Education of First Nations Australians about cancer—what evidence is there around its effectiveness? A narrative review

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Summary

Poorer cancer prevention and control outcomes for First Nations Australians have resulted in a need for improved health literacy, that is their capacity as individuals to access, understand, and use information in ways that promote and maintain good health. This narrative review explores the evidence on how education programs work to improve First Nations Australians' understanding of cancer, and how this leads to more effective use of prevention, screening and treatment services. Limited to the Australian context, a bibliographic search using terms structured around four main concepts: Aboriginal, Cancer, Australia, and Intervention (health literacy, health promotion) was undertaken in May 2024 for publications from January 2000. Studies that evaluated interventions or initiatives aimed to educate (that is, to increase awareness, knowledge and influence behaviours) across the cancer journey (excluding palliative care) were included. Fourteen evaluated initiatives drawn from peer-reviewed papers, published reports and peak body case studies were included in the review. All included papers were assessed with three major areas considered important for determining the effectiveness of cancer education for First Nations Australians: 1) acceptability: delivery in a format that is acceptable to community and health services, 2) impact: having a positive impact on people's access to and understanding of the cancer pathway and/or increases intended or actual participation, and 3) viability: successfully navigating the challenges of viably implementing, sustaining and scaling up an initiative. This review highlights several factors that contribute to the effectiveness of cancer education initiatives targeting First Nations Australians: culturally tailored initiatives, co-design and consultation during development, capacity building to create supportive, trusting environments for accessible cancer education; local ownership and empowerment, integration with existing healthcare systems, flexibility and multi-pronged approaches. Challenges and areas for further efforts in developing cancer health literacy are also described. Relatively few initiatives are evaluated: most of these have focussed on screening and treatment.

Keywords: **Aboriginal and Torres Strait Islander; First Nations Australian; Indigenous; Cancer education; Health promotion; Primary health care; Cancer screening; Cancer prevention; Awareness; Prevention; Health literacy**

Introduction

Health literacy is globally recognised as a pivotal determinant of health outcomes.[1] The World Health Organisation defines health literacy as the capacity of individuals to access, understand, and use information in ways that promote and maintain good health.[2] This capability is crucial in managing chronic and complex conditions such as cancer, where informed understanding and management of the disease influences health outcomes.[1,3] Enhancing cancer health literacy (in terms of access, understanding and behaviour) is essential for reducing disparities in cancer outcomes between Aboriginal and Torres Strait Islander peoples—hereafter respectfully referred to as First Nations people—and non-First Nations people. Enhanced health literacy among First Nations people supports prevention, diagnosis, disease management, empowering individuals to make informed health decisions, improving health-related quality of life,[4] and reducing morbidity and mortality rates associated with cancer.[5,6]

Health literacy has been separated into two components by The Australian Commission on Safety and Quality in Health Care. Individual health literacy is the skills, knowledge, motivation and capacity of a person to access, understand, appraise and apply information to make effective decisions about health and health care and take appropriate action. The health literacy environment refers to the infrastructure, policies, processes, materials, people and relationships that make up the health system and which impact how people access, understand, appraise and apply health-related information and

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services.[7] Having low individual health literacy means an individual may not be able to effectively exercise their choice or voice when making healthcare decisions; individual consumers with poorer knowledge experience poorer health outcomes and is likely to have higher use of health services and more adverse outcomes.[2,8,9] For complex chronic diseases such as cancer, it has been recommended that healthcare providers pay attention to providing patient-centred information, to fulfil patient education needs for high quality clear information as this is associated with better health-related quality of life and lower levels of anxiety and depression.[10]

Educational interventions designed to enhance health literacy are recognised internationally to increase awareness, foster engagement in preventive behaviours, and improve adherence to treatment and follow-up across the cancer care continuum.[1,11,12] Patients who are educated are likely to be better able to understand their health needs, follow instructions, advocate for themselves and their families, and communicate effectively with health providers.[13] A program in the United States integrated cancer education with patient navigation for Native Americans, significantly improving screening rates and early cancer detection.[14] In Alaskan communities, digital storytelling, which merges traditional storytelling with modern technology, effectively increased cancer awareness and facilitated comfortable discussions about cancer, showing the value of culturally tailored educational methods.[15] In Australia, a *Find Cancer Early* media campaign successfully improved knowledge of cancer symptoms and encouraged health-seeking behaviours in rural and remote populations.[16] While this campaign was not specifically designed for First Nations Australians, rural and remote communities include First Nations people. Such educational interventions are critical for addressing the cancer survival disparities faced by First Nations people, who want programs that resonate with their perspectives on health and wellbeing and integrate traditional knowledge and practices.

There is a wealth of existing educational resources addressing a range of cancer-related topics developed to educate First Nations Australians and health professionals (that support First Nations Australians). These resources address the importance of screening, understanding cancer and the diagnosis process, surgery and treatment options, along with specific resources for males and females. Resources such as Cancer Australia's Women's Business Workshop for breast and gynaecological cancers[17] and the Lung Cancer in our Mob handbook[18] are examples of tailored tools designed to meet the specific needs of First Nations Australians. These resources are further supported by the Our Mob Our Cancer website (Cancer Australia 2022), which provides accessible information to both First Nations Australians and healthcare professionals. Although these resources address a range of cancer-related topics, the effectiveness of their delivery and resonance with First Nations communities and whether they lead to changes in behaviour remains largely unevaluated. Research indicates that while existing resources are essential, they often fall short of effectively engaging First Nations people due to cultural and linguistic barriers.[19]

Understanding the need for improved cancer literacy, The National Aboriginal Community Controlled Health Organisation's (NACCHO) Cancer Plan[20] and Cancer Australia's National Optimal Care Pathway for Aboriginal and Torres Strait Islander People with Cancer[21] both provide frameworks for enhancing cancer education and health literacy within First Nations communities. These frameworks emphasise the importance of culturally congruent approaches that respect and incorporate the values, beliefs, and practices of First Nations Australians. While developing and enhancing cancer literacy is a crucial step towards improving health outcomes, it is important to evaluate these interventions to determine their effectiveness; assessing whether these educational efforts lead to tangible improvements in access to care, understanding of cancer, and behavioural change underpins improvements. Without such evaluations, there is a risk that well-intentioned programs may not achieve their desired outcomes, leaving existing disparities unaddressed.

This narrative review examines cancer education initiatives directed at both First Nations Australians and healthcare professionals that support First Nations people, evaluating their effectiveness in enhancing cancer health literacy (access, knowledge and behaviour) among First Nations communities. By exploring the effectiveness, the review seeks to bridge the gap in documented strategies and enhance our understanding of how educational initiatives can contribute to cancer literacy and address differences in cancer outcomes among First Nations people. Leadership from the primary author, a proud Ugarem Le woman of the Meriam Nation in the Eastern Torres Strait, ensured that First Nations' perspectives were central to the discussion.

Methods

Search strategy

The literature search was guided by the expertise of librarians from the University of Western Australia and the University of Newcastle. The primary databases used included Embase, MEDLINE, CINAHL, and Google Scholar. Reference lists of pertinent articles were reviewed, and grey literature was hand searched. The search was conducted in May 2024 for publications from January 2000 to May 2024. The search terms used were structured around four main concepts: Aboriginal, Cancer, Australia, and Intervention (health literacy, health promotion) as follows.

