Knowledge, attitudes, and behaviours towards cancer screening in indigenous populations: a systematic review



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Cancer mortality among indigenous peoples is increasing, but these populations commonly under use cancer-screening services. This systematic review explores knowledge, attitudes, and behaviours towards cancer screening among indigenous peoples worldwide. Searches of major bibliographic databases identified primary studies published in English up to March, 2014; of 33 eligible studies, three were cohort studies, 27 cross-sectional, and three case-control. Knowledge of and participation in screening was greater for breast cancer than for other cancers. Indigenous peoples tended to have less knowledge, less favourable attitudes, and a higher propensity to refuse screening than non-indigenous populations. The most common factors affecting knowledge, attitudes, and behaviours towards cancer screening included access to screening, knowledge about cancer and screening, educational attainment, perceived necessity of screening, and age. Greater understanding of knowledge, attitudes, and behaviours towards cancer screening in diverse indigenous cultures is needed so that culturally appropriate cancer prevention programmes can be provided.

Introduction

Cancer is the third most common cause of death worldwide, leading to 7.5 million deaths in 2008.1 In terms of disability-adjusted life-years, the economic cost attributed to cancer in that year was US\$895 billion, without the direct costs of treatment.2 The physical, emotional, social, and spiritual effects on patients and families are immeasurable.3 In an attempt to reduce cancer incidence and the subsequent burden, secondary preventive measures, such as cancer screening, have become available.4 Screening can enable early detection of cancerous changes leading to better treatment outcomes.5 Targeted appropriately, screening can reduce mortality from breast and lung cancers by 20% and that from colon and cervical cancers by as much as 70% and 80%.5

Indigenous peoples are ethnically diverse with unique cultures, and constitute about 5% of the world's population and 15% of the economically disadvantaged population worldwide.6 Many live in geographically remote areas where access to health-care facilities and cancer-screening services is limited.6 Therefore, indigenous peoples can experience a high emotional and financial burden during cancer treatment.7 Death incidence from causes such as suicide6 and accidental injuries8 at young ages, before cancer might be expected to develop, is higher among some indigenous populations than non-indigenous populations. However, in Canada9 and Australia,10 where the life expectancy of indigenous populations is increasing, the incidence of cancer is now growing faster in indigenous than in nonindigenous peoples. 11,12 Moreover, some indigenous groups such as Alaska Natives and Native Hawaiians have higher cancer mortality rates than do nonindigenous populations.13 This disparity is also apparent between Maori and non-Maori people.14 Poor uptake of cancer-screening services among indigenous peoples15 could contribute to delayed diagnosis, more advanced cancer at diagnosis, and less favourable clinical outcomes,13 which are common features in medically underserved populations.16

Participation in cancer screening is affected by socioeconomic factors, such as income and health-insurance coverage, 17 as well as psychological factors including fear, 18 and self-efficacy in completion of the screening tests.¹⁷ Other relevant factors are language barriers,19 knowledge and awareness about available services, 19,20 whether culturally tailored screening programmes are available,19 lack of familiarity with preventive measures,19 and distrust of the health-care system and health-care providers.²⁰ Cultural norms and beliefs also influence an individual's intent to take part in cancer screening. 19,20

Indigenous cultures have unique perspectives on cancer and cancer screening; in most indigenous populations the word cancer does not exist and the disease is considered to be new.21 Understanding of knowledge, attitudes, and behaviours towards cancer screening among indigenous peoples is therefore necessary so that culturally appropriate cancer-screening services can be provided and encouraged and the cost of cancer care lowered. 22 This Review used a comprehensive approach to identify the scientific evidence on the perspectives of indigenous populations towards cancer screening, knowledge, attitudes, and behaviours towards participation in cancer screening, and barriers and facilitators that affect these behaviours among indigenous populations.

Search strategy and selection criteria

We searched the three major databases, Embase, PubMed, and SciELO, and Pimatiswin (a journal of aboriginal and indigenous community health), which was not included in these databases, for papers published in English up to March, 2014. Medical subject headings or text words used in the searches were "cancer screening" and "knowledge", "attitude", or "behav* (behavior)" combined with (ie, AND) "Indigen* (Indigenous)", "Aborigin* (Aboriginals)", "Native* (Natives)", or each of indigenous groups identified by two sources, Indigenous Peoples' Food System and Well-being: Interventions and Policies for Healthy Communities²³ and Wikipedia²⁴ (appendix). The See Online for appendix

Lancet Oncol 2014; 15: e504-16

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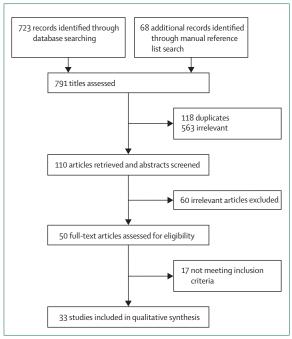


Figure: Literature selection flow chart

extraction from Embase, PubMed, and SciELO was restricted to original studies that focused on indigenous groups still living in their countries of origin. References cited in the selected studies were searched for further relevant articles. The figure shows the flow of the process of selecting and including relevant studies for this Review according to the PRISMA guidelines.²⁵

Data extraction

The selected papers were reviewed according to STROBE guidelines²⁶ and the following data were extracted in a compilation table: general information about the study (first author's name, year of publication, the place where the study was done, and type of cancer studied); information about the study population (ethnicity, age, sex, and sample size); and a brief description of the findings about knowledge, attitudes, and behaviours towards cancer screening. The number of studies that reported factors that facilitate or hinder participation in cancer screening by indigenous populations was counted.

