastScreen WA[25]
- A growing number of research studies and projects have been trialling HPV self-sampling; this may overcome barriers to clinician-collected cervical screening and improve women’s participation.[29] Specific initiatives are being undertaken to address this issue with a focus on targeted outreach activities and collaboration with primary healthcare
- One major theme of a number of studies was the colonial legacy and its influence on the accessibility of cancer screening and services for Aboriginal and Torres Strait Islanders and other Indigenous peoples, and their experiences of these services. Respectful and meaningful Aboriginal and Torres Strait Islander involvement at all levels of decision-making in patients’ cancer journeys; employment of Aboriginal and Torres Strait Islander staff; appropriate care coordination involving multidisciplinary teams of experts including Aboriginal liaison officers and social workers; and the adoption of cultural safety measures within hospitals and health services would reaffirm Aboriginal and Torres Strait Islander peoples’ confidence and trust in Western health systems.[41, 42, 126]

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Appendices

Appendix 1—Description of chronic disease management model

Chronic disease models/ approaches/ strategies/ interventions as described in the literature	Description of strategies	Evaluation outcomes
Home-based outreach case management of chronic disease exploratory (HOME) study[142, 143]	A home-based case management model of patient-centred multidisciplinary care for Aboriginal and Torres Strait Islander people with complex CD that was integrated into a primary healthcare service. The HOME study model of care had two distinct phases. **Phase One:** comprehensive needs assessment that aimed to identify what each patient participant needed to be healthy and facilitated a process for them to identify their health and wellbeing goals **Phase Two:** ensure the health and social care systems met the identified needs of each patient participant and supported them to achieve their goals.	**6–8 months between the baseline and 6-month assessments evaluation:** • High levels of satisfaction with the model of care • Patient participants became more involved in their PHC • Rates of depression decreased from about two-thirds to one-third of participants • Patients' individual needs and requirements were identified and then the necessary care was ensured • Significant improvements in systolic blood pressure and diabetes control • The model of care, with its formal multidisciplinary case conferences and nurses dedicated to case managing the care of patients with complex healthcare needs, became an

Chronic disease models/ approaches/ strategies/ interventions as described in the literature	Description of strategies	Evaluation outcomes
		integral and valued strategy in the armoury of chronic disease care provided by the PHC. **12-month evaluation:** • 60 participants were enrolled in the study and 37 (62%) completed the 12-month assessment • After receiving outreach case management for 12 months, 73% of participants had good, very good or excellent self-rated health status compared with 33% at baseline ($p<0.001$) • 19% of participants had depression compared with 44% at baseline ($p = 0.03$) • Significant increases in appointments with allied health professionals ($p < 0.001$) and medical specialists other than general practitioners ($p = 0.001$) were observed at 12 months compared with baseline rates • Mean systolic blood pressure decreased over time ($p = 0.02$), but there were no significant changes in mean HbA1c, body mass index or diastolic blood pressure.
Nurse-practitioner-led approach[133]	The Durri Aboriginal Corporation Medical Service is an Aboriginal Community Controlled Health Service (ACCHS) in Kempsey, NSW, with a significant Aboriginal patient population identified with chronic kidney disease (CKD). The ACCHS engaged a nurse practitioner to lead a systematic	• The CKD project has improved access to essential healthcare for vulnerable and at-risk populations, with 187 patients to date having been identified with kidney disease and staged for its severity

Chronic disease models/ approaches/ strategies/ interventions as described in the literature	Description of strategies	Evaluation outcomes
	approach to the identification and treatment of CKD. This nurse-practitioner-led approach was supported by a partnership formed between the nurse practitioner, the ACCHS, a nephrologist from a referral hospital and a statewide NGO.	• All patients who have been staged also have information regarding contraindicated medications attached to their patient record, which GPs view before being able to prescribe medication • Patients have also been able to discuss their bush medicine remedies and, where possible, incorporate these into their management • As a result of the nurse practitioner's audit, Durri GPs now automatically see CKD high-risk flags, or codes, in electronic records when patients present for acute care and seize the opportunity to refer them for CKD assessments • This service has also generated a strong interest in and a better understanding of CKD through general awareness raising and education • The project has also enhanced telehealth collaboration with nephrologists, who currently have 21 patients in their care.
Day respite facility[144, 145]	The Alice Springs Palliative Care Service of the Northern Territory Department of Health is a consultancy service that covers the Southern Region of the Northern Territory into the Anangu Pitjantjatjara Yankunytjatjara (APY) Lands of SA and the Ngaanyatjarra lands of WA.	After the service had been operating for 10 months, a qualitative evaluation was conducted to investigate the experiences of people involved in the use and operation of the service: • An improvement in quality of life for respite patients and their carers was observed

Chronic disease models/ approaches/ strategies/ interventions as described in the literature	Description of strategies	Evaluation outcomes
	A flexible, community based, culturally appropriate respite service was established in Alice Springs.	• The respite service enabled improved care coordination of chronic and complex patients as well as improved medication compliance and symptom management • Cost-effectiveness was assessed in another evaluation where respite service use and hospital use data were collected over two time periods: 12 months prior to the establishment of the service and the first 10 months of the operation of the service. Overall, a mean cost saving of $1882.50 per episode for hospital admissions was observed, with a reduction in: hospital admissions; mean length of stay; intensive care unit (ICU) hours; and ventilator hours.
Digital health technology[137]	A scoping review (Choukou, et al. 2021) investigated existing telehealth solutions that have been implemented to serve Indigenous Older Adults. Eight types of telehealth solutions for Indigenous OAs were identified: - Teleconsultation via videoconference - Mobile telemedicine clinic - Telephone - Health screening by remote screening equipment - Portable device attached to patient's smartphone - Home monitoring unit and 'store and forward' - Medical data processing and storage	There has been limited uptake of telehealth by community health clinics, the NT health system and by individuals in remote locations for a variety of reasons, particularly inadequate access to broadband. In this context, St Clair et al. (2018) have reported how through collaboration, the NI/AMSANT/B4BA Telehealth and Digital Inclusion Program has demonstrated the value of uncontended and unlimited internet access in implementing telehealth and continues to build on current knowledge by evaluating the uptake of telehealth and developing a model of innovative service delivery to increase expansion of telehealth and