- **Aboriginal:** Indigen*, aborigin*, Torres Strait Islander*, First Australian*, First Nation*
- **Cancer:** Neoplasms, cancer*, malignan*, carcinoma*, oncolog*
- **Australia:** Australia, New South Wales, Victoria, Queensland, Northern Territory, Tasmania, Australian Capital Territory, Western Australia, South Australia, NSW, VIC, NT, SA, WA, QLD, TAS, ACT
- **Intervention:** Health education, educat*, intervention*, self manage, program, health literacy or literacy, prevent*, understanding, knowledge, initiative, strateg*, campaign, self-manage*, evaluat*, awareness or intent*

Inclusion and exclusion criteria

The review included studies that evaluated interventions or initiatives aimed to educate (that is, increase awareness, knowledge and influence behaviours) across the cancer journey-excluding palliative care- and encompassing prevention and screening, diagnosis, treatment, and survivorship. Both qualitative and quantitative evaluation designs were considered, including those focusing on healthcare provider education that, in turn, aimed to educate First Nations Australians. Studies exploring patient experiences incorporating education and cancer literacy elements were also included.

Specifically, the review considered papers intending to directly enhance cancer literacy among First Nations Australians and those aimed at improving the cancer experience through the involvement of navigators or health professionals where education or health literacy was a defined component of the intervention. Studies that were primarily about care coordination and which included explicit elements of cancer education were included.

Studies were excluded if they recommended improvements without evaluating specific interventions, if they focused on care coordination without a defined educational component, or focused solely on preventive health without a literacy component. Conference abstracts were excluded.

Selection of studies

All titles and abstracts identified in the database search were independently screened for eligibility. Two reviewers (CC, TS) retrieved full copies of potentially eligible articles or those with insufficient information to decide and assessed them for meeting inclusion criteria, with any difficulties or discrepancies resolved through discussions with the authorship team.

Development and refinement of a framework for assessing effectiveness of cancer education

Various evaluation frameworks were reviewed for their utility in assessing the effectiveness of cancer education interventions overall[22–27]; none were ideal for the context of this review. Informed by these and team discussions, the authors refined the content and language for a framework focussed on assessing the effectiveness of cancer education, the design of which was influenced by: 1. Existing (scientific) models and literature and the characteristics described to explain/influence outcomes such as behaviour change models and health literacy; 2. The criteria/characteristics reported in the evaluations that we felt suitable for reporting in our narrative review (for example, the role of co-design, implementation challenges and facilitators, sustainability of initiatives etc).

To test and refine the framework, a structured assessment table was developed to systematically apply the framework's key elements to each included study. Studies were assessed using a binary tick/cross system to indicate whether an element was explicitly addressed. This process allowed for identifying gaps in the initial framework and guided refinements amongst the authors to ensure that core elements were clearly defined, consistently applied and culturally relevant. More specifically, the testing phase involved reviewing different elements from models of behaviour change and health literacy—including from Booker et al. (2014) who developed a three-tiered system to evaluate community-based cancer education interventions which classified outcomes as proximal (knowledge and attitude change), intermediate (behaviour change), and distal (morbidity/mortality effects).[27] However, upon applying these elements to the included studies, it was found to be impractical as few studies reported clear behavioural outcomes or long-term health impacts (morbidity/mortality), leading to the removal of the three-tiered system.

Additionally, it became evident that there were relationship-based approaches-such as navigators, peer support and community-led initiatives-that differed from population-based campaigns in delivering cancer education to First Nations Australians. This distinction reinforced the need to have a framework that evaluated interventions by incorporating cultural appropriateness, accessibility, and community engagement as essential indicators of effectiveness. Recognising the importance of trust, shared knowledge, and cultural safety in First Nations cancer education, the refined framework ensured that evaluations captured educational outcomes and the ways in which interventions aligned with First Nations ways of knowing, being, and doing.

Data extraction and synthesis

One reviewer extracted data from all potential articles into an Excel spreadsheet, and two reviewers verified it for accuracy. The data extracted included study characteristics, intervention target, intervention type, and impact. A narrative synthesis was conducted to summarise the studies. Characteristics of included studies were tabulated, and data on initiatives and outcomes were descriptively synthesised. No assessment was made of the scientific rigour of the evaluations, but rather the focus was on their efficacy for improving cancer education among First Nations Australians.

Results

Fourteen evaluated initiatives were included in the review drawn from a mix of peer-reviewed papers, published reports and peak body case studies. Eight evaluations were related to tumour-specific initiatives (four bowel screening, three cervical cancer screening, and one breast health and screening) with the remaining six evaluations not specific to a cancer type, instead focussed either on improving understanding of cancer and the cancer pathway or supporting First Nations people to participate in the cancer pathway (Tables 1 and 2). These evaluated programs were undertaken across all Australian states and territories (except for the Australian Capital Territory) and included regional and remote targeted locations with a mix of qualitative and quantitative data collection.

During the analysis, three major themes were considered important for determining the effectiveness of cancer education for First Nations Australians: 1) delivery in a format that is acceptable to community and health services, 2) having a positive impact on people's access to and understanding of the cancer pathway and/or increases intended or actual participation, and 3) successfully navigating the challenges of viably implementing, sustaining and scaling up an initiative. As detailed in the Methods, these findings, along with existing evaluation models, informed the development of a framework that captures the core elements necessary for effective cancer education. Fig. 1 visually represents the framework used in this review to describe the effectiveness of cancer education for First Nations Australians.

While all studies aimed to improve cancer literacy, they differed in scope, implementation, and evaluation methods. Some interventions focused on targeted education for individuals, while others took a population-based approach. Table 3 summarises the findings from the reviewed studies, structured under the three major domains of the developed framework: Acceptability, Impact, and Viability. The table presents how each initiative aligns with the key elements of effectiveness identified in the review, including cultural alignment, capacity building, usability, access, understanding, behaviour change, implementation, sustainability, and scalability, and these are elaborated on in more detail below.

Acceptability

Evaluating the acceptability of cancer literacy initiatives for First Nations Australians involved assessing how well these programs align with community values, cultural practices, and local priorities. Key factors included the integration of Indigenous knowledge systems, the use of culturally relevant mediums, and the co-design process, which fosters community ownership and engagement. Additionally, the usability of initiatives is crucial, with simpler, culturally appropriate models showing greater success in promoting cancer education and participation.

Cultural alignment

The acceptability of cancer education initiatives was consistently linked to respectful consultation and collaboration with communities to ensure alignment with local priorities and values.[28,30,39] Co-design of initiatives fostered community ownership and empowerment through active participation.[34,38–40] Integrating Indigenous knowledge systems and cultural practices increased cultural relevance. For example, nurse-led cervical screening models respected cultural sensitivities around Women's Business[34,38]; visual media such as flip charts, DVDs, and art exhibits featuring First Nations artwork resonated with communities[29–31,35,40]; and storytelling demystified cancer and the cancer pathway by sharing lived experiences.[30,33,36] Humour was also effectively used to destigmatise bowel screening.[37]

Capacity building

Building community capacity to deliver cancer education was linked to a deeper understanding of local contexts and barriers.[28] Tailored training programs for Aboriginal Health Professionals improved staff knowledge and confidence, empowering them to educate their communities about cancer.[28,32,39] These professionals played a crucial role in providing cultural education to non-Indigenous staff,[39] while trained community members facilitated access and engagement through local networks.[30,34,36,39] In hospital settings, patient navigators from the community acted as trusted intermediaries between patients and healthcare providers.[28,39]

Useability

The initiatives were more effective when they addressed an identified cancer education need and were delivered in a format that was easy to understand and engage with for both community and health services. For example, visual resources such as DVDs and flipcharts were effective in some settings **but were underutilised in others due to a lack of provider engagement *. Supportive care initiatives streamlined cancer care coordination for clients and healthcare providers.[28,30,33,36,39] Nurse-led initiatives improved understanding of cancer and simplified access and participation in screening.[29,31,33,34,38,41]

Impact

Evaluating the impact of cancer literacy initiatives for First Nations Australians involved examining how these programs enhanced access to education, improve understanding of cancer, and encourage participation in the cancer care pathway. Impactful initiatives adopted culturally tailored approaches to addressing logistical, systemic, and cultural barriers, while fostering greater engagement and behavioural change within communities.