Findings

We identified 723 publications through our search, and an additional 68 from a manual reference list search. We removed 118 duplicates and deemed 563 articles to be irrelevant by quickly screening titles. The remaining 110 articles were retrieved for further review. 60 articles were irrelevant because they examined the prevalence of cancer, barriers to cancer screening (without investigating knowledge, attitudes, and behaviours toward cancer screening), development and assessment of culturally

appropriate intervention, and knowledge and perception toward cancer screening among cancer patients or people with other comorbidities (eg, obesity, diabetes). Full articles were assessed on the remaining 50 potential articles. Of these, we excluded 17 articles: ten secondary review papers and seven articles on indigenous people who had migrated to other countries, because changes in lifestyle and environment after migration might have affected their knowledge, attitudes, and behaviours towards cancer screening. The remaining 33 studies were included in our Review after quality assessment. The characteristics and results of the studies were summarised in table 1. 21 studies were done in the USA, six in Canada, three in Australia, two in Nigeria, and one each in New Zealand and Norway (one study was undertaken in both Nigeria and the USA). The indigenous populations studied were Alaska Natives, Samoans, Chamorros, Chuukese, Marshallese, Native Hawaiians, Native Americans (including Apsaalooke, Hopi, and Lumbee), First Nations (including Oii-Cree, Ojibwa, and Cree), Inuit, Métis, Aboriginal Australian, Torres Strait Islanders, indigenous Nigerians (including Igbo), Maori, and Sami. Three were cohort studies, 27 were cross-sectional studies, and three were case-control studies.

Knowledge was described in 20 papers, attitudes in 20, and behaviours in 28. 19 studies pertained to screening for breast cancer, 15 to screening for cervical cancer, seven to screening for colorectal cancer, three to screening for prostate cancer, and two to cancer screening in general. 21 studies used administered surveys, six used self-administered surveys, five used retrospective chart review, and three used focus groups (data not shown). 25 studies described knowledge, attitudes, and behaviours exclusively in indigenous peoples, and eight described diverse ethnic groups including indigenous populations.

Knowledge about cancer screening

Knowledge about cancer screening varied by type of cancer, population, and the country in which the indigenous peoples live. Knowledge about mammography was examined in seven studies, knowledge about breast self-examination in five, and knowledge about clinical breast examination in four. The proportion of participants in one study who reported knowing about mammography was much lower in Marshallese and Chuukese women than in Native Hawaiian women (8% vs 87%).44 Among Native American women, a greater proportion reported knowing about the procedure and its recommended frequency for clinical breast examination than for mammography, but more women knew about the recommended age for first mammography than for first clinical breast examination.31,33 10% of Native American women in one study reported that they did not know where to seek mammography.37 Despite the implementation of a provincial self-referral programme in New Brunswick for mammography since 1995, 70% of First Nations participants believed that they had to see a family

	Study design				Findings		
	Study location; ethnicity	Age (years)	Sample size	Cancer type	Knowledge	Attitudes	Behaviours
Cohort studies							
Tsark and Braun (2001) ²⁷	HI, USA; Native Hawaiian	≥35	F=323 (1990); F=117 (2000; also participated in 1990)	Breast cancer	Knew about higher risk associated with family history of breast cancer, high-fat diet, smoking, not exercising regularly, taking oral contraceptives. Less likely to know about risks associated with early menarche, late menopause, bearing first child after age 30 years, not breastfeeding. Knowledge did not change over 10 years	1990: not fatalistic about cancer; most agreed that regular BSE could detect cancer at the most curable time; a few felt embarrassment or pain. 2000: more viewed BSE favourably; a few viewed mammography as a good diagnostic tool; less concern or embarrassment about screening procedure	1990: 41% practised regular BSE; 55% followed CBE guidelines; 39% had ever had mammography; 14% complied with mammography guidelines. 2000: 52% practised regular BSE; 68% followed CBE guidelines; 96% had ever had mammography; 62% followed mammography guidelines. All behaviours improved over the 10 years
von Friederichs- Fitzwater et al (2010) ²⁸	CA, USA; Native American, Alaska Native	≥40	F=161	Breast cancer	After intervention:* higher proportion of correct answers to questions about risk factors of breast cancer, and more women agreed with benefit from early detection. More women agreed that obesity is a risk factor in postmenopausal women, and age is the most important risk factor	Willing to have mammography, and thought breast cancer a serious condition. After intervention: more favourable beliefs and attitudes about prognosis and treatment; more willing to have mammography by female practitioner, and travel >80 km to access a cancer screening clinic; less likely to ignore diagnosis and believe cancer resulted in death	After intervention: more women intended to have mammography. 1 year after intervention: 75% intended to get a mammogram; of those, 95% did so. 80% without intention to obtain a mammogram obtained one
Day et al (2011) ²⁹	Nationwide USA; Alaska Native	≥50	M=57529; F=84505	Colorectal cancer			1996–2004: 4% followed recommended screening; 0-7% had colonoscopy. 2000–04: 1% had had DCBE; 0-3% flexible sigmoidoscopy. 2003–04: 2% had had FOBT
Cross-sectional							
Provost (1996) ³⁰	AK, USA; Alaska Native	>18	F=4516	Cervical cancer			62% (64% in age-group 18–44 years, 58% 45–64 years, and 52% ≥65 years) had cervical Pap smear test over 2 years (vs national goal of 85%)
Giuliano et al (1998) ³¹	AZ, USA; Native American (Hopi)	≥40	F=314	Breast cancer	CBE: 82% knew about procedure; 65% about frequency; 8% about age at first test. Mammography: 56% knew about procedure; 46% about frequency; 17% about age at first mammogram	39% thought breast cancer caused death; 22% perceived high risk of breast cancer; 55% believed CBE could detect cancer, and 54% worried about the results. 59% believed mammography could detect cancer and 59% were worried about the results	81% had ever had CBE; 61% yearly. 45% of age-group 40–49 years had ever had mammography, 26% in previous 2 years; 46% of ≥50 years had ever had, 28% in previous 2 years
Coughlin et al (1999) ³²	All states except AR, RI, WY, PR, DC, USA; Native American, Alaska Native	≥40	F=2438	Breast cancer			Lowest mammography participation among age-groups 40–49 years and 265 years. CBE and mammography participation similar for Alaska and non-Alaska residents
Coughlin et al (1999) ³²	All states except AR, RI, WY, PR, DC, USA; Native American, Alaska Native	≥18	F=4961	Cervical cancer			92% had had cervical Pap smear test, 81% in previous 3 years; higher rates in Alaska residents than in non-residents
Risendal et al (1999) ³³	AZ, USA; Native American	≥40	F=168	Breast cancer	CBE: 83% knew about procedure; 74% about recommended frequency; 9% about age at first test. Mammography: 66% knew about procedure; 57% about frequency; 41% about age at first mammogram; 70% about available free mammography programme	23% believed breast cancer caused death; 87% believed early detection was important; 72% believed cancers were preventable; 50% believed CBE could detect cancer and 16% worried about the results; 66% believed mammography could detect cancer and 17% were worried about the results	79% had ever had CBE (vs 90% nationwide); 51% in previous year (vs 74% nationwide); 56% had ever had mammography (vs 82% national rate); 35% in previous 2 years (vs 69% nationwide). 51% had ever had both CBE and mammography (vs 77% nationwide) and 26% had had both in previous 2 years (vs 62% nationwide)
							(Table 1 continues on next page)