Chronic disease models/ approaches/ strategies/ interventions as described in the literature	Description of strategies	Evaluation outcomes
	- Telehealth promotion	access to internet resources (including video-conferencing) for local health, education and other community based organisations, evaluating video-conferencing, diagnostic devices, communications hardware and software used in telehealth. The use of telehealth in the Laynhapuy Homelands has resulted in early diagnosis and treatment, more accurate assessments for evacuations and acute care retrievals, provided video-conferencing for case consultations, allowing patients to see familiar faces (e.g. clinicians they have known for years), family meetings to facilitate more informed and timely decision-making, more opportunities for staff and patient education, assistance in the induction and supervision of new staff, improved patient safety and direct observation of staff and trainee GPs.
Community engagement and culture-centred approach He Pikinga Waiora (HPW)	The HPW framework's intention is to apply a holistic and collaborative approach to health research; one that 'embraces collaborative efforts among community, academic, and other stakeholders who gather and use research and data to build on the strengths and priorities of the community for multilevel strategies to improve health and social equity'. The HPW	The HPW framework forms the basis of the process evaluation tool, which measures how well the research partners (both community and academic) and the partnership as a whole are following the framework while in the process of developing and implementing an intervention. There are 22 items for community engagement, 22 for cultural centredness, seven for systems thinking, six for integrated knowledge translation and

Chronic disease models/ approaches/ strategies/ interventions as described in the literature	Description of strategies	Evaluation outcomes
Implementation Framework[134]	framework has Indigenous self-determination at its core, and four elements that are essential to implementation: - Community engagement: the shared decision-making and communication responsibilities between academic and community members and researchers - Cultural centredness: the involvement of community members in defining and solving problems along with sharing resources for transformation - Systems thinking and holism: the complexity and interrelatedness among various stakeholders related to a health issue - Integrated knowledge translation: the engagement of end-users (people implementing or using an intervention) throughout the research process to ensure 'buy-in' (Oetzel et al. 2017).[135] Translating research into practice is an important issue for implementing health interventions effectively for Indigenous communities. He Pikinga Waiora (HPW) is a recent implementation framework that provides a strong foundation for designing and implementing health interventions in Indigenous communities for non-communicable diseases, focusing on community engagement, a culture-centred approach, systems thinking and integrated knowledge	five open-ended interview questions. The evaluation team has concluded that the HPW implementation framework, along with its process evaluation tool, is an effective means for implementation teams to help guide participatory work for relationship-building, trust and synergy along with larger system impact. Twenty-one studies were included. Health topics included diabetes, nutrition, weight loss, cancer and general health. The key themes were as follows: i. 2/3 of studies demonstrated high levels of community engagement ii. From the culture-centred approach, 2/3 of studies reflected moderate to high levels of community voice/ agency although only a third of the studies included structural changes and researcher reflexivity iii. About ¼ of studies included multilevel outcomes and activities consistent with systems thinking, 40% had individual-level outcomes with some systems thinking, and 33% included individual-level outcomes and limited systems thinking

Chronic disease models/ approaches/ strategies/ interventions as described in the literature	Description of strategies	Evaluation outcomes
	translation. This review addresses the following research question: How are the elements of the HPW Implementation Framework reflected in studies involving the implementation of a non-communicable disease health intervention in an Indigenous community? A systematic review was conducted using multiple databases. Studies were included if they involved the implementation or evaluation of a health intervention targeting non-communicable diseases for Indigenous communities in Australia, Canada, NZ or the US.	iv. Almost 40% of studies included high levels of end-user (e.g. policy makers and tribal leaders) engagement reflective of integrated knowledge translation, but nearly half had limited end-user engagement.
One Stop Liver Shop[139]	One Stop Liver Shop was iteratively developed in conjunction with one very remote community clinic, more than 500 km away or a two-hour flight from Darwin. The One Stop Liver Shop consists of a specialist doctor, a community based Aboriginal Health Practitioner (AHP), a sonographer and a clinical nurse specialist. The team brings along a portable ultrasound scan (USS), a transient elastography (FibroScan®) and mobile devices for education using the Hep B Story app— a mobile application designed to provide CHB-related education in the patient's first language, Yolngu Matha or English. Two community based educators, as well as the coordinating AHPs, have been trained and supported to deliver the education using this app in a culturally safe and respectful way. The nearest health facility is a district hospital,	Hla et al. (2020) examined the impact of this novel care delivery model with regards to the CHB care cascade in this community through a five-year period from 2013–18, and compared that figure to targets set by the national strategy and against NT and national averages. They identified and reviewed the cascade of care for 83 people living with CHB (the community has 2206 people according to the 2016 national census). Based on contemporary data, which found 6.08% of Aboriginal adults in the region were HBsAg sero-positive, the reviewers estimated there were about 134 people in the community living with CHB. This equated to 61.9% of those living with CHB in this community being aware of their diagnosis, which is in keeping with state and national figures.

Chronic disease models/ approaches/ strategies/ interventions as described in the literature	Description of strategies	Evaluation outcomes
	which is 128km away in direct distance but without direct flights or road access. The One Stop Liver Shop visits occur four times a year for two days’ duration, equating to 16 clinical sessions per annum.	The holistic approach of the One Stop Shop model is effective; however, its applicability is dependent on many factors such as access to diagnostic equipment, trained medical staff (GP prescribers, nurses and AHPs), community based educators and educational resources in the local language. This may not be feasible in every remote setting.
Mobile health[141]	The universal presence and functionality of mobile devices offers the potential for mobile health (mHealth) to create equitable health opportunities. A systematic review was conducted by Hobson et al. (2019) to identify the characteristics of mHealth interventions (study locations, health topic and modality) evaluated with FN populations and to summarise the outcomes reported for intervention use, user perspectives including cultural responsiveness, and clinical effectiveness. Out of 1053 unique records, 13 studies (five randomised controlled trials and eight quasi-experimental designs) were included in the final analysis. Studies were conducted in Australia (n=9), the US (n=2), and NZ (n=2). The most common challenge addressed was mental health and suicide (n=5). Intervention modalities included text messaging (n=5), apps (n=4), multimedia messaging (n=1), tablet software (n=1), or a combination of short messaging service (SMS) and apps (n=1). Results showed mixed engagement	mHealth modalities, including SMS and apps, appear favourable for delivery of health interventions in FN populations, particularly in the area of mental health and suicide prevention. Importantly, FN expertise was strongly embedded within the studies, supplementing favourable use and user engagement. However, evidence of efficacy is still limited.