Author and year	Title	Evaluated audience	Evaluation period and place	Study design	Intervention type	Tumour type	Limitations
Bernardes 2018[28]	*Lessons learned from a pilot study of an Indigenous patient navigator intervention in Queensland, Australia*	First Nations cancer patients	2013–14 Queensland public hospital	Indigenous Patient Navigator (IPN) training Baseline survey with n = 18 First Nations cancer patients participating in the initiative; follow-up survey with n = 7 participating patients	Pilot IPN to support First Nations cancer patients (post-diagnosis)	Non-specific	Single-site pilot with small sample; low follow-up participation (n = 7 of 18); short 2-month evaluation period; potential bias as the navigator was also the data collector.
Bierbaum 2017[29]	*Challenges to uptake of cancer education resources by rural Aboriginal Health Worker: the cancer Healing Messages flipchart experience*	AHWs and other HCPs working with First Nations clients	2010 SA	N = 166 AHWs participated in educational workshops to support the resource Post intervention survey of n = 18 AHWs & HCP working with First Nations clients	Flipchart & training	Non-specific	Low post-intervention survey response (n = 18 of 166 trained); minimal in-practice use of resource (n = 4); metropolitan-skewed sample despite rural focus; unable to assess training impact due to poor survey recruitment.
Byers 2018[30]	*Awareness, acceptability and access to screening mammography for remote Aboriginal women [letter]*	First Nations women in remote communities eligible for breast screening	2017 Women in very remote communities in NT/Central Australia	Not reported	Information sessions, educational resources and supported access to remote screening	Breast screening	An evaluation of an innovation in program delivery so no ethics approval. Hence, published in letter format with limited methodological detail. Strong relationship with educator and limited community sizes may limit generalisability and scalability.
Christou 2014[31]	*Missed opportunities in educating Aboriginal Australians about bowel cancer screening: whose job is it anyway?*	HCPs working with First Nations clients First Nations people	2009 Hospital outpatient clinics and Aboriginal health organisations WA	Post intervention survey of n = 26 flipchart recipients, supplemented with n = 11 AHPs recruited from a bowel cancer education course (that included the flipchart)	Flipchart	Bowel screening	Low post-intervention response rates: resource mailed out without training had poor uptake; limited in-practice use (n = 11); AHPs cited time constraints and low prioritisation as barriers to use.
Croager 2010[32]	*Impact of a short, culturally relevant training course on cancer knowledge and confidence in Western Australia's Aboriginal Health Professionals*	Aboriginal Health Professionals (AHPs)	2008 Metropolitan and regional WA	Daily process-evaluation and pre-post impact-evaluation survey of n = 35 AHPs.	Training course	Non-specific	Short-term gains in confidence not sustained at follow-up; unclear final sample size; skewed sample (mostly female and rural AHPs) limits generalisability.
Cuesta-Briand 2016[33]	*'Connecting tracks': exploring the roles of an Aboriginal women's cancer support network*	First Nations cancer patients (women), carers, network providers and service providers	2008 Regional town WA	n = 24 semi-structured interviews comprising Aboriginal and mainstream service providers, network members and clients	Cancer Women's Cancer Support Network	Non-specific	Interviews conducted when the network had options for less than a year, and therefore still establishing itself. Data collected from one-site only (a regional location) and therefore generalisability of findings a potential issue across cultural and geographical locations
Dutton 2020[34]	*Uptake and acceptability of human papillomavirus self-sampling in rural and remote Aboriginal communities: evaluation of a nurse-led community engagement model*	First Nations women eligible, but under-screened, for cervical cancer Rural and remote NSW	2016–18 8 primary health care sites across rural and remote NSW	Program eligibility survey (n = 216) pre-program and evaluation survey (n = 200) administered during program follow-up	Nurse-led self-collection screening & training	Cervical screening	Unknown number of women approached but declined or were ineligible. Screening history was self-reported and may be misrepresented; long data collection period and staff turnover disrupted consistency.
Haigh 2016[35]	*Talking about the not talked about: use of, and reactions to, a DVD promoting bowel cancer screening to Aboriginal people*	First Nations community and HCPs	2013 WA	Focus Groups and interviews with n = 67 participants encompassing development and distribution of the DVD, and HCPs and First Nations community exposed to the DVD	DVD	Bowel screening	Delayed participant recruitment and low distribution limited reach; possible response bias due to recruitment via ACCHOs with health-seeking behaviour. The sensitive topic area can skew conversation in the focus groups towards more outspoken people.
Ivers 2019[36]	*Home to health care to hospital: evaluation of a cancer care team based in Australian aboriginal primary care*	First Nations community, cancer patients and ACCHS HCPs	2015 ACCHS site–Regional NSW	Interviews with n = 8 cancer patients and n = 8 stakeholders/staff	Cancer Care Support Team	Non-specific	Non-specific

(Table 1 continues on next page)

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Author and year	Title	Evaluated audience	Evaluation period and place	Study design	Intervention type	Tumour type	Limitations
Lofti-Jam 2019[37]	*Increasing bowel cancer screening participation: integrating population-wide, primary care and more targeted approaches*	First Nations Australians (18+ years)	2017–18 Regional Victoria	Pre-post-performance survey of n = 43 First Nations Australians across five locations The First Nations initiative was reported as part of an evaluation of Cancer Council Victoria's bowel cancer screening campaign.	Touring comedy Show	Bowel screening	National Bowel Cancer Screening data is not consistently uploaded into Patient Health Record making it difficult to determine impact of the targeted initiative. No opportunity to gauge retention of messaging over time without a longer post-intervention lag time.
Meiselbach 2023[38]	*Do it for yourself: Australia's first experience of universal eligibility for self-collection cervical screening increases access for Aboriginal and Torres Strait Islander women*	First Nations women aged 25–66 years	2021-22 ACCHO site Victoria	Co-design: workshop & semi-structured interview with n = 7 First Nations women and n = 2 ACCHO staff. Implementation: Post-screening survey with n = 37 screening participants	Nurse-led self-collection screening (including co-design)	Cervical screening	The site chosen for the trial had high, pre-existing nurse-led commitment to increasing cancer screening; may not generalise to GP-led or less-engaged services. A non-Indigenous nurse led the program; however, they had spent a long period of time building trust in the community.
Reilly 2018[39]	*Aboriginal experience of the cancer and care coordination: lessons from the Cancer Data and Aboriginal Disparities (CanDAD) narratives*	First Nations cancer patients, carers and service providers	January 2015 and July 2016 SA	Qualitative assessment: semi-structured interviews with n = 29 First Nations cancer patients, n = 11 carers, and n = 22 HCPs	Aboriginal Care Coordinator programmes	Non-specific	Recruitment by ACCs potentially led to a bias towards participants who viewed ACCs more favourably. An initial deductive approach to data analysis (based on contemporary definitions of the cancer pathway and health policies) potentially limited broader definitions of attributes being more fully explored.

ACCHO = Aboriginal Community Controlled Health Organisation; ACC = Aboriginal Cancer Coordinator; AHP = Aboriginal Health Professional; AHW = Aboriginal Health Worker; HCP = Health Care Provider; IPN = Indigenous Patient Navigator; NSW = New South Wales; NT = Northern Territory; SA = South Australia; WA = Western Australia.