	Study design				Findings				
	Study location; ethnicity	Age (years)	Sample size	Cancer type	Knowledge	Attitudes	Behaviours		
Continued from	<u> </u>		3,20						
Ishida et al (2001)³⁴	HI, USA; Samoan, American Samoan	≥40	F=15	Breast cancer	12 knew about BSE; knowledge of recommended frequency varied	2 felt BSE was unnecessary because they received CBE; 8 tabooed touching breasts	Most did BSE more often than monthly; 13 had mammography, 5 at least yearly		
Mishra et al (2001) ⁴	American Samoa, HI, CA, USA; Samoan	≥30	F=720	Breast cancer	58% of women ≥40 years had heard of mammography		56% of age-group ≥30 years had ever had CBE, 48% in previous year; 29% of ≥40 years had ever had CBE; 28% of ≥50 years had CBE in previous 2 years. 33% of ≥40 years had ever had mammography, 29% in previous 2 years; 31% of ≥50 year had had mammography in previous 2 years		
Tanjasiri and Sablan-Santos (2001) ³⁵	Southern CA, USA; Chamorro	≥40	F=22	Breast cancer			37% had done BSE; 93% had had CBE; 77% had had mammography		
Tatemichi et al (2002) ³⁶	NB, Canada; First Nations	50-69	F=129	Breast cancer	42% knew about recommended monthly BSE; only 29% knew about the provincial self-referral screening programme	71% believed mammography could detect breast cancer early; 5% feared the result; 7% thought mammography was painful, and 5% were ashamed about having a mammogram	76% did BSE, 29% weekly; 62% had yearly CBE; 79% had had mammography, 65% in previous 2 years		
Paskett et al (2004) ³⁷	NC, USA; white, African American, Native American (Lumbee)	>40	F=892 (371 Native American)	Breast cancer	Native American: 52% could name mammography; 10% did not know where to access and when to begin; most knew importance of having yearly mammography, higher risk with age, what BSE was; 76% thought women should not stop mammography; 51% thought the only good treatment is mastectomy; 56% thought never bearing a child reduced risk of breast cancer	Native American: 27% felt shame about receiving mammography; 37% were extremely or moderately concerned about developing breast cancer; some believed mammography could cause cancer (20%), or it was painful and unnecessary (39%); 24% perceived high risk of breast cancer	Native American: 19% had never had mammography; 59% had had mammography in previous 3 years, 22% >3 years ago. 9% had never had CBE; 51% had had CBE in previous year, 40% >1 year ago		
Paskett et al (2004) ³⁷	NC, USA; white, African American, Native American (Lumbee)	>40	F=892 (371 Native American)	Cervical cancer	42% of Native Americans could name cervical Pap smear test		Native American: 2% had never had cervical Pap smear test; 81% had had cervical Pap smear test within previous 3 years; 16% >3 years ago		
Steven et al (2004) ³⁸	Northwestern ON, Canada; Italian, Finnish, Ukrainian, First Nations (Oji-Cree, Ojibwa)	≥40	F=105 (30 First Nations)	Breast cancer	White Canadians were more likely than other ethnic groups to know about BSE	First Nations were more likely than other groups to feel loss of privacy and uncomfortable about doing BSE, and having male practitioners for BSE	First Nations were more likely than other groups to refuse screening		
Steven et al (2004) ³⁸	Northwestern ON, Canada; Italian, Finnish, Ukrainian, First Nations (Oji-Cree, Ojibwa)	≥40	F=105 (30 First Nations)	Cervical cancer			33% of First Nations refused cervica examination		
Farmer et al (2005) ³⁹	NC, USA; Native American (Lumbee)	≥40	F=456	Breast cancer			85% of women did BSE regularly; 86% of women had ever had mammography		
Farmer et al (2005) ³⁹	NC, USA; Native American (Lumbee)	≥40	F=456	Cervical cancer			99% of women had had cervical Pap smear test		
Farmer et al (2005) ³⁹	NC, USA; Native American (Lumbee)	≥40	M=333; F=456	Colon cancer			55% of men and 49% of women ha been checked for colon cancer		
Farmer et al (2005) ³⁹	NC, USA; Native American (Lumbee)	≥40	M=333	Prostate cancer			60% of men had been screened for prostate cancer		
Kelly et al (2007) ⁴⁰	NC, USA; African American, European American, Native American (Lumbee)	≥51	M=43; F=128 (57 total Lumbee)	Colorectal cancer			No significant difference in participation between ethnic group		
							(Table 1 continues on next page		