Chronic disease models/ approaches/ strategies/ interventions as described in the literature	Description of strategies	Evaluation outcomes
	with the intervention (n=3); favourable user perspectives including acceptability and cultural appropriateness (n=6); and mixed outcomes for clinical effectiveness (n=10).	
Models of care incorporating district hospitals[140]	A rapid review was conducted by Nancarrow and colleagues (2015) to identify models of care that incorporate district hospitals and have relevance to the Australian rural and remote context. Most of the papers were from Australia, in particular Queensland (seven studies). However, only a few of them specifically focused on the district hospital *per se*; rather, the majority described an integrated model of service delivery for the community of which the district hospital represented one component in this continuum of care. Out of 1626 articles and reports, 24 data sources were included: 21 peer-reviewed publications and three from the grey literature. Identified models of care related specifically to maternal and child health, end-of-life care, cancer care services, Aboriginal health, mental health, surgery and emergency care.	District hospitals form an important part of vertically integrated models of care in Australia. Effective models of care aim to keep health services close to home. There is scope for networked models of care that keep health care within the community supported by hub-and-spoke models of service delivery. There were several consistent themes underpinning rural and remote models of care relevant to district hospitals. Specifically, the model of care should start with a clearly identified community need, community consultation and the formation of a strong clinical services plan. Most of the models of care included in this review had either an implicit or explicit aim to **keep care 'close to home' wherever possible**. This was facilitated through the use of networked and integrated service models, often with a local service backed up by a higher-level tertiary service, and sometimes supported through eHealth.

Chronic disease models/ approaches/ strategies/ interventions as described in the literature	Description of strategies	Evaluation outcomes
Community initiated health service partnership	A unique community initiated health service partnership was developed between a community controlled Aboriginal health organisation, a government hospital and a population health unit, in order to overcome the challenges of delivering primary healthcare to a dispersed, highly disadvantaged Aboriginal population in the Fitzroy Valley in the Kimberley region of WA, a very remote area. This area covers an area of 30,000 km^2 with a population of ~3500 people dispersed across 44 communities. Three key elements were apparent: *Local community participation*—Extensive community consultation resulted in trusting relationships and clarity about a shared vision with local healthcare providers. *Leadership and vision*—Committed local leadership was required to overcome the many bureaucratic barriers to new models of care. *Formal partnership*—The formal documents and Memorandum of Understanding enabled many of the linkages, such as a single shared electronic record and access to Commonwealth funding for primary healthcare.	Reorientation of **health service delivery was** closely aligned with known steps for successful organisational change: i. Creating a climate for change through community participation and leadership ii. Engaging and enabling the whole organisation, achieved through the formal partnership iii. Implementing and sustaining change through the new integrated health service. The shared goals and clear delineation of responsibilities achieved through the partnership reoriented an essentially acute hospital-based service to a prevention-focused comprehensive primary healthcare service, with a focus on systematic screening for chronic disease, interdisciplinary follow-up, health promotion, community advocacy and primary prevention. This formal partnership enabled the primary healthcare service to meet the major challenges of providing a sustainable, prevention-focused service in a very remote and socially disadvantaged area.

Appendix 2—Summary table of articles describing strategies and models used/ trialled to make cancer screening accessible to Indigenous communities in Australia, NZ and Canada

No.	Author(s), year country, location	Study population	Methodology	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
1.	Adcock et al. (2019), NZ (regional)	Māori women	Mixed methods	Cervical screening	HPV self-testing	• A strengths-based Whanau approach to HPV education • Empathetic delivery of services • Ensure standard recall, opportunistic in-clinic invitations to self-test, and targeted outreach • Flexibility—primary healthcare workers working closely with community health providers • Multiple options of picking up or delivering HPV self-test kit • Having good support and education to increase women's	• Three out of four survey participants would accept the self-test	Level I (generalisable study; Daly)

No.	Author(s), year country, location	Study population	Methodology	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
						confidence about doing it • The post/mail was the lead preference for receiving and returning HPV self-test kits • A strong preference for HPV self-testing to happen at home with no support necessary • A preference for either a text or phone call from a health practitioner		
2.	Brewer et al. (2019), NZ (regional)	Pacific Islander, Māori, Asian, other ethnicity	Descriptive quantitative study (pilot study)	Cervical screening	HPV self-testing Three self-sampling devices were tested: 1. HerSwab 2. delphi Screener	• Positive about the self-sampling devices • Instructions were clear • Devices easy to use • Majority used only one sampling kit	• Un- and under-screened women generally find self-sampling acceptable • All sample types are suitable for use with the cobas HPV test.	Level III (descriptive study; Daly)

No.	Author(s), year country, location	Study population	Methodology	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
					3. cobas CT/NG Swab			
3.	Bryant, et al. (2021), Aus, NZ, Can and US		Literature review	Cancer screening	• Four RCTs included: • Text message reminders • Telephone call reminders • HPV self-sampling • Mailing of Faecal Immunochemical Test (FIT) kits • Two pilot projects • One opportunistic screening • Four pilot mobile screening		• Seven studies (4 RCTs for colorectal and cervical screening) reported increased participation in breast, cervical, colorectal and cervical cancer screening programs in Indigenous populations • Five studies showed promise of increased participation based on the factors that	Level I (generalisable study; Daly)

No.	Author(s), year country, location	Study population	Methodology	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
					One transitional research study: plan-do-study-act (PDSA) cycles.		influence people's screening practices, such as knowledge, attitude or intent to screen.	
4.	Byers et al. (2018), Aus (remote NT)	Aboriginal and Torres Strait Islander women	Letter to the editors describing a project	Breast screening	Mobile screening mammography service that adopted a hub and spoke model	• Remote outreach midwife in collaboration with community members developed a breast cancer awareness project • Information session about breast health • Senior Aboriginal and Torres Strait Islander women became informed ‘ambassadors’ promoting screening and women’s health • Further community sessions organised	50% of eligible women from three very remote communities in Central Australia undertook mammography screening, and some participated in cervical screening as well.	Level IV (single case study; Daly)

No.	Author(s), year country, location	Study population	Methodology	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
						• Remote outreach midwife coordinating the project • Aboriginal and Torres Strait Islander health practitioners facilitated cross-cultural communication and understanding for non-Aboriginal clinicians • Traditional Aboriginal and Torres Strait Islander ceremonies and activities took place on those days.		
5.	Chow et al., (2020), Can (rural and remote)	The Wequedong Lodge cancer patients	Descriptive quantitative study (project report)	Cancer screening	Opportunistic screening	• Educate eligible people about cancer screening and connect women with breast screening appointments • Later, all three organised cancer screening programs	• Over the duration of the program, 24% (66/275) of age-eligible female clients had a mammogram booked	Level III (descriptive study; Daly)