Table 1: **Peer-reviewed literature evaluating cancer education initiatives for First Nations Australians.**

Improved access

Cancer education initiatives effectively removed or reduced logistical, systemic, and cultural barriers to participation in the cancer pathway. Culturally tailored supportive care, such as Indigenous Patient Navigators, facilitated access to information and engagement for First Nations people.[28,39] ACCHS-coordinated care teams and alternative screening pathways[34,36,38,41] improved access through community outreach and primary care integration. Expanding eligibility criteria for self-sampling cervical screening allowed greater flexibility in how women accessed screening.[38] Volunteer-based networks, community ambassadors, and engagement workers[30,33,34] increased access through advocacy and community engagement, while trusted community members improved logistical and informational access. Events like Aboriginal art exhibits and comedy shows addressed logistical and cultural barriers, making screening more accessible.[37,40] Culturally appropriate resources within ACCHSs also improved access to education.[29,31]

Improved understanding

Culturally tailored support, such as Indigenous Patient Navigators and Cancer Support Networks, provided platforms for disseminating cancer information and improving confidence in navigating the cancer pathway.[28,33,39] Self-sampling cervical screening increased women's confidence, promoting further health-seeking behaviour.[34,38] Educational DVDs improved understanding of bowel cancer screening, particularly in remote communities.[30,35] Creative initiatives like art exhibits and comedy shows enhanced cancer awareness,[37,40] and training courses boosted AHWs' confidence and knowledge, improving patient care.[16,29]

Improved intent or behaviour

While many initiatives improved access and understanding, not all reported shifts in participation. Culturally tailored screening initiatives were most effective in increasing participation, addressing logistical barriers and reducing feelings of fear or shame.[30,34,35,37,38,41] Trusted community members and trained staff played a key role in supporting participation in screening,[28,30,34,39] and Cancer Council Victoria reported high intent to screen following culturally tailored events.[40]

Viability

The long-term viability of cancer education initiatives depends on addressing challenges related to implementation, sustainability, and scalability. While cultural relevance is crucial, lasting impact requires a robust

First Author and year	Title	Evaluated audience	Evaluation period and place	Study design	Intervention type	Tumour type	Limitations
Cancer Council Victoria 2020[40]	**Cervical Screening Campaign:** *Case study: Women's Business Flipchart* *Case study: Sistas Get Checked Cervical Art Show*	HCPs working with First Nations women (25–74 years)	2019–20 Two ACCHO sites in regional Victoria	HCP interviews (number of interviews not reported) Short intercept interview post-viewing art show. 121 attended the art show across the two sites (number of interviews not reported)	Flipchart and touring art show	Cervical screening	Conducted at two regional ACCHO sites in Victoria limits generalisation of findings more widely across the state and/or interstate and beyond ACCHO clients. Different models of care across ACCHO network are challenging for scalability. COVID required flipchart delivery format to be switched to digital format.
Menzies School of Health Research 2020[41]	**Report:** *National Indigenous Bowel Screening Pilot–Final Report*	Primary healthcare staff First Nations people, National	2018–19 N = 47 Primary healthcare centres across Australia	Pre- and post-training survey with n = 196 staff across sites participating in the National Indigenous Bowel Screening Pilot (NIBSP).	Alternative screening program & training	Bowel screening	COVID-19 disrupted data collection and training. Long lag time (up to 15 months) between staff training and being interviewed led to recall bias regarding resources and materials supplied to them. Four health centres identified as in 'hot zones' requested face-to-face training in administering the Alternative Pathway, however, training was unable to be delivered to these sites. The online participant details form was not conducive for use in a busy health centre and not integrated into their Clinical Information Systems. Participation rates were difficult to calculate given system limitations affected data accuracy and integration.

ACCHO = Aboriginal Community Controlled Health Organisation; AHP = Aboriginal Health Professional; AHW = Aboriginal Health Worker; HCP = Health Care Provider; IPN = Indigenous Patient Navigator; NSW = New South Wales; NT = Northern Territory; SA = South Australia; WA = Western Australia.

Table 2: **Grey literature evaluating cancer education initiatives for First Nations Australians.**

framework for ongoing support and expansion. The literature consistently identified facilitators and barriers to sustaining and scaling initiatives, with evaluations highlighting key factors necessary for maintaining relevance and improving First Nations community cancer literacy.

Implementation

The successful implementation of cancer education initiatives depended on recruiting and training appropriate staff, which posed challenges when multiple criteria, such as being a community member and understanding the cancer pathway, needed to be met.[28,35,41,42] Embedding clinic champions or trusted community members enhanced advocacy within communities.[28,34,38] Practice-level support was critical, but limited uptake occurred when the initiative did not align with healthcare provider priorities.[31,35,42] Flexibility in delivery, such as adapting to individual preferences or external circumstances like COVID-19, was also

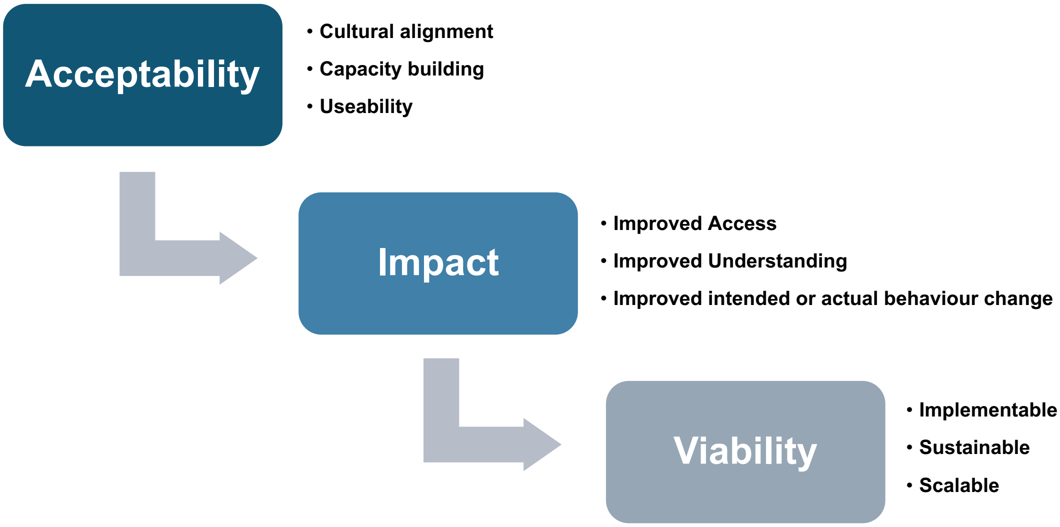

Fig. 1: Framework for assessing effectiveness of cancer education interventions for First Nations Peoples.