	Study design				Findings		
	Study location; ethnicity	Age (years)	Sample size	Cancer type	Knowledge	Attitudes	Behaviours
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Balajadia et al (2008) ⁴¹	Guam; Chamorro	≥50	F=149	Breast cancer	95% had heard of BSE; 87% had heard of CBE; 100% had heard of mammography; 94% knew that mammography could detect breast cancer early	3% considered ancient spirits caused cancer; 8% believed traditional healers could treat cancer; 4% would get cancer treatment from traditional healers; 43% feared detecting breast cancer	64% had had CBE in previous year; 83% had had mammography in previous 2 years
Balajadia et al (2008) ⁴¹	Guam; Chamorro	≥50	F=149	Cervical cancer	82% knew that cervical Pap smear test could detect cervical cancer early; 10% needed more information about cervical Pap smear test	-	99% had had cervical Pap smear test
Balajadia et al (2008)41	Guam; Chamorro	≥50	M=117	Prostate cancer	43% had heard of PSA		39% had had PSA test, 20% in previous year
Balajadia et al (2008) ⁴¹	Guam; Chamorro	≥50	M=117; F=149	Colorectal cancer			38% ever had FOBT; 16% ever had sigmoidoscopy; 33% ever had colonoscopy
Puaina et al (2008) ⁴²	American Samoa, USA; Samoan	≥50	M=60	General cancer		Believed preventing disease was unnatural; tabooed body parts touched by others	
Smith et al (2008) ⁴³	MT, USA; Native American (Apsaalooke)	≥18	F=101	Cervical cancer		86% felt comfortable during cervical Pap smear test	96% had had cervical Pap smear test, 86% at a facility on reserve, 62% within a year, 22% 1–2 years ago, 16% >2 years ago
Aitaoto et al (2009) ⁴⁴	HI, USA; Filipino, Hawaiian, Marshallese, Chuukese	42-69	F=33 (27 Natives)	Breast cancer	Hawaiian: 100% had heard of cancer; 87% knew about mammography. Chuukese and Marshallese: 100% had heard of cancer; 8% knew about mammography		Natives were more likely to use screening if motivated by family or group. 73% of Hawaiians had had mammography. No Chuukese or Marshallese had ever had mammography
Aitaoto et al (2009) ⁴⁴	HI, USA; Filipino, Hawaiian, Marshallese, Chuukese	42-69	F=33 (27 Natives)	Cervical cancer	Hawaiian: 100% knew about cervical Pap smear test. Chuukese and Marshallese: 50% knew about cervical Pap smear test	•	93% of Hawaiians had had cervical Pap smear test. 50% of Chuukese and Marshallese had had cervical Pap smear test during pregnancy, but not regularly
O'Brien et al (2009) ⁴⁵	Nationwide Canada; First Nations (Cree)	Not specified	F=8	Cervical cancer	Participants had limited knowledge and wanted more information about screening	Felt embarrassment and uncomfortable discussing private body parts; emphasised spirituality; prayed before screening; some reported tension between western and traditional cultures and medicines	
Odedina et al (2009) ⁴⁶	Ogun state, Nigeria, and TX, USA; Indigenous Nigerian and US Nigerian	35-79	M=249 (128 Indigenous, 121 US Nigerian)	Prostate cancer	Indigenous Nigerians had lower prostate cancer knowledge score than US NIgerians	Both groups: favourable towards screening; high perceived behavioural control about participation in screening; scared about cancer. Indigenous Nigerian: less favourable towards screening; felt more difficulty in receiving screening tests; lower perceived risk of cancer	Indigenous Nigerian: 91% never tested for cancer; 6% prostate screening in previous year; 3% had prostate screening >1 year ago. US Nigerian: 39% never tested for cancer; 44% had prostate screening in previous year, 17% >1 year ago. US Nigerians were more likely than indigenous Nigerians to have intention to take screening test
Shahid et al (2009) ⁴⁷	WA, Australia; Aboriginal Australian	≥30	F=37	General cancer	Limited and vague understanding of cancer screening	Some associated cancer with spirituality and fatalism, resulting in acceptance of cancer, fear or shame of detecting cancer and delay in cancer screening; some believed screening would prevent cancer; a few viewed screening as a diagnostic method	
							(Table 1 continues on next page

	Study design				Findings		
	Study location; ethnicity	Age (years)	Sample size	Cancer type	Knowledge	Attitudes	Behaviours
Continued from	previous page						
McDonald and Trenholm (2010) ⁴⁸	NU, NT, NL, northern SK, MB, QB, Canada; Inuit, Métis, First Nations, and non-Aboriginal peoples	50-65	F=2429	Breast cancer			Inuit were less likely to have had mammography than were non- Aboriginal peoples. Métis and First Nations had lower mammography rate compared with non-Aboriginal peoples (not significant)
McDonald and Trenholm (2010) ⁴⁸	NU, NT, NL, northern SK, MB, QB, Canada; Inuit, Métis, First Nations, and non-Aboriginal peoples	21-65	F=6412	Cervical cancer			Inuit were less likely to have had cervical Pap smear test in previous 3 years than were non-Aboriginal peoples
Wu et al (2010) ⁴⁹	American Samoa, USA; Samoan	≥18	F=28	Breast cancer	59% aware of mammography; 67% had heard of CBE	Fatalistic view on cancer; believed prayer could treat a serious medical condition	28% had had mammography; >50 years had never had mammography; 50% had had CBE
Wu et al (2010) ⁴⁹	American Samoa, USA; Samoan	≥18	F=28	Cervical cancer	76% aware of cervical Pap smear test		62% had had cervical Pap smear test
Cerigo et al (2012) ⁵⁰	QC, Canada; Inuit	18-69	F=175	Cervical cancer	46% knew correct cervical Pap smear test purpose; 60% wanted practitioner to explain each step	37% felt embarrassment during cervical Pap smear test, more so in women of ≥35 years; 49% reported pain	96% had had cervical Pap smear test; 80% within previous year; 72% intended to have a cervical Pap smear test in the next year
Christou and Thompson (2012) ⁵¹	WA, Australia; Aboriginal Australian, Torres Strait Islanders	≥35	M=22; F=71	Colorectal cancer	30% heard of FOBT; 14% knew about FOBT; most agreed FOBT beneficial; 36% did not understand how to do FOBT	82% believed bowel cancer could be cured if found early; 35% thought nothing could be done to prevent it; 24% felt shame, 53% confident to do FOBT; 39% were afraid about cancer diagnosis	51% screened for any type of cancer within previous 2 years, 15% had had colonoscopy, 6% had had FOBT
Eze et al (2012) ⁵²	Afikpo town, Ebonyi State, Southeast Nigeria; Igbo	≥20	F=360	Cervical cancer	32% knew that cervical cancer was preventable; 25% had heard of cervix screening; 21% knew where to get screening		0.6% ever had cervical screening; 63% were willing to be screened
Javanparast et al (2012) [≌]	Metropolitan Adelaide and remote South Australia; Greek, Vietnamese, Iranian, Anglo- Australian, Indigenous Australian	50–75 (except 6 Indigenous Australians <50)	M=53; F=68 (23 Indigenous Australians; M=11, F=12)	Colorectal cancer		Positive view on screening; receiving FOBT kit was anxiety- provoking and procedure was unpleasant; non-Anglo-Australians were more likely to fear diagnosis and have fatalistic view	Non-Anglo-Australians were more likely than Anglo-Australians to avoid screening
Pitama et al (2012) ⁵⁴	Auckland, Wellington, Christchurch, New Plymouth, New Zealand; Maori	40-66	M=6; F=24	Colorectal cancer	Medical terminology caused disempowerment; felt lack of appropriate health literature; unaware of symptoms of colorectal cancer	Unfamiliar with screening; negative experiences of any screening programme; reported absence of culturally competent clinicians	
Cerigo et al (2013) ⁵⁵	QC, Canada; Inuit	21-69	F=403	Cervical cancer			25% had not had cervical Pap smear test in previous 3 years (18% of 21–29 years, 28% of 20–44 years, 30% of ≥45 years); 17% had never had cervical Pap smear test
Case-control st	udies						
Lanier et al (1999) ⁵⁶	AK, USA; Alaska Native	≥20	F=481 (cases†) F=250 (controls)	Breast cancer‡			44% did BSE monthly; 69% had had CBE, highest rate in age-group 50-59 years; 39% (67% of >50 years) had had mammography within previous year
Lanier et al (1999) ⁵⁶	AK, USA; Alaska Native	≥20	F=481 (cases†) F=250 (controls)	Cervical cancer			Before intervention: 72% had had last cervical Pap smear test in previous year; lowest rate in age-group ≥60 years. After intervention: more women had had ≥2 cervical Pap smear tests; greater improvement in cervical Pap smear test rate with evening clinic vs day clinic (64% vs 44%)
							(Table 1 continues on next page)