No.	Author(s), year country, location	Study population	Methodology	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
						(breast, cervical, colorectal) were offered to eligible clients • Administrative support • An Indigenous program screening liaison was available as a dedicated on-site support • Availability of on-site staff who provided culturally sensitive services in clients' first languages.	• Of these booked women, 91% (60/66) completed an Ontario Breast Screening Program screening (53/60) or diagnostic (7/60) mammogram • Out of the 81% of eligible women, 8% (45/554) completed a Pap test. • Out of the 333 age-eligible clients that attended appointments when colorectal screening was offered (2015–16) 32% (106/333)	

No.	Author(s), year country, location	Study population	Methodology	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
							were provided with an FOBT kit. • A satisfaction survey was implemented in 2015 and was completed by 58% (396/684) of 2015 and 2016 program attendees.	
6.	Diaz et al. (2019), Aus (national)	Primary healthcare Clients from 135 Aboriginal and Torres Strait Islander primary healthcare centres	Clinical audit records	Cervical screening	Continuous quality improvement (CQI) program	• Aboriginal and Torres Strait Islander leadership • Female practitioners • Trained Aboriginal and Torres Strait Islander health workers • Higher level of screening in remote regions of Australia • Sustained participation in the continuous quality improvement	• Wide variation across the participating primary healthcare centres in the proportion of active female clients who had a cervical screening test in each two-year audit period	Level I (generalisable study; Daly) Level III-3 (NHMRC)

No.	Author(s), year country, location	Study population	Methodology	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
						program was a key driver behind higher screening • Supportive organisational structure, the nature and degree of community linkages, the availability of systems and infrastructure to support ongoing continuous quality monitoring • Supportive broader policy, workforce and environmental factors.	• Indigenous primary healthcare centres in very remote areas tended to record higher proportions of cervical screening than for centres in other areas • Overall, the average cervical screening coverage rate across the participating centres was 50 % (interquartile range (IQR): 29–67%).	

No.	Author(s), year country, location	Study population	Methodology	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
7.	Dorrington, et al. (2015), Aus (urban)	One Aboriginal Community Controlled Health Service's clients	Rapid-plan-do-study-act (PDSA) cycles	Cervical screening	Translational research and continuous quality improvement (CQI) program	• Knowledge was acquired from community and service consultation and used within the CQI process • Extensive service consultation, which allowed prioritisation of local barriers and facilitators, and identification of what could be affected by internal changes • Health professionals positively influenced Pap smear uptake • General practitioner promotion was crucial • Reminding during a consultation • Having appointments available • Use of PDSA cycles was intensive.	• There was a 40% increase in yearly Pap smear numbers in 2012 (n = 217), the year in which the study was conducted, compared with the average for 2009–2011 of 154 (range 139–163). • Seventy-seven women had a Pap smear during the consultation in which the data collection tool was used (36%) compared with only six women who were screened early,	Level I (generalisable study; Daly Level III-3 (NHMRC)

No.	Author(s), year country, location	Study population	Methodology	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
							while 46% of women known to be requiring a Pap smear did not have one in the consultation assessed.	
8.	Dutton, et al. (2020), Aus (rural and remote)	Aboriginal and Torres Strait Islander women, never-screened and under-screened	Descriptive quantitative study	Cervical screening	HPV self-testing	• Ability to complete the test at home • Accessibility and privacy • Simplicity of the test • Being in charge of women's business • Appropriateness of the self-sampling kit content.	• 92.6% completed the follow-up evaluation survey • More than 90% of women were highly satisfied with the kit and the process involved • 96% would use the HPV self-sampling kit again • 98.5% would recommend the	Level I (generalisable study; Daly)

No.	Author(s), year country, location	Study population	Methodology	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
							kit to other women • Self-sampling removed the shame, intimidation, embarrassment and pain that was associated with clinician-collected Pap tests.	
9.	Lofti-Jam et al. (2019), Aus (national)	Organisation in practice	Descriptive study	Colorectal screening	Screening Interventions: 1) Mass media public health campaign 2) Targeted education and support programs (An Aboriginal-specific comedy	• Humour is an effective health communication strategy in Indigenous communities • GP endorsement was one of the strongest motivational factors.	A pre–post population survey of 1700 individuals aged 50–74 years found that: • 80% of Victorians and 24% of South Australians were aware of one campaign element • 40% of those exposed	Level IV (single case study; Daly)

No.	Author(s), year country, location	Study population	Methodology	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
					show about bowel cancer screening) 3) Primary care engagement and health systems improvements.		discussed the message with someone else • 97% found it believable • 87% felt it relevant • 87% reported feeling greater perceived control over their future health • 69% reported the campaign made them think about how their family and friends would feel if they got bowel cancer • Victorians showed a significant increase in the rate of iFOBT kit returns during and	

No.	Author(s), year country, location	Study population	Methodology	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
							soon after the campaign • The comedy show was very well received • A sample of 43 attendees completed evaluation surveys before and after the show • 76% reported they had a good or very good understanding of bowel screening, compared with 30% prior • 96% reported they were confident to use the test • 88% intended to screen within the next 12 months.	

No.	Author(s), year country, location	Study population	Methodology	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
10.	MacDonald et al. (2021), NZ (regional)	Māori- and non-Māori women	Cluster randomised controlled trial (RCT)	Primary care clinics	HPV self-testing	• The offer was made through usual primary care processes—opportunistically at clinics, at home or community centre—by a trusted nurse, doctor or kaiāwhina, using usual recall systems.	• 59% uptake of screening, almost three times that of the control • Primary care clinicians incorporated the offer of this test into routine work, suggesting that introducing self-testing would be sustainable for primary care in NZ • An increased screening rate for under-screened non-Māori • The majority of women who accepted screening in the intervention arm	Level I (generalisable study; Daly) Level II (NHMRC)