First Author & initiative	Acceptability			Impact			Viability	
	Cultural alignment	Capacity building	Useability	Access	Knowledge/ understanding	Intention or behaviour	Implementation (execution of the initiative)	Sustainability & scalability
Bernardes[28] Patient navigator	✓ Culturally appropriate patient navigation and cancer education provided by First Nations Patient Navigators	✓	✓ Highly acceptable for patients	✓ Improved patient access to treatment	✓ Improved patient understanding of cancer and services and supports along the pathway; evidence of increased health seeking behaviour	✓ Reportedly higher participation rates in cancer treatment	✓ Recruiting locally fostered trust & rapport; trust relationship and ability to connect helped demystify cancer treatment and care processes; IPN helped bridge cultural & communication gaps between indigenous patients and healthcare providers X Recruiting & training appropriate staff from community; system-level challenge to embedding IPN within the hospital (e.g. finding physical space within the hospital to host the initiative); complexity of cancer pathway, and explaining it to patients, posed challenges for navigators; privacy a concern for some community members	✓ **Key success factors** The IPN model of care had potential to be adapted and scaled up by tailoring to local community needs; requires trust-based collaboration with hospitals to be sustainable X **Challenges**: the resource-intensive nature of the initiative challenges broader scalability; IPN recruitment, training and retention challenges would be amplified when scaled; system-based challenges related to embedding IPNs in hospitals need to be overcome for sustainability and scalability
Bierbaum[29] Flipchart & training	✓ Culturally informed design Resource available in Pitjantjatjara	✓	✓ AHWs considered the visual format and appropriate artwork appropriate to support cancer education	✓ Improved staff access to cancer resources	✓ Improved staff confidence to deliver cancer education	X Limited staff uptake resulted in no change in community intent or behaviour	✓ Culturally relevant and simple design and content of the flipchart made complex information more accessible; training in the resource supported engagement; adaptable format facilitated cancer education X Flipchart distribution challenges, especially in remote areas; perceived relevance at the start of the cancer pathway limits utility; AHWs feeling unprepared, generally, to deliver cancer education content; competing workplace priorities and engagement resulted in low uptake for GPs and AHWs.	✓ **Key success factors**: flexibility of the flipchart to be used in a variety of settings suggests the format is promising to support health education more broadly X **Challenges**: training essential for engagement and appropriate use of the resource; high staff turnover a potential barrier to use and risk of misuse if new staff untrained;
Byers[30] Description of community education delivery as part of service	✓ Community consultation, collaboration and co-design	✓	✓ Highly acceptable for patients	✓ Improved eligible community members access to breast cancer screening	✓ Improved understanding of women's health, cancer and the importance of breast cancer screening	✓ Reportedly high rates of participation in breast screening and intent to re-screen and advocate for screening within community	✓ Engaging female community elders to act 'ambassadors' promoting screening and women's health; AHPs facilitating cross-cultural communication; a suite of culturally appropriate education resources such as locally produced DVD in first language; addressing anxiety for women travelling and staying away from home and country; being considerate of cultural commitments when scheduling travel X High level of health literacy support required to create understanding of cancer and preparedness to travel for mobile breast screening	✓ **Key success factors**: collaboration between community, AHPs, and a host of services and agencies a strong foundation for sustainability; opportunity presented for women to access other health resources and clinical services as part of the breast screening initiative warrants scaling the initiative X **Challenges**: reliance on accessing mobile screening; requirement for ongoing funding and high levels of coordination across community and agencies for the initiative to be sustainable and scalable

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First Author & initiative	Acceptability			Impact			Viability	
	Cultural alignment	Capacity building	Useability	Access	Knowledge/ understanding	Intention or behaviour	Implementation (execution of the initiative)	Sustainability & scalability
Christou & Thompson[31] Flipchart	✓ Culturally informed design Community feedback	✓	O Respondents reported that the flipchart was suitable, easy to use and clear, however only one-third had actually used it.	✓ Involvement of AHPs had potential to make bowel screening information more accessible	✓ Reportedly useful resources for improving knowledge of bowel cancer	X No evidence of the course impacting intended or actual participation in the cancer pathway	✓ Culturally tailored messaging facilitated better engagement with the initiative; community trust in AHPs facilitated delivery of cancer education X Logistical challenges distributing the flipcharts, especially in remote areas, impacted reach; misalignment between the goals of the initiative and the priorities of healthcare providers, hindered the initiative's success	✓ **Key success factors**: flexibility of the flipchart to be adapted to other health education needs beyond bowel screening. X **Challenges**: system reform required to support HCPs to spend time on bowel screening education; distribution issues a key challenge for scalability
Croager[32] Training	✓ Culturally informed design Community feedback First Nations presenters or co-presenters	✓	✓ Short-course format accommodates AHP work commitments	✓ Improved AHP access to cancer education	✓ Improved AHP understanding of cancer and confidence to deliver cancer education	X No evidence of attitudinal or behaviour change re: uptake in bowel cancer screening	✓ Culturally relevant content and appropriate approaches to delivering training reportedly successful in building AHP knowledge about cancer and the confidence to educate community; short course format allowed participants to quickly gain knowledge and skills without taking too much time away from work X The short course format provided only basic level of knowledge and information retention largely short-term	✓ **Key success factors**: cultural relevance of the training a solid foundation for scalability; short duration accommodates workload and competing priorities for AHPs making the initiative feasible to replicate more widely X **Challenges**: information learned in the short training course not sustained longer term; ongoing education, refresher courses and/or resources required for scaling up
Cuesta-Briand[33] Cancer support network	✓ Led by First Nations women	✓	O Acceptable for women being supported but resisted by HCPs	✓ Improved patient access to cancer services and education	✓ Improved understanding of cancer & pathway for patients	X No evidence of attitudinal or behaviour change	✓ The peer-support model provided by women from community who shared similar experiences fostered trust and a sense of community; strong community involvement was key to successful implementation X Geographic and logistical challenges such as transport for women in remote areas limited access to the network; lack of integration between the support network and the broader healthcare system made it difficult to ensure that the support provided by the network was aligned with formal cancer care services.	✓ **Key success factors**: sense of ownership over the network and empowerment helped maintain momentum of the initiative; potential for the model to be adapted to other community to address other health issues X **Challenges**: system-based challenges aligning support offered by the network with mainstream healthcare provider service delivery required in order for peer-support model to be sustainable; risk of burnout among network facilitators further challenges sustainability; significant resources required to establish the networks and maintain them over time poses challenges for scalability

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First Author & initiative	Acceptability			Impact			Viability	
	Cultural alignment	Capacity building	Useability	Access	Knowledge/ understanding	Intention or behaviour	Implementation (execution of the initiative)	Sustainability & scalability
Dutton[34] Nurse-led screening	✓ Co-designed with First Nations women	✓	✓ Model of support acceptable to women and service providers	✓ Improved eligible community members access to cervical cancer screening	✓ Improved understanding of cervical cancer and importance of screening and empowered them with the confidence to self-sample	✓ Reportedly higher participation rates in cervical cancer screening	✓ Nurse-led community engagement facilitated acceptance and confidence among women to self-sample; the self-sampling method aligned with cultural privacy values and increased autonomy increasing uptake and acceptance; community participation promoted and supported the initiative further building trust and engagement X More challenging distributing kits to remote communities and providing ongoing support; high investment in resources and community engagement; low health literacy in some locations added complexity	✓ **Key success factors**: the nurse-led model, community-focussed model has potential to scale up more widely, especially given the privacy benefits for women who may have resisted traditional cervical cancer screening X **Challenges**: Staff turnover and the need for ongoing community engagement and advocacy, threatens sustainability; scaling the initiative would be resource-intensive, requiring significant investment in training, logistics, and the ongoing supply of self-sampling kits; the challenges of reaching remote areas and maintaining engagement would also need to be addressed for successful scalability.
Haigh[35] DVD	✓ Developed with community input	X	O Format acceptable to community; bowel screening education a low priority for GPs hence low interest in the resource	X Access limited by lack of engagement in the initiative	✓ Improved understanding of bowel cancer and importance of screening when initiative was used	X Behaviour change limited by poor distribution and promotion	✓ Use of culturally relevant language, imagery and messages facilitated acceptance and engagement with the bowel cancer; the DVD format made the content easier to share and understand; the openness in addressing bowel cancer had cut-through with intended audience X Distribution of the DVD to intended audiences, especially in remote and rural locations was challenging; bowel cancer screening conversation not being regarded as a high priority for HCPs led to the DVD being under-utilised	✓ **Key success factors**: when the DVD was effectively promoted, community understanding increased making it a sustainable format for health education X **Challenges**: sustainability of the initiative hampered by challenging distribution networks and ongoing reliance on funding for production and distribution; long term sustainability requires system level change in order for HCPs to promote viewing of the DVD; adapting the DVD content for different communities might be necessary for broader scalability, adding complexity to scaling up the initiative
Ivers[36] Cancer Care Team	✓ Led by First Nations health service provider Delivered by First Nations and non-First Nations staff	✓	✓ Model of care acceptable to community	✓ Improved patient access to information about cancer and the cancer pathway	✓ Improved patient understanding of how to navigate cancer and the health system	✓ Reportedly higher participation rates in cancer treatment	✓ The integrated care approach provided seamless support to cancer patients across the cancer continuum, tailoring support to improve continuity of care; being based in an Aboriginal Medical Service (AMS) setting provided a culturally safe framework X The initiative was time and resource costly to implement; managing integrated patient care was logistically complex and challenged by a lack of coordination between primary care, hospital systems and other support services	✓ **Key success factors**: likelihood of sustainability enhanced by being part of local AMS service where there is already established trust within community X **Challenges**: maintaining the care team and ensuring continuity of culturally tailored services required continuous investment, which posed a challenge to long-term sustainability and scalability