	Study design				Findings		
	Study location; ethnicity	Age (years)	Sample size	Cancer type	Knowledge	Attitudes	Behaviours
Continued fron	n previous page						
Wampler et al (2006) ⁵⁷	Northern Plains Indian Reservation, USA; Native American	≥41	F=144 (cases§) F=127 (controls)	Breast cancer	73% (cases) and 56% (controls) knew about higher risk with age; most women knew about increased risk with family history of breast cancer and benefit of cancer screening; some had limited knowledge about cause of, risk factors for, and symptoms of breast cancer	98% (cases) and 88% (controls) would have mammography if a health-care provider recommended it; 83% (cases) and 65% (controls) were willing to travel long distances to get a mammogram; preferred female staff, screening clinic on reserve	
Norum et al (2012) ⁵⁸	Northern Norway; Sami, non-Sami people	50–69	F=10 122 (Sami); F=10 358 (non-Sami)	Breast cancer	.	•	81% of all Norwegian, 78% of Sami, and 75% of non-Sami attended mammography

BSE=breast self-examination. CBE=clinical breast examination. FOBT=faecal occult blood testing. PSA=prostate-specific antigen test. DCBE=double-contrast barium enema. *Intervention included watching a culturally tailored DVD that featured Native celebrities and medicine women and discussion in talking circles. †Cases received an intervention of assistance with scheduling of screening appointments in day or evening clinics, culturally sensitive educational materials, and regular follow-up by phone or mail. ‡Intervention was not related to breast cancer; however, questionnaires included some features of behaviours towards breast-cancer screening. §Cases were women who had had mammography in the previous year.

Table 1: General characteristics of the studies about knowledge, attitudes, and behaviours towards cancer screening in indigenous populations

physician for a referral.36 Cree First Nations women reported that they had inadequate information about cervical cancer and cancer screening.45 In a study of Inuit women, almost half had heard about cervical cancer and showed knowledge of the purpose of the cervical Pap smear test; 60% preferred to have a practitioner explain each step during the procedure.50 About 20% of Igbo women in Nigeria knew specific clinics where they could access a cervical-cancer screening service. 52 The two studies on knowledge about colorectal cancer were done in Australia⁵¹ and New Zealand.⁵⁴ Although 78% of Indigenous Australians agreed with the benefit of colorectal screening, only 14% reported knowing what faecal occult blood testing was; after they were given an explanation of the test, only 30% reported having heard of it, and 36% said they did not know how to undertake it.51 Qualitative data from Maori health-care providers in a New Zealand bowelscreening pilot study found that medical terminology and absence of appropriate health literature prevented Maori from understanding screening for colorectal cancer.54 43% of Chamorro participants in Guam reported knowledge of the prostate-specific antigen test.41 Indigenous Nigerians scored lower on prostate cancer knowledge than did Nigerian Americans. 46

Attitudes towards cancer screening

Attitudes towards cancer screening also varied across indigenous populations. Several studies reported favourable attitudes towards cancer screening among indigenous peoples, ^{27,28,43,46,53,57} particularly in the peoples who had received a culturally appropriate intervention²⁸ or screening services⁴³ and in the peoples who had experienced cancer screening previously.⁵⁷ In an American study which involved an intervention of

watching a culturally tailored DVD and discussion in talking circles (a traditional method of sharing and discussing issues) about breast-cancer screening, more participants believed that screening could detect cancer early when it was curable and were willing to travel substantial distances to access screening services.28 Some Native American women thought that mammography was unnecessary,37 and were not convinced of the detecting ability of breast screening, 31,37 or believed that radiation from mammography was a cause of breast cancer.37 Underestimation of the need for breast selfexamination among Samoan women who were undergoing clinical breast examination was noted.34 Native American,31,37,59 Chamorro,41 Canadian First Nations36,45 and Inuit,50 Aboriginal Australian, and Torres Strait Islanders 47,51 reported pain during screening, shame from being screened, and worries about possible diagnosis of cancer. Touching and discussing "private body parts" were taboo for some Samoan^{34,42} and Cree women.⁴⁵ Canadian First Nations women were more likely to report feeling nervous and loss of privacy than were Italian, Ukrainian, and Finnish Canadians.³⁸ Odedina and colleagues⁴⁶ found favourable attitudes toward prostate-cancer screening among indigenous Nigerians but the attitudes were less favourable than those of Nigerian immigrants in the USA. The impact of religion and traditional medicine on screening was inconsistent. Several studies reported a fatalistic view of cancer and the belief that screening was unnatural and unacceptable among Aboriginal Australian and Torres Strait Islanders, 47,51 Samoans, 42,49 and Cree First Nations.45 By contrast, in the Native Hawaiian populations, Tsark and Braun²⁷ observed a slight shift towards favourable attitudes over 10 years without any intervention and attributed this change to

the age of participating women increasing during the 10 years, leading to greater concern about breast cancer.