No.	Author(s), year country, location	Study population	Methodology	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
							accepted the HPV self-test.	
11.	McLachlan et al. (2018), Aus	Under-screened and never-screened women	Mixed methods	Primary healthcare	HPV self-testing (pilot project)	• Flexible approaches • Explanation, information and training • Extensive efforts to monitor, support and engage women to follow up • Opportunities to develop trusting, empathetic relationships with health professionals • Recognition of participants' past experiences were critical to the successful completion of the self-collection pathway. • A well-implemented process, led by trusted, knowledgeable, and	• The overall participation rate in screening (self-collection or Pap test) was 85.7% (84 women), with 79 women self-collecting • 85% (10 women) of participants who tested positive for HPV successfully received their results and completed follow-up procedures as required.	Level III (descriptive study; Daly)

No.	Author(s), year country, location	Study population	Methodology	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
						engaged health care professionals.		
12.	Mema et al. (2017), Can (rural and remote)	Hard-to-reach women	Descriptive study		Mobile screening test	• Screening facilities were taken to the communities, which removed the access barrier and increased awareness • An enhanced mobile program that provides client-centred one-stop shopping for breast, cervical and colorectal cancer screening services.	• Successful in increasing participation in screening for cervical and colorectal cancer compared with the Screen Test program among women who received a mammogram through the mobile service.	Level III (descriptive study; Daly)
13.	Sandiford et al. (2019), NZ	Māori, Pacific and Asian individuals who failed to return a bowel	Quasi-experimental research design		Telephone follow-up	• Active telephone follow-up service • The telephone calls helped to formally 'opt out' those subjects for whom a CRC screening	• The imputed potential overall increase in participation in the active follow-up group was 2.0%	Level I (generalisable study; Daly) Level II (NHMRC)

No.	Author(s), year country, location	Study population	Methodology	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
		cancer screening kit within four weeks				test would be inappropriate, and those who had made an informed decision not to undertake the test.	(95% CI¼0.6%–3.4%) • However, the impact of follow-up varied significantly by ethnicity and deprivation. The imputed increase in participation was significant for Māori (5.2; CI¼1.8%–8.5%) and Pacific (3.6%; CI¼0.7%–6.4%), but not for Asian ethnicities (0.7%; CI¼_1.1%–2.4%) • The imputed increase was significant among high-deprivation participants (3.9%; CI¼2.0%–5.9%), but not among	

No.	Author(s), year country, location	Study population	Methodology	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
							low-deprivation participants (0.3%; CI¼_1.6%–2.2%).	
14.	Sandiford et al. (2018) NZ	All eligible individuals	Interrupted time series analysis (quasi-experimental research design)		A community laboratory drop-off (CLD) alternative to postal return in New Zealand's bowel screening pilot	• Little or no additional cost • A flyer added to the bowel screening test kit offered CLD as an alternative to returning the kit by post.	• Overall, 26% of invitees used the CLD option • The effect of the CLD option on participation varied significantly by age, gender and ethnicity • There was a significant increase in participation among males (+1.75%; P = 0.002); patients under 60 (+1.65%; P = 0.006); Māori and Pacific (+2.88%; P =	Level II (conceptual study; Daly)

No.	Author(s), year country, location	Study population	Methodology	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
							0.029); and in the European/other ethnic group (+1.04%; P = 0.045) but not in Asians.	
15.	Whop et al. (2021), Aus	Indigenous women	Literature review		HPV vaccination HPV-based screening Self-sampling	• Family and community collective involvement in decision-making and health promotion • Role of Elders and female family members for sexual health education and broader traditional teaching (multi-generational collective in this decision-making process) • Several facilitators that can overcome barriers to screen include openly talking about screening,		Level I (generalisable study; Daly) Level I (NHMRC)

No.	Author(s), year country, location	Study population	Methodology	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
						trusting relationships with health professionals, and overcoming logistical barriers and privacy concerns (especially for women employed at health centres) • Importantly, women who screen still describe needing to overcome fear, shame or past negative experiences • Other enablers include access to female health professionals (including Indigenous health workers) and locally devised health plans that aim to improve access, GP knowledge, recall systems, targeted culturally relevant health		

No.	Author(s), year country, location	Study population	Methodology	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
						promotion, and population registers • Some suggested strategies are the use of patient navigators and self-sampling for HPV testing. The use of patient navigators, community members, or Indigenous liaison officers can help women to navigate through screening and treatment pathways—making appointments, attending appointments, organising transportation, being a support person and facilitating consultations with healthcare providers • Trust, credibility and accountability are key;		

No.	Author(s), year country, location	Study population	Methodology	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
						therefore health providers involved in cervical screening services and interventions with Indigenous women need to provide culturally safe care • Flexibility in delivery was important at all steps in the pathway • Providing appropriate support both before the test, when delivering the results, and in the decision-making regarding treatment was also important.		
16.	Zehbe et al. (2017), Can, communities in Northwest Ontario	First Nations women	Participatory action research	Community setting	Self-administered vs provider-directed sampling	• Convenience factors: more privacy, no appointment needed • Self-sampling is less painful	A comparative analysis of preferred methods of cervical screening.	Level III (descriptive study)

No.	Author(s), year country, location	Study population	Methodology	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
						• High comfort with self-sampling.		

Appendix 3—Summary table of articles describing strategies and models used/trialled to make cancer screening accessible to Indigenous communities in Australia, NZ and Canada

No	Author(s), year country, location	Study population	Method	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
1.	Bernardes et al. (2018), Aus	Aboriginal and Torres Strait Islander peoples with cancer	Qualitative study	Hospital	Patient Navigator Model	• Availability of a person who the patient can talk to and who shows compassion • Privacy • Collective bonds within the community	- Patient satisfaction survey completed - Patients' unmet needs or concerns, such as travel issues, accommodation worries, addressed - Patients' partners' needs were also addressed,	Level III (descriptive study; Daly)

No	Author(s), year country, location	Study population	Method	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
						• Balance between personal assistance and support that is not perceived as intrusive • Relationship with the host institutions, staff members and the researchers built and nurtured to integrate the intervention into the routine of the service.	resulting in the patients feeling less worried - Worries related to death and dying were addressed - Patients' anxiety lessened by the Navigators providing necessary support and information.	
2.	Carruthers et al. (2019), Aus, rural and remote	Patient records in one cancer centre	Medical records review	Radiation therapy	Comprehensive cancer care	• Remote patients had funded accommodation and daily transport for the treatment • Maintain electronic communication with their home community • Indigenous Liaison Officer (ILO) works through cultural barriers and provides appropriate supportive care needs • Coordination of timely access to psychosocial, social welfare	Attendance during radiation therapy showed significant improvement over time for Aboriginal and Torres Strait Islander patients, from 70.6% to 81.6%.	Level I (generalisable study; Daly) Level III-3 (NHMRC)