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First Author & initiative	Acceptability			Impact			Viability	
	Cultural alignment	Capacity building	Useability	Access	Knowledge/ understanding	Intention or behaviour	Implementation (execution of the initiative)	Sustainability & scalability
Lofti-Jam, & Cancer Council Victoria[37,40] Comedy show	✓ Developed in response to community recommendations in collaboration with First Nations comedian	X	✓ Format acceptable to community	✓ Improved community access to information about bowel cancer and screening	✓ Improved community understanding of the importance of bowel cancer screening	✓ Reported intention to screen for breast cancer, and advocate for screening with friends and family, was high as a result of the initiative	✓ Tailored approach, leveraging culturally appropriate communication format, proved effective at educating the intended audience X Time and funding to develop comedy show/customised event	✓ **Key success factors**: comedy show format culturally acceptable, may require some customisation when scaled up more widely X **Challenges**: tailored approach more resource intensive compared with population-wide cancer education approach; content may require customisation when scaled up more widely and refreshed over time; ongoing support and integration with local health services important to maintain engagement and participation
Meiselbach[38] Nurse-led screening	✓ Co-designed with a rural First Nations health service and First Nations women	✓	✓ Model of support acceptable to women and service providers	✓ Improved eligible community members access to cervical cancer screening	✓ Improved understanding of cervical cancer and importance of screening and empowered them with the confidence to self-sample	✓ Reportedly higher rates of participation in cervical screening among underscreened women	✓ First Nations-led and community-designed initiative; involvement of AHWs promoting the initiative; female nurse advocating for self-collection cervical screening in community and explaining the test to patients X Logistical challenges, particularly in remote areas, distributing the kits and ensuring samples returned in a timely manner; additional support required for some women to understand the self-collection process due to lower health literacy levels	✓ **Key success factors**: 'Champions' within community and participating ACCHOs important for sustained engagement in the initiative to advocate for the test and build confidence in women to self-test; process-model ready for adopting into routine practice at a service-level X **Challenges**: Scaling the initiative to other areas, particularly remote regions, would require significant investments in logistics, infrastructure, and training; expanding the initiative would be resource-intensive due to the need for consistent kit distribution and follow-up services; diverse models of care across ACCHOs may also be a challenge for scaling up
Reilly[39] Cancer Co-ordinator	✓ Culturally appropriate care coordination by First Nations Cancer Care Coordinators	✓	✓ Highly acceptable for patients	✓ Improved patient access to treatment	✓ Improved patient understanding of cancer and services and supports along the pathway; evidence of increased health seeking behaviour	✓ Reportedly higher participation rates in cancer treatment	✓ Involvement of AHWs and community leaders in the care process increased trust and engagement from patients; a focus on holistic and patient-centred care resonated with patients X Systemic barriers to using the healthcare system; delivering consistent care coordination was challenging in remote locations	✓ **Key success factors**: involvement of AHWs in care coordination a foundation for sustainability X **Challenges**: reliance on external financial support to ensure longer-term viability; scaling to other regions or communities requires significant investment in infrastructure, training and resource allocation

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First Author & initiative	Acceptability			Impact			Viability	
	Cultural alignment	Capacity building	Useability	Access	Knowledge/ understanding	Intention or behaviour	Implementation (execution of the initiative)	Sustainability & scalability
Cancer Council Victoria[40] Flipchart & art show	✓ Co-designed with First Nations health service and First Nations women	✓	✓ Model of care acceptable to women (flipchart and art show) and service providers (flipchart)	✓ Improved staff access to cancer resources	✓ Improved staff confidence and capacity to deliver cervical screening education; improved women's understanding and importance of cervical cancer screening	✓ Reported intention to screen for breast cancer, and advocate for screening with friends and family, was high	✓ Design and delivery of the initiatives involved community leaders and elders; artwork created by influential Aboriginal artist; art show exhibited at ACCHOs ensuring cultural safe, private and supported space to have conversations about cervical cancer. X Delivery format adapted to accommodate challenges of COVID (flipchart offered in digital format)	✓ **Key success factors**: culturally sensitive and visual nature of the initiative is highly adaptable to other women's health topics; integrating the initiative with local healthcare providers ensures ongoing health support of messages delivered by the artwork X **Challenges**: significant financial and logistical challenges to scaling the initiative up, particularly to remote locations; different models of care across ACCHO network may be a challenge to scaling the model uniformly.
Menzies[41] HCP-led screening	✓ Community consultation, collaboration and co-design	✓	O Format acceptable to community; taxing on service providers	✓ Improved access to screening kits, information and support	✓ Improved understanding of the importance and relevance of the screening process	✓ Significantly higher participation in bowel cancer screening; kits returned much more promptly than usual pathway	✓ Involvement of IHWs (Indigenous Health Workers) and community leaders helped build trust and encourage participation in the pilot; being trialled in Indigenous healthcare services across the country X Distribution challenges in remote communities impacted reach; high investment in staff training to implement the initiative; updating NBCSP patient records was inconsistently or incorrectly administered across sites, especially where there was staff turnover; a temporary workaround needed to be introduced as many HCPs struggled with complex and time-consuming data processes	✓ **Key success factors**: if rolled out more broadly, the alternative pathway has potential to close the gap between indigenous and non-indigenous Australians participating in bowel cancer screening—rates of participation in the alternative model of care were on par with non-indigenous Australians and achieved greater reach among eligible under-screened people; the alternative pathway was reported as cost-effective relative to the mainstream bowel screening process; X **Challenges**: sustainability reliant on ongoing funding and resources to maintain community engagement and service delivery; requires investment in ongoing staff training to implement the initiative; structural barriers, such as the complex system for reporting patient information to the NBCSP registrar, need to be addressed to be sustainable or scalable

Key: ✓ This element is demonstrated or reported in the article; **O** There are contradictory findings about this element in the article; **X** This element is not demonstrated or reported in the article. ACCHO = Aboriginal Community Controlled Health Organisation; AHP = Aboriginal Health Professional; AHW = Aboriginal Health Worker; GP = General Practitioner; HCP = Health Care Provider; IPN = Indigenous Patient Navigator; NSW = New South Wales; NT = Northern Territory; SA = South Australia; WA = Western Australia.