Behaviours towards cancer screening

Behaviours towards cancer screening were generally measured by rates of participation in screening and differed among indigenous populations. 37% of Chamorro women,35 69% of Alaska Native women,56 and 76% of Canadian First Nations women36 had done at least one breast self-examination during their lifetime (as frequently as weekly³⁶). The proportions of indigenous women who had undergone clinical breast examination varied more widely: 29-56% of Samoan women, 4,49 62% of First Nations women,³⁶ 64–93% of Chamorro women,41,35 69% of Alaska Native women,56 and 79-81% of Native American women. 31,33 These women mostly underwent clinical breast examination once a year. 31,36,37,41 83% of Samoan women⁴ but none of Marshallese and Chuukese women had ever had mammography,44 whereas greater participation (78-96%) was observed for First Nations,36 Native Hawaiian,27 Native American,39 and Sami women.58 The proportion of women who had undergone mammography lately (within the 1 or 2 years before the study) ranged from 33% to 83% among Samoan,4 Native American,33 Alaskan Native,56 First Nations,36 and Chamorro⁴¹ women. Indigenous

populations had lower participation and were more likely to refuse breast-cancer screening than Australians of Greek, Vietnamese, Iranian, or British origin,53 non-Aboriginal people in Canada,38,48 and white and African Americans in the USA.37 Conversely, when Native Hawaiian women were investigated during 10 years, participation in breast-cancer screening increased without any intervention.27 The proportion of Native Hawaiian women who practised regular breast selfexamination and who underwent mammography at least once in their lifetime increased by about 10% and 60%, respectively. Meanwhile, the proportions of women who complied with breast self-examination mammography guidelines increased by about 13% and 50%, respectively.27

Participation in cervical screening varied widely. Some indigenous groups had high proportions of women undergoing cervical Pap smear testing (92–99% for Native Hawaiian, ⁴⁴ Native American, ^{32,37,39,43} Inuit, ⁵⁰ and Chamorro ⁴¹), but other groups had lower rates (50–62% for Samoan, ⁴⁹ Alaska Native, ³⁰ Chuukese, and Marshallese ⁴⁴). In particular, less than 1% of Igbo women in Nigeria had had a cervical Pap smear test but 63% expressed willingness to be screened. ⁵² About 80% of Native American, ^{32,38} Alaska Native, ³² and Inuit ⁵⁵ women had had cervical Pap smear tests regularly within a 3-year period. However, half of

	Type of cancer	Frequency
Facilitators		
Access to appropriate screening	Breast, 4.28,31,33-35,38.41 cervical, 30,38.41.43,48.55 colorectal, 29,31,51,53,54 prostate ⁴¹	17
Knowledge about cancer and screening (eg, media advertisement, physician's recommendation)	Breast, 31.33.34.35.28.38.54 cervical, 32.43.38 colorectal, 40.51.53.54 prostate ⁴¹	13
Education	Breast, 4.28,31-33.35 cervical, 32,48 colorectal, 39,40.51 prostate 39,41	11
Age	Breast, 4.35,48 cervical, 32,41,55 colorectal, 40 prostate 39	8
Income	Breast, 4.35.57 cervical, 32.41 colorectal 51	6
Experience with cancer or other cancer screening	Breast, 31,33,56 cervical, 38 colorectal 40,51	6
Self-rated health and susceptibility to cancer	Breast, 31,32,35 colorectal, 39,51 prostate ³⁹	5
Marital status	Breast, 4.35 colorectal 51	3
Cultural beliefs	Breast ^{4,33,35}	3
Lifestyle (eg, smoking and physical activity)	Breast, ^{32,33} cervical, ³² colorectal, ³⁹ prostate ³⁹	3
Sex	Colorectal ^{29,40}	2
History of childbirth	Cervical ⁵⁵	1
Barriers		
Lack of access to appropriate screening	Breast, 31.33.34.36.37.41.44 cervical, 32.44 colorectal, 41.51.53.54 prostate ⁴¹	11
Not feeling cancer screening is necessary	Breast, 27,32,34,41 cervical, 32 colorectal 51	5
Lack of skills or knowledge of screening	Breast, 24,27,41,44 cervical, 44 colorectal 51	5
Competing priorities	Breast, 34,37,41,44 cervical44	4
Marital status	Breast, 31.48.54 cervical 48	3
Cultural beliefs	Breast, 31.44 cervical 44	2
Lifestyle (eg, smoking and physical activity)	Breast, ⁵⁶ cervical ³²	2
Age	Cervical ⁴⁸	1
Income and employment status	Breast, ³² cervical ³²	1
Language	Colorectal ⁵³	1
Doubt about test accuracy	Colorectal [™]	1

Chuukese and Marshallese women had had a cervical Pap smear test only during pregnancy. Studies reported that indigenous women were less likely to have cervical Pap smear tests done than women of other ethnicities in the USA and Canada.

Of the six studies related to behaviours in relation to screening for colorectal cancer, ^{29,39,40,41,51,53} one found that among Native Americans, 55% of men and 49% of women had been screened for colon cancer. ³⁹ Participation rates in colonoscopy, faecal occult blood testing, ^{29,51} double-contrast barium enema, and flexible sigmoidoscopy ²⁹ ranged from 0·3% to 15% among Native American and Indigenous Australians. Among Chamorro, 38%, 16%, and 33% had ever had faecal occult blood testing. sigmoidoscopy, and colonoscopy, respectively. ⁴¹ About 60% of Native American men had been screened for prostate cancer ³⁹ and 39% of Chamorro men had had at least one prostate-specific antigen test. ⁴¹

Patterns of behaviours among indigenous peoples in comparison with other ethnic groups were inconsistent. Sami women in Norway reported greater participation in the national breast-cancer-screening service than non-Sami women.58 No significant difference in the uptake of the cervical-screening service was observed between indigenous and nonindigenous women in the USA.37 Participation in screening for colorectal cancer did not differ significantly between Native Americans and other ethnic groups in the USA, 40 but non-Anglo-Australians (including Indigenous Australians) had a greater tendency to avoid colorectal-cancer screening than did Anglo-Australians.53 Odedina and colleagues66 noted differences in uptake of screening for prostate cancer between indigenous Nigerian men (9%) and American Nigerian men (61%).