No	Author(s), year country, location	Study population	Method	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
						and other allied health services during treatment • Cancer centres introduced a cultural security policy • Cancer education and training workshops to educate and upskill 25 NT GPs, including Aboriginal health practitioners.		
3.	Christie et al. (2021), international	Indigenous women in high-income countries	Systematic review	Breast cancer		• Initiative that focused on resourcing community-led initiatives • Partnerships with ACCHS • Involved community members in planning and implementing evidence • 'Co-design' with Aboriginal communities • Evaluation of successful, cost-effective and sustainable strengths-based solutions to health challenges	• Increased uptake of care • Provided culturally safe care.	Level I (generalisable study; Daly)

No	Author(s), year country, location	Study population	Method	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
						• Researchers, clinicians and community members work together • Community engagement • Community governance • Capacity building was a key factor • Experiences of the family are fundamental • Culture makes a real difference • Indigenous methodologies and Indigenous researchers were the key.		
4.	Chynoweth et al. (2020), Aus, policy paper	Aboriginal and Torres Strait Islander peoples	Policy paper	Cancer care overall	Optimal cancer care	• Patient-centred care • Safe and quality care • Multidisciplinary care • Supportive care • Care coordination • Communication • Research and clinical trials • Cultural safety of the services, especially at the primary healthcare level, to support		Level III (descriptive study; Daly)

No	Author(s), year country, location	Study population	Method	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
						early presentation and diagnosis • Inclusion of Aboriginal and Torres Strait Islander health professionals and liaison officers • Cross-jurisdictional cancer experts.		
5.	Cuesta-Briand et al. (2015), Aus, rural	Aboriginal and Torres Strait Islander women	Qualitative	Cancer support group	Aboriginal Women's Cancer Support Network	• Peer-support • Emotional, practical and informational support • Became ‘community navigators' or ‘cancer navigators’ • Bridged the gap in cancer service delivery, acting as a 'cultural broker' by providing a culturally safe space for women • Engaged in culturally safe health promotion and education initiatives • Fostered social interaction		Level II (conceptual study; Daly)

No	Author(s), year country, location	Study population	Method	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
						• Found comfort in relations to shared cultural and upbringing experiences within the network • Actively engaged in grassroots health promotion and education.		
6.	De Witt et al. (2018), Aus, urban, regional, remote	Aboriginal and Torres Strait Islander and non-Aboriginal health professionals	Qualitative	Cancer care		• Culturally competent and responsive care • Aboriginal and Torres Strait Islander staff - - for health checks - - to discuss medical concerns - to provide clarity about cancer diagnosis - at the interface between the primary healthcare and hospital setting during patient hospitalisation • Psychological support for patients and families - visual presence of Aboriginal and Torres Strait Islander staff to respond to patients' needs		Level II (conceptual study; Daly)

No	Author(s), year country, location	Study population	Method	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
						- ‘having a yarn’ to see how they are - seek out and follow up patients - provide support for the patients and family - accompany patients to appointments - help to navigate the system - patient needs - referrals from hospital staff - availability of ALOs • Meeting patients’ needs • Aboriginal and Torres Strait Islander staff - made patients more confident - play a crucial role in understanding Aboriginal and Torres Strait Islander patients’ concerns and talking through these concerns with patients - Aboriginal and Torres Strait Islander staff are in a better		

No	Author(s), year country, location	Study population	Method	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
						position to provide practical assistance - advocates for Indigenous health - advocates for Indigenous patients • Organisation; follow up patient appointments; elect to be the patient's contact person • Taking on a trouble-shooter role to manage unforeseen difficulties • Ensuring patients receive continuity of care and quality care • Locating, accompanying and transporting patients to appointments to encourage attendance • Taking on the role of interpreter to explain cancer treatment pathways • Services available through ACCHS		

No	Author(s), year country, location	Study population	Method	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
						• More partnerships with ACCHS may lead to improved cancer care for Aboriginal and Torres Strait Islander peoples.		
7.	Durey et al. (2017), Aus, urban, regional and rural	Health professionals	Mixed	Cancer care	Cancer-specific cultural safety workshop	Working Together to improve cancer care for Aboriginal and Torres Strait Islander Australians—two-hour workshop used theory, case studies and group discussions to explore barriers and facilitating factors to delivering culturally safe care to Aboriginal people with cancer.	Relationship, communication and awareness all improved after the workshop and persisted up to two months after the workshop. **Baseline** • Good communication • Respect • Awareness of cultural differences and sensitivity. **Post-workshop** • Depth of understanding increased • Health professionals to treat Aboriginal patients with respect	Level III (descriptive study; Daly)

No	Author(s), year country, location	Study population	Method	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
							• Health professionals started examining their own behaviour • Helpful and informative • Increased participants' knowledge of Aboriginal culture • Increased their confidence • Wanted a list of dos and don'ts. **Two-months post-workshop** • Reflected on how they communicated with Aboriginal patients • Viewed Aboriginal people more holistically in the context of the culture, community, language and family • Health professionals avoided using medical jargon	

No	Author(s), year country, location	Study population	Method	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
							- Health professionals feeling less fearful of saying the wrong thing, or saying nothing - Increased health professional confidence - Health professionals considered building trust with their patients.	
8.	Garvey et al. (2016), Aus, urban and regional	Clinical staff and Adult Aboriginal and Torres Strait Islander patients	Mixed	Cancer care	SCNAT-IP tool devised in care	- SCNAT-IP assessment would be most useful at the beginning of the treatment trajectory, supplemented by reassessment at time points throughout the cancer journey.	- Majority Aboriginal and Torres Strait Islander cancer patients liked being asked about their unmet supportive care needs - Questions and format of the SCNAT-IP acceptable - Process of needs assessment using SCNAT-IP helpful - Screening for unmet needs and distress shown to improve communication between patients and	Level III (descriptive study; Daly)