Table 3: **Reported effectiveness of cancer education initiatives for First Nations Australians.**

essential.[34,40] Distribution and structural challenges, especially in remote areas, hindered resource access and implementation.[28,30,31,41] Costs associated with implementation and securing funding were significant barriers.[36,37] Additionally, tensions such as privacy concerns or conflicts between networks and healthcare providers affected engagement and implementation.[28,33]

Sustainability

The sustainability of cancer education initiatives depended on several key factors, including maintaining practice-level support and ensuring initiatives align with healthcare provider priorities.[35,42] Community ownership and engagement are crucial for sustaining momentum, with individuals who have positive experiences often becoming advocates, sharing knowledge within their communities.[30,33,36,38] Empowering communities through capacity-building, peer-support networks, and local leadership strengthens advocacy for cancer care services.[30,34,37,40] Workforce stability and ongoing professional development are essential to prevent knowledge loss and misuse of resources.[28,29,32,35] Cost considerations, including the time and financial resources needed for continued program delivery, influenced sustainability.[28,34,36]

Scalability

Most evaluations alluded to key considerations for scaling up cancer education programs. Having a distribution network, such as ACCHOs, was essential for scaling up AHW and nurse-led initiatives by providing a trusted destination for community.[32,34,36,38,41] Visual mediums, such as flipcharts and DVDs, show promise for wider health education use.[29,31,35] System-level reform is required to expand some programs, for example, improving hospital access and infrastructure is required to expand patient navigator programs[28] and providing primary healthcare providers with more resources in order to prioritise cancer screening education.[31,33,35]

Discussion

What works

This review highlights several factors that contribute to the effectiveness of cancer education initiatives targeting First Nations Australians, with varying degrees of effectiveness across acceptability, impact and viability. These are summarised in Table 4.

One key factor contributing to the acceptability of these initiatives is the culturally aligned, community-driven approaches that target specific needs rather than adopting broad, population-wide strategies. By recognising the unique cultural, social, and health barriers faced by First Nations people, these targeted interventions resonate with the intended audience, fostering engagement and relevance.[43] Culturally tailored initiatives, such as alternative Indigenous screening models, have demonstrated that cancer education efforts are most effective when designed to respond to an identified gap in cancer literacy or pathway participation within the community. This tailored approach ensures that educational materials and programs speak directly to the lived experiences and cultural values of First Nations peoples.[6]

Consultation and co-design with First Nations communities have also been shown to enhance the acceptability and impact of cancer education programs. Increasingly there is recognition of the importance of co-design and consumer voice in development of health programs, and that this has particular importance in the context of socially disadvantaged and First Nations people, given the lack of voice and inclusion in education and planning of services that has occurred historically. Interventions that involve communities in both the design and delivery phases create a sense of ownership and trust, which is important for the successful implementation of these initiatives.

By involving local community leaders, Aboriginal Health Workers (AHWs), and Indigenous Patient Navigators, cancer education initiatives have created more supportive and trusting environments essential for overcoming barriers to access and fostering empowerment. For example, the Indigenous Patient Navigator program[28,39] embedded culturally safe navigation within hospital systems, supporting First Nations and non-Indigenous health professionals by fostering cultural understanding and easing patients' journey through the cancer care pathway. Similarly, evidence from Indigenous communities in the USA has shown that Cultural Navigators can mitigate barriers to healthcare, underscoring the potential benefits of a similar approach in the Australian context.[14] This approach not only helps navigate the healthcare system's complexity but also contributes to building lasting relationships between the healthcare providers and the communities they serve. Such approaches align with the key principles for best practice approaches to co-design with Aboriginal and Torres Strait Islander peoples adopted by Cancer Australia.[21] Australia's Aboriginal and Torres Strait Islander Cancer Plan is underpinned by key principles and best practices for co-design in health with First Nations Australians, specifically around First Nations leadership, a culturally grounded approach, respect, benefit to community, inclusive partnerships and transparency and evaluation.[44]

Capacity building has been another factor in the effectiveness of cancer education programs in these communities. Empowering First Nations people to take active roles in delivering cancer education helps build trust and accessibility within the community, enhancing the impact and reach of educational efforts. Importantly, capacity building supports local ownership of cancer education initiatives and empowers both individuals and the community to advocate for their health needs and

What we know works

- **Culturally tailored initiatives**: Targeted approaches, rather than population-based, most likely to resonate with First Nations communities; alternative/Indigenous screening models. All evaluated initiatives were tailored to First Nations community
    - o Initiatives respond to an identified cancer education or pathway participation need
- **Consultation and Co-design**: Interventions co-designed with the contribution or interest of the community, and involvement in delivery, can enhance the relevance and impact of cancer education
- **Capacity building**: First Nations people critical in the delivery of programs (creating supportive, trusting environments and hence more accessible cancer education; ownership and empowerment locally)
- **Community empowerment**: Empowering First Nations people through cancer literacy can give them the confidence to make informed decisions and advocate for their needs, and the needs of their community
- **Integration with existing healthcare systems**: Indigenous Patient Navigator embedded in hospital
- **Flexibility and adaptation**: Capacity to pivot/be flexible to accommodate changing circumstances or needs of community.
- **Multi-pronged approaches** are potentially more effective embedding understanding and longer-term intent or behavioural change

What needs work/challenges

- **Initiative not prioritised/valued by HCPs**: Low engagement or ownership regarding cancer education (e.g. some HCPs/GPs did not perceive cancer education as their responsibility, especially with complex/high needs clients
- **Initiative time-consuming or cumbersome to use**: low uptake where initiative not perceived as user-friendly
- **Initiative reliant on training for successful implementation and advocacy**: staff-turnover/retention can lead to under-use (motivation and advocacy diluted) or misuse (requires cost and time-effective approaches to training new starters)
- **HCP time and cost burden**: initiative distracts from/diminishes capacity of service providers to deliver core business; and/or time-consuming to administer (see earlier comment)
- **Privacy**: Capacity building from within local community can lead to concerns re: 'knowing my business'
- **Pre-existing fears/conceptions**: There is disconnect between preventive health and cancer outcomes; mistrust of institutional healthcare

What's missing

- **Relatively few initiatives are carefully evaluated and/or results shared** more widely:
    - o Programs operating in community may be effective, but are either not evaluated or the results not shared
    - o Initiatives may be replicated across different communities without the opportunity to incorporate learnings from previous evaluations (what to leverage, what to work on)
    - o Challenges with having appropriate ethics approval, or robust design for evaluation
- **Focus on screening and treatment**: Cancer education and engagement initiatives skewed towards screening and treatment pathway of the cancer pathway
    - o Limited coverage on the nexus between primary & tertiary care
    - o Little work on survivorship post-treatment/remission, cancer-specific palliative education and experience.

HCP = Health Care Providers.

Table 4: **A summary of efforts to improve health literacy around cancer in First Nations Australians.**

make informed decisions regarding their cancer care. It also helps to spread knowledge, ensure sustainability and help ensure culturally safe support and information is provided. Improving health literacy among Indigenous Australians is an important way to support self-determination and autonomy in both individuals and communities, by enhancing knowledge and improving health outcomes.[26] ACCHS are designated a key role in the development and delivery of health literacy programs given their position for support of integrated health promotion, ensuring information and programs must be accessible, locally relevant, trauma-aware, healing-informed, inclusive, culturally safe and responsive.[20]

Flexibility and adaptation have also proven important for the effectiveness of cancer education initiatives. The ability to pivot and accommodate changing circumstances or community needs allows these programs to remain relevant and responsive. During the COVID-19 pandemic, for example, cancer screening initiatives adapted their delivery models to maintain engagement and ensure continued participation, even amid unprecedented disruptions.[45] Programs that demonstrate the ability to adapt have a better chance of sustaining long-term behavioural changes in their communities.

There are many considerations in improving Indigenous health literacy around cancer and efforts are needed at multiple levels with a wide range of stakeholders engaged. Given the diversity and complexity of interventions to build health literacy across cancer journeys, multi-pronged approaches that increase knowledge and understanding and improve organisational health literacy and systems are especially important.