Factors possibly affecting behaviours in relation to cancer screening and the frequency of reporting in the studies are summarised in table 2. The five most frequently reported factors were access to appropriate screening, knowledge about cancer and screening, educational attainment, perceived need for screening, and age.

Access to appropriate screening services

Location of residence affected access to screening. Indigenous individuals who lived away from screening facilities were less likely to participate in cancer screening than people who lived nearer, 30,37,44,48 whereas people living where they could walk to clinics had a higher participation rate. 4,41,55 Giuliano and colleagues 11 reported an absence of screening facilities on the Hopi reserve and lower mammography rates among the indigenous peoples living on-reserve than off-reserve. Access to screening was also affected by availability of transport 44 and clinics and physicians in the community. 29,32,33,34,38-51 An evening cervical-screening programme was more convenient for Alaska Native women than a daytime programme, and significantly improved uptake of cervical Pap smear testing. 56 In several

studies, use of screening services was also affected by whether they were culturally appropriate, ^{28,53,54} including having same-sex screening staff, particularly for women. ^{28,34,38,43,56} If same-sex technicians were available, an individual was more likely to use a cancer-screening service. ^{33,35,44} Furthermore, some studies noted a positive association between having medical insurance and accessing screening for breast cancer. ^{4,33,34,35,37}

Knowledge about cancer and screening

Recommendations from physicians for screening and media advertisements on cancer improved knowledge and intention to obtain screening services^{34,41,54,55,57} and increased knowledge about cancer,^{41,54} cancer screening procedures,^{27,28,31,33,43,51} screening benefits,⁵¹ screening guidelines,^{33,40} and provided more information about access to screening services.³⁸ Indigenous individuals with greater knowledge about cancer and cancer screening were more likely to take part in cancer screening than individuals with limited knowledge,^{4,27,33,34,40,41,51,53}

Educational attainment

North American studies showed that indigenous individuals with at least 12 years of education were likely to be screened for breast, 4.31,32,33,35 cervical, 32,48 colorectal, 39,40 and prostate 39,41 cancers. Similarly, an Australian study reported an association between having at least 8 years of education and an increased intention to participate in colorectal-cancer screening. 51 An intervention among Native Americans was more successful in improving behaviours towards cancer screening in individuals with more education than in individuals with less education. 28

Perceived need for screening

Indigenous peoples who perceived the risk of cancer as high and cancer screening as important were more likely to obtain screening for breast^{27,32,34} and colorectal⁵¹ cancers than indigenous peoples without such perceptions. Some studies showed that individuals with good self-rated health or low perceived susceptibility to cancer were also more likely to take part in screening for breast,^{31,35} colorectal, and prostate cancers than individuals without these attributes.³⁹

Age

The age at which the greatest participation in cancer screening occurred varied by the demographic characteristics of each study. Generally, younger individuals were more likely to take part in clinical breast examination,⁴ cervical Pap smear testing,^{32,41,55} and screening for prostate³⁹ and colorectal⁴⁰ cancers than were older individuals. For mammography, the behavioural pattern by age was inconsistent. In one study,³⁵ younger participants were less likely to undergo mammography than were older participants; however, in another,³² younger and older age-groups were less

likely to undergo mammography than the in-between group. One study noted that the participation rate for clinical breast examination was higher for individuals aged 50 years or older than for younger women, and the mammography participation rate did not differ significantly between the age-groups.⁴ However, another study³⁵ noted a higher mammography participation rate for women aged 50 years and older than for younger individuals. McDonald and Trenholm⁴⁵ reported no association between age and mammography or cervical Pap smear testing.

Summary

This Review explored knowledge, attitudes, and behaviours towards cancer screening in many distinct indigenous peoples living in countries with disparate economic, political, and historical profiles. Knowledge, attitudes, and behaviours vary with cancer type and population. The Review also identified five common factors affecting behaviours toward cancer screening in indigenous peoples, which are also observed in other populations. 19,20,59-61

Many indigenous cultures inseparably link medicine and religion.7 A shared fatalistic belief among some populations is that diseases are the result of a curse put on a person for a bad activity.21,53 With beliefs that artifacts or ceremonies can restore balance and harmony to physical, mental, and spiritual well-being,7 some indigenous peoples perceive cancer screening as unnecessary31,51 and might feel reluctant to access screening. Cancer is a new disease for some indigenous peoples.20 Some indigenous peoples in the USA, Canada, New Zealand, and Australia believe that cancer is a disease brought by foreigners during colonisation.^{7,21,51} Therefore, perceived susceptibility to cancer and appreciation of cancer screening can be limited, and better understanding of the biomedical concept of cancer and the importance of cancer screening is needed among some indigenous populations.

Each indigenous population and its culture is unique; in addition, the respective country's available services and clinical guidelines for various types of cancer screening must be taken into account. For example, Australia has implemented a national bowel-cancer screening programme since 2006;51 this programme could have contributed to more favourable knowledge, attitudes, and behaviours toward bowel-cancer screening in indigenous peoples in Australia than in New Zealand, which has not yet introduced national colorectal-cancer screening.62 By contrast, the proportion of Native Hawaiians who had ever had mammography almost doubled (from 39% to 73%) between 199027 and 2009.44 possibly because the Hawaii Breast and Cervical Cancer Control Program was introduced in 1993.63 Knowledge, attitudes, and behaviours towards cervical-cancer screening among populations living in countries such as Nigeria, where infrastructural resources for cervicalare limited.52 have limited cancer screening

comparability with populations living in countries where screening programmes are available, such as Australia. Furthermore, cancer-screening programmes within a country could have regional differences. Differences within and between countries could have affected the results in some studies in this Review. However, examination of the effect of national or regional cancer-screening programmes available for distinct indigenous populations was beyond the scope of this Review.