No	Author(s), year country, location	Study population	Method	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
							clinicians and enhance psychosocial referrals • Better meet the needs of under-served population.	
9.	Ivers, et al. (2019), Aus	Aboriginal and Torres Strait Islander clients and health professionals	Qualitative	Primary care setting	Cancer care team (CCT) consists of an Aboriginal health worker, counsellor and enrolled nurse employed for two days a week, supported by a GP	• Supported patients from pre-diagnosis while investigations were being undertaken, at diagnosis and through treatment, such as, surgery, chemotherapy and radiation therapy, and follow-up, including palliative care and grief support. • Coordinated preventive programs. - CCT workers were present during the initial stage of cancer care, and that was critical - Workers also amended appointments with clients - CCT had knowledge of and facilitated access to services,	• Acceptability and accessibility of cancer care services • Improved accessibility of cancer care services, included availability of home visits, transport and accompaniment to tertiary settings • Service was viewed as ‘culturally safe‘ • Felt reassured that the service existed • Some clients and stakeholders said they would not have accessed treatment without CCT assistance.	Level III (descriptive study; Daly)

No	Author(s), year country, location	Study population	Method	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
						both in primary and secondary care - CCT explained medical terminologies - CCT provided counselling services to relieve depression, stress, anxiety, anger and loneliness - Based at an ACCHS, which was critical.		
10.	Jull et al. (2019), Can, urban	Inuit participants	Qualitative	Cancer treatment	Shared decision-making (SDM) strategy	• The SDM strategy has to be used early in the cancer care journey • The SDM strategy booklet made it easy to talk about what was important.	• Positive response from the patients • Will help negotiate the healthcare system • Users were happy to share information about the use of the SDM strategy with other patients who have cancer • The SDM strategy helped to engage with a patient	Level III (descriptive study; Daly)

No	Author(s), year country, location	Study population	Method	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
							- The booklet helps us to talk about what is important - Relational features are identified as core competencies in the conduct of SDM - It is also referred as 'decision coaching'.	
11.	Lethborg et al. (2021), Aus, urban	Aboriginal and Torres Strait Islander cancer patients	Mixed	Cancer treatment and management	Quality improvement framework Participants' medical records review	- Culturally appropriate engagement and communication - Connect with each patient and family - Understanding community, history and kinship - Mutual trust and understanding built - Yarning or talking informally was used to connect and earn trust	- All participants' care plans included discussion with their family - A total of 26 referrals made to community services - Staff care plans showed the importance of Country for eight cancer patients, and cultural ceremonies were enabled for six cancer patient participants - Shared decision-making between the cancer patient participant, family, staff and	Level III (descriptive study; Daly)

No	Author(s), year country, location	Study population	Method	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
						- Circular rather than linear communication and discussion - Meeting each person 'where they are[were]' (a core value of social work) but this could not have happened without the skilled Yarning and Dadirri (deep listening) offered by Aboriginal hospital liaison officer and social work staff. • Co-designed care plans - Questions phrased in different ways - Shared decision-making between the cancer patients, family, staff and community members • Providing appropriate information and practical assistance	community members enabled better access, care planning and continuity of care.	

No	Author(s), year country, location	Study population	Method	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
						- Specific cancer resources for Aboriginal and Torres Strait Islander people - Targeted and appropriately written information for inclusion in individualised support plans - Financial resources (Centrelink and grant schemes); transport information (public transport cards, subsidies and assistance with parking costs); accommodation support; hospital system support (hospital map and services booklets) - community services support - health literacy information (individualised and culturally relevant); diagnosis support (dispel myths and encourage hope)		

No	Author(s), year country, location	Study population	Method	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
						- family cohesion support (information for carers and children, cancer services, carer support, school support and conflict management). • This process and resultant model of care have worked well because of the whole-of-organisation working together with a strong commitment to co-learning for both the health service and the Aboriginal and Torres Strait Islander community.		
12.	Ristevski et al. (2019), Aus, Gippsland region, Victoria	Aboriginal and Torres Strait Islander cancer patients	Qualitative		Culturally appropriate survivorship models of care	• Culture and family were central to treatment and survivorship experiences of Aboriginal patients • Being 'on country' is important when people are sick • Having family presence reduced feelings of isolation and increase feelings of safety		Level III (descriptive study; Daly)

No	Author(s), year country, location	Study population	Method	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
						- Involvement of an Aboriginal liaison officer is a culturally safe source of support - Cultural supports are part of the multidisciplinary care team and should move beyond the hospital setting, building information and communication processes with mainstream and Aboriginal community health and primary care organisations to support cancer survivors in community settings.		
13.	Roberts et al. (2020) Roberts et al. (2019), Can, regional	Inuit cancer patients and families	Personal experience and hospital-based, service-related study	Cancer treatment and management	The Champlain Indigenous Cancer Program (CICP) The culturally safe	- Patient-centred - Culturally appropriate - Land-based - Nurse navigator not only build relationships with the First Nations patients, but also those treating them - Nurse navigator developed an unconventional approach to	- The CICP achieved far-reaching success - From 2017–2018 there has been a 400%+ increase in patient encounters with the nurse navigator. - Clinicians report an increased awareness and understanding of the	Level IV (single case study; Daly)

No	Author(s), year country, location	Study population	Method	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
					advocacy model of care	connect with Inuit patients. She prioritised developing therapeutic, rusting relationships with patients and families • Non-clinical and does not replace any service within the hospital • It is not case management • It involves a triage of needs based on what the patient and family determine their needs are • Establish trust and to be that important link between the patients and the cancer care team.	unique context of Inuit patients and families • Within the Inuit community, an increase in self-referrals • The program is also continuing to increase access to cultural awareness education for staff to combat misunderstandings about Inuit peoples.	
14.	Slater et al. (2016), NZ, national	Māori healthcare providers	Quantitative (survey)	Māori health provider organis-ations	Māori health professionals involvement	• Māori health professionals deliver a wide range of programs including cancer prevention services focused on health promotion, advocacy, information and support.	• Information (64%) • Advocacy (63%) • Transport (58%) • Health promotion (55%) • Provision of nursing care (36%)	Level I (Generalisable Study; Daly)

No	Author(s), year country, location	Study population	Method	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
					in cancer care		• GP care (32%) • Disease state management (26%) • Palliative care (24%) • Other support and services including support for whānau (family), respite care, counselling and psychotherapy, support group programs, funeral support, celebrations, rongoā (medicine) and accommodation (18%) • Advocacy and practical support, including transport and support for clinician and other appointments such as welfare agencies and electricity companies (27%) • Clinical services, including oncology departments, specialists and community nursing care (20%).	