Challenges

Despite the many successes of targeted, community-driven strategies, several challenges continue to limit the broader and sustained effectiveness of cancer education initiatives in First Nations communities. These include the social, economic and cultural determinants of health which affect the education and understanding of First Nations people.

Transitioning from improved knowledge about cancer and cancer prevention to actual behaviour change is a challenge common across populations. However, First Nations people face additional barriers, including historical mistrust of healthcare systems, logistical challenges, and the lasting effects of past traumas.[46] Despite enhanced cancer education and knowledge, many communities continue to report low participation in cancer screening services, indicating that information alone is insufficient to overcome entrenched socio-cultural and systemic obstacles.[47] Pre-existing fears and misconceptions about cancer, coupled with these systemic barriers, persist as significant obstacles to behaviour change. While cancer education initiatives improve cancer literacy and knowledge, there is often a disconnect between preventive health education and participation in the cancer care pathway. As Treloar and colleagues highlighted, multi-faceted, grassroots approaches that integrate education, community involvement, and ongoing support are more likely to lead to lasting behavioural change.[6] Overcoming these deeply ingrained barriers requires knowledge dissemination, trust-building, and sustained engagement at both the community and healthcare system levels.

Another key challenge is the limited engagement and prioritisation of cancer education by healthcare providers, especially those managing complex or high-needs patients. In some cases, cancer education is not viewed as a priority, which can lead to lower uptake and weaker advocacy within communities. This can also reflect services being overwhelmed with other service demands in an understaffed environment.[19] Additionally, certain cancer education initiatives were perceived as time-consuming or cumbersome, limiting their practicality in high-pressure clinical environments.[31] This underscores the importance of designing user-friendly interventions that integrate smoothly into existing workflows.[42] The reliance on trained staff for the successful delivery and advocacy of these initiatives also presents sustainability challenges, particularly in settings with high staff turnover. Without sustained training, the effectiveness of programs can diminish, leading to under-utilisation or misapplication. Moreover, the time and cost burden on HCPs implementing these programs can detract from their capacity to deliver core healthcare services.

Another challenge identified is the lack of peer-reviewed evaluations for many community-based initiatives. This does not necessarily reflect the quality or impact of these programs but highlights the challenges posed by increasing ethical and administrative requirements for conducting formal health research. Health research ethics and governance processes have become more duplicative and demanding over time, including those involving First Nations research. Thus, Byers and colleagues description of a successful breast cancer education program implemented in a remote setting[30] was documented through a letter to the editor rather than as a formal research study, reflecting the demands associated with securing ethics approval which they considered too onerous for workers focussed on delivering a functioning approach. Other worthy initiatives which could contribute to building knowledge and engagement in high needs settings with a limited workforce are never published. While alternative evaluation methodologies such as quality improvement projects or community-based participatory research can provide valuable insights, they may also face barriers to reporting of systematic data collection and publication without Human Ethics Research Committee clearance. Health service delivery is core business to improve First Nations health, rather than research and evaluation with publication, so this means the examples that critically examine efforts to improve health literacy are limited. This restricts the sharing of models shown to be successful and hinders the replication of effective practices across different communities. A consequence may be that models that have never been evaluated are shared without the critical lens of evaluation ever applied. Ethics processes must enable activities that both safeguard First Nations communities and enable knowledge-sharing to strengthen future cancer education initiatives. This could be addressed by building capacity within services to participate in evaluation, research and peer review processes and through health service partnerships with researchers. Ethics processes must ensure they encourage rather than discourage evaluation.[48,49] The useful principles for evaluating cultural appropriateness of interventions described by Maddox and colleagues could guide the development of health service and program evaluations in the cancer space and align with the findings from our review.[50]

Addressing the gaps

This review has identified several issues to inform future efforts. Unsurprisingly, one was the challenges of sustaining initiatives beyond initial funding and despite the turnover of trained staff, which poses difficulties with maintaining ongoing training and professional development related to these programs. Ensuring the stability of initiatives requires initial funding and commitment to workforce capacity building and resource allocation that supports the ongoing delivery and evolution of these programs. However, these considerations align with broader calls for structural changes that support the sustainability of health programs in communities, recognising that short-term, project-based funding is inadequate for addressing complex health issues in meaningful and enduring ways. Future policy and research should prioritise the development of sustainable funding frameworks that recognise that health promotion and disease prevention work in First Nation communities require long-term and sustained commitment.

Further research is needed to strengthen the evidence base on cancer education interventions, but it must be culturally appropriate and aligned with the needs of First Nations communities. Barriers such as limited workforce capacity, short-term funding, and complex ethics requirements must be addressed to ensure feasible and meaningful future studies. While large-scale studies, including longitudinal research, could offer valuable insights, future research should prioritise culturally informed approaches that also centre Indigenous leadership. Anderson et al. (2022) outlined key principles for co-design in First Nations health, emphasising that culturally grounded approaches, respect, and benefit to community must be central to research and evaluation efforts.

Strengths and limitations

This narrative review provides valuable insights into the effectiveness of cancer education initiatives for First Nations Australians. A key strength of this narrative review is the development of a structured framework for assessing effectiveness, which synthesises available evidence and provides a practical tool for future program development and evaluation and a foundation for strengthening future efforts. Additionally, this review takes a pragmatic approach, ensuring that valuable lessons from existing initiatives are captured, despite the limited number of published articles. Given the relative scarcity of published evaluations in this area, the inclusion of grey literature and reports beyond peer-reviewed articles allows for a broader understanding of cancer education efforts in First Nations communities.

However, several limitations must be acknowledged. Reviews, in their approach, are limited by the quality and quantity of literature available for inclusion. This narrative review identifies key factors contributing to effectiveness and is based on the available evidence. Unlike a systematic review, this study did not apply formal quality appraisal criteria to assess the methodological rigour of included studies. Given the already small pool of available literature, applying exclusion criteria based on study quality would have significantly reduced the scope of this review, limiting the ability to capture key insights into what has worked and what challenges remain. As a result, some included studies had a small sample size, lacked post-intervention assessment, or did not provide long-term follow-up data, limiting the strength of the authors' conclusions. Additionally, this review does not directly evaluate cancer education initiatives but synthesises and analyses existing evaluation findings.

Despite these limitations, this paper makes an important contribution by consolidating existing knowledge and providing a structured framework to assess the effectiveness of cancer education initiatives. The framework offers a tool for future program design, evaluation, and funding priorities, ensuring that initiatives are built upon evidence-based principles and Indigenous-led approaches. By acknowledging the current gaps in evidence, this review also highlights the need for more rigorous, long-term evaluations of cancer education programs to inform future policy and practice.

Conclusion

Health education programs that build understanding and skills around cancer and use of services are essential to improving cancer outcome for First Nations Australians. While the principles and approaches for the development of cancer health literacy programs for First Nations Australians are well described and descriptions of many programs are available, the evidence base for their effectiveness remains limited. Despite successes with co-design and interventions being led by First Nations Australians, challenges persist in evaluating interventions and translating increased awareness into sustained behavioural change. Complementary efforts to build organisational health literacy are needed so that health literacy is embedded in the systems, organisational policies and practices of health services with attention to ensuring that interpersonal communication is effective. Health information available for First Nations community members and patients must be clear and focused on key relevant issues. Achieving better cancer outcomes requires long-term commitment to removing systemic barriers rather than short-term and project-based funding, and there must be an emphasis on rigorous evaluation and the sharing of outcomes to strengthen future initiatives.

Contributors

Conceptualisation–CC, TS, ET, ST; Data curation–CC, TS; Formal analysis–CC, TS; Methodology–CC, TS, ET, ST; Project administration–CC, ST; Visualisation–CC, TS; Writing—original draft CC, TS; Writing—review & editing CC, TS, ET, ST.

Declaration of interests

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