The cancer-specific patient navigation programmes in North America^{66,67} have been successful, but they might not be transferable to indigenous groups in other parts of the world. One of the features of the programmes is that they focus on identifying and addressing barriers to accessing cancer-related care at the individual level.66 Although the efficacy and true effect are questionable,67 the programmes have potential for improving uptake of cancer screening by people who are medically underserved in both indigenous on and non-indigenous populations.66 Outreach services, such as patient navigation programmes, can allow culturally tailored promotion for cancer screening and greatly improve participation in cancer screening among indigenous peoples.68 The availability and extent of such services vary among different countries.

Individuals obtain information on cancer and cancer screening from the media. 51,69 Greater knowledge about screening for certain cancers can result from vigorous public awareness campaigns.51 For example, Australian television news over-reports breast, cervical, and skin cancers compared with other cancers. 69 Biased distribution of information through mass media might partly explain differing knowledge about various types of cancer and screening. Another source of information is health professionals.20 For care providers to appropriately provide information about and services for cancer screening, being culturally competent and sensitive are crucial. Each indigenous population is unique in terms of beliefs about, and practices in, medicine and health. Health-care practice might inadequately incorporate indigenous culture, so some indigenous people might avoid it and become medically underserved. Christou and colleagues¹⁵ concluded from their literature review that a national bowel-cancer screening programme had inadvertently excluded culturally diverse groups, particularly indigenous peoples, because the social and cultural values of the group were not reflected, which is a substantial barrier to cancer screening. Moreover, some Canadian Aboriginal mothers experienced challenges from care providers, who might have had insufficient cultural understanding, and therefore were subsequently hesitant about accessing health care.70

Lack of availability of screening facilities in the geographical area, 19,60 culturally inappropriate screening services, 19 opposite-sex practitioners, 28,34,56 lack of health

insurance,⁵⁹ and language barriers⁵⁹ restrict access to cancer screening in both indigenous and non-indigenous populations. Populations living in regions where screening facilities are limited have to travel substantial distances to receive screening services. Taboos about the touching of private body parts by self or others^{34,42,45} make screening of the body by opposite-sex staff unacceptable.³⁸ Furthermore, since limited income can restrain individuals from seeking cancer-screening services, ^{35,53,61} having health insurance could be essential.^{71,72}

The evidence was consistent that individuals with at least 12 years of education have a greater tendency to use cancer-screening services than individuals who have fewer years of formal education. Individuals with higher educational attainment might be more health conscious and able to access screening facilities more conveniently than indigenous individuals with less institutional education. Although educational attainment is not directly associated with knowledge about cancer screening, greater literacy improves the ability to understand translated knowledge. People with less formal educational attainment might need more support to increase uptake of cancer screening.

A positive association between age and reduced uptake of cancer screening among non-indigenous populations was reported previously, particularly for colorectal cancer.⁶¹ The inverted U-shaped pattern of participation in breast screening noted by Coughlin and colleagues³² was also apparent in screening for colorectal cancer in the general Australian population.73 This pattern might be due to lack of time and low perceived risk of cancer among younger individuals,74 and lower potential benefit of screening and decreasing life expectancy among older individuals,59 resulting in low uptake of cancer screening among younger and older age groups than the in-between age groups. Despite a general positive relation between age and cancer screening uptake, we noted inconsistent patterns in our Review. We speculate that in each indigenous population, other factors (eg, access to screening facilities) have a greater effect on the behaviours of participants compared with age.

Most of the studies included in this Review used quantitative study designs with robust sample sizes, supplemented by valuable qualitative information. Each study was assessed according to the STROBE statement. In addition, comparable results among subpopulations of indigenous groups were observed (eg, similar studies among Native Americans yielded comparable results), supporting the validity of these studies. Thus, this Review provides a valid summary of the existing evidence on knowledge, attitudes, and behaviours that affect cancer screening among the indigenous groups for which studies were identified.

Limitations of the Review arise from the small numbers of publications for diverse indigenous populations. Most studies included in this Review were done in the USA, with emphasis on screening for breast and cervical cancers. Three of the four Oceanic studies focused on colorectal-cancer screening, and none on breast or cervical screening. Restricted studies on some indigenous populations, such as indigenous Nigerian, Maori, and Sami people, cannot represent the whole respective population. The search criteria restricting papers to those published in English could have resulted in exclusion of relevant studies. A secondary search for papers published in other languages yielded only six additional papers, all of which would have been excluded after review of the abstracts (which were available in English). The specific search terms used and the listing of indigenous groups might have resulted in omission of some of the many relevant populations. For example, our search criteria yielded only studies of South American populations as immigrants in other countries, but none of South American indigenous groups living in their native lands. The findings, therefore, cannot be generalised to all indigenous populations. Other important factors, such as perceptions of care providers towards different racial groups,75 affect cancer treatment, but were outside the scope of our Review. The complexities of behaviours of patients and care providers should be taken into account, as well as the unique features of each population.

Conclusion

This Review compiled information about access to various types of cancer screening from many distinct indigenous groups living in countries with disparate socioeconomic profiles. We found that knowledge about cancer screening varies according to cancer type and indigenous ethnicity. Attitudes toward cancer screening are becoming more favourable, although in some indigenous cultures traditional beliefs and practices still affect perceptions of cancer screening. Patterns of behaviours towards cancer screening among indigenous populations are inconsistent. The same factors that affect behaviours towards cancer screening in non-indigenous populations were also identified in indigenous populations. These factors might affect each indigenous population in different ways, potentially explaining why the studies did not show a definite pattern of behaviours among indigenous peoples themselves or in comparison with non-indigenous peoples. These conclusions are derived from studies investigating a limited number of indigenous groups; therefore, interpretation of these results must take into account different clinical guidelines and scopes of services in their respective countries. Greater understanding of knowledge, attitudes, and behaviours towards cancer screening among ethnically diverse indigenous peoples is needed to provide optimum cancer-screening services and reduce disease burden.

Contributors

FK developed the conception and methodology of the Review and drafted and finalised the paper. SLJ drafted the paper. AC, CG, NJ, and SS critically reviewed the paper. SS oversaw all aspects of the project. Each listed author approved the final version submitted for publication.

Declaration of interests

We declare no competing interests.

Acknowledgments

We thank James Talbot, Chief Medical Officer of Health, Alberta Health, who reviewed the paper and offered critical comments. Funding was provided by Alberta Innovates - Health Solutions.

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