No	Author(s), year country, location	Study population	Method	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
							Additional cancer support that could be provided with increased funding includes: • Support for whānau • Māori cancer support nurses • Māori-focused psychotherapy and counselling, culturally appropriate home help • 24-hour nursing support, mirimiri (traditional healing) and rongoā • cancer resources and information specific to Māori.	
15.	Taylor et al. (2018), Aus, national	Cancer services	Mixed (survey and interviews)	Cancer treatment centres		PLEASE SEE APPENDIX 4 BELOW		Level I (generalisable study; Daly)

No	Author(s), year country, location	Study population	Method	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
	Taylor et al. (2018)							
16.	Taylor et al. (2020) Taylor et al. (2021)	Cancer services	Case study	Cancer treatment centres		PLEASE SEE APPENDIX 4 BELOW		Level II or Level IV (conceptual or single case study; Daly)
17.	Thewes, et al. (2016), Aus	Aboriginal and Torres Strait Islander cancer patients and staff	Qualitative	Cancer treatment and manage-ment	The Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP) in routine care	• Multiple benefits of the SCNAT-IP were identified, including its comprehensiveness, its systematic approach to needs assessment and the opportunities for early intervention that other less formal assessments methods did not offer • The most commonly identified barriers to using the tool were the time needed to arrange an appointment and to complete	• The majority of participants liked being asked about their needs, did not mind taking the time to answer questions and generally found the process very helpful • The process made the patients feel heard and it linked them to services • Patients felt empowered by the process of needs assessment	Level I (generalisable study; Daly)

No	Author(s), year country, location	Study population	Method	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
						the interview at the patient's pace - Logistical problems were especially common for rural or remote patients - Should have been completed earlier in the cancer journey.	- Most participants found the tool very easy to understand and all liked the format of being asked the questions by health profession staff - They were satisfied with the timing of the questionnaire - Many patients supported the idea of universal screening for Aboriginal and Torres Strait Islander cancer patients, noting that it would educate staff about Aboriginal and Torres Strait Islander patient needs - It educated patients about what help is available to them and what to expect during treatment - It led to improved communication with	

No	Author(s), year country, location	Study population	Method	Types of services	Models	Critical elements	Outcomes/ indicators of success	Hierarchy of evidence
							Aboriginal health workers, and nursing and medical staff.	

Appendix 4—Detailed examples or description of culturally appropriate initiatives of Australian cancer services identified by Taylor et al. 2018–2021[41, 42, 125, 126]

Key activities, initiatives or policies implemented	Detailed/ more tangible examples of initiatives
Trained workforce with effective communication skills	• Employment of Indigenous staff (roles included Indigenous liaison officers (ILOs), cancer care coordinators, project officers, frontline administrative staff). The ILO was automatically involved with any Indigenous patient, usually on the patient's first visit, which helped the safe transition of Indigenous patients into the cancer centres, and a co-working model; the ILO also spent additional time educating Indigenous patients about their treatment to help them feel more comfortable • Multidisciplinary team approach to plan and deliver cancer care. The ILO was a valued member of the multidisciplinary team, attending regular clinical meetings and speaking on behalf of Indigenous patients; the ILO provided an important navigator or care coordinator role • Education programs as part of professional development for the Indigenous health workers (IHWs). These included cancer education sessions, site visits to the cancer treatment centre, placement with other cancer services • Cultural awareness training for non-Indigenous staff (12 out of 14 services made it compulsory; training ranged from a two-hour webinar to a one-day face-to-face workshop.
Best practice care	• Increased flexibility in their clinical practice • Offered outdoor consultations • Provided a shorter treatment program • Provided access to clinical staff of the appropriate gender • Grouped Indigenous patient appointments together • Changed the physical environment (planned or already done) to improve the cultural safety of the treatment centre (examples: flying the Aboriginal flag, installing artwork by local Indigenous artists, displaying a welcome statement in the centre's entrance in local language, consulting the local Indigenous community when planning to build a new cancer centre or renovating the existing centre) • Incorporated suggested features into the structure of the building (examples: outdoor waiting areas, efforts to 'bring the outside in' by installing windows with views of nature, a colour scheme that represented the local landscape, fish tanks to represent the local waterways, installing a light box above the radiotherapy machine)

Key activities, initiatives or policies implemented	Detailed/ more tangible examples of initiatives
	• Processes or positions in place to support Indigenous patients throughout their cancer journey (not just while undergoing treatment) • Two services employed Indigenous Cancer Care Coordinators whose role was to support the patients during their entire time at the cancer service • Developed an Indigenous Cancer Patients Pathway that incorporated cultural needs to be considered at each stage of the treatment continuum • Family involvement ensured, usually by holding one or more family meetings (in person or via video conferencing) before starting treatment and sometimes during treatment • One remote service was developing a formalised Survivorship Program which include a one-on-one counselling session about the patient's needs after completing treatment • Worked with local health networks when striving to deliver best practice care (ACCHS, Primary Health Network, Cancer Council, palliative care organisations, Indigenous community representatives). This breaks down silos, pools resources and coordinates care for Indigenous patients • One regional service formed an Aboriginal Cancer Network that worked on different projects in relation to prevention, screening, treatment, survivorship and palliative care • Offered an outreach service in efforts to improve care (medical oncologist flew to a remote site on a regular basis to conduct clinics; home visits by nurses or social workers). When medical professionals visit remote Indigenous communities it, in turn, helps build their capacity, giving them a better understanding of patients' living conditions • Formalised telemedicine or tele-oncology services (running oncology clinics, supporting IHWs, delivering education and training to health professionals, holding family meetings with patients and their families).
Knowledge, attitudes and understanding of cancer	• Involved engaged communities • Developed in-house resources (n = 10) such as brochures, booklets, posters, videos, magnets, cancer service directory, pins • Resources developed with input from the local Indigenous community and using local languages where appropriate • Used patients as advocates • Community engagement (n = 10), e.g. a cancer service running community education sessions; one cancer centre held open days to raise awareness of cancer or the centre.
Prevention and screening programs	• Ran women's cancer screening programs for the local Indigenous communities (n = 4) • One was planning to run a workshop on prostate cancer.

Key activities, initiatives or policies implemented	Detailed/ more tangible examples of initiatives
Capacity to deliver quality services	• Ongoing activities to support continuous improvement (n = 4) (surveying past patients and obtaining feedback from open days and community education sessions) • The Aboriginal and Torres Strait Islander Quality Improvement Framework and Toolkit for Hospital Staff (AQIFTHS) was used by one service • Some services ensured correct identification of Aboriginal or Torres Strait Islander status at admission • Provided specific 'identification training' to frontline staff about how to ask the question respectfully • Efforts have improved data quality, with success being measured by a high concordance in identification when audited.