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Review Article

Achieving cervical cancer elimination among Indigenous women



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A B S T R A C T

Achieving the World Health Organisation (WHO) cervical cancer elimination target of fewer than four new cases per 100,000 woman-years requires scaling up HPV vaccination of girls, cervical screening, and pre-cancer and cancer treatment. We reviewed data from four high-income colonised countries (Australia, Canada, Aotearoa New Zealand (NZ), and the United States (US)) to identify how each is currently performing compared to the cervical cancer incidence elimination and triple-intervention targets, nationally and in Indigenous women. We also summarise barriers and enablers to meeting targets for Indigenous women.

To achieve elimination, cervical cancer incidence must be reduced by 74% in Indigenous women in Australia, and 63% in Maori women in NZ; data were not published in sufficient detail to compare incidence in Indigenous women in Canada or the US to the WHO target. Only Australia meets the vaccination coverage target, but uptake appears comparatively equitable within Australia, NZ and the US, whereas there appears to be a substantial gap in Canada. Screening coverage is lower for Indigenous women in all four countries though the differential varies by country. Currently, only Australia universally offers HPV-based screening. Data on pre-cancer and cancer treatment were limited in all countries.

Large inequities in cervical cancer currently exist for Indigenous peoples in Australia, Canada, New Zealand and the US, and elimination is not on track for all women in these countries. Current data gaps hinder improvements. These countries must urgently address their systemic failure to care and provide health care for Indigenous women.

1. Background: Indigenous women

The health and wellbeing of Indigenous women is vital to the health and wellbeing of Indigenous peoples. Indigenous women have culturally significant roles and responsibilities including, but not limited to, as carers (mothers, daughters, grandmothers, sisters, aunts), managing households, (United Nations Office of the Special Adviser on Gender Issues and Advancement of Women, 2009; Burns et al., 2010) and inter-generational holders of cultural knowledge, customs and lore.

Systematic disadvantage poses significant health risk for Indigenous peoples worldwide. (Burns et al., 2010; United Nations, 2009; Anderson

et al., 2016; United Nations, 2015) Indigenous women experience disproportionately higher levels of poor health and wellbeing, (United Nations. Department of Economic and Social Affairs: Indigenous Peoples: United Nations, 2020; Ministry of Health, 2015) impacted by gendered power imbalances and compounded by racism, marginalization and discrimination. (UNICEF, UN Women, UNFPA, 2013) Indigenous women are staunch advocates and leaders for Indigenous peoples. Through their work, Indigenous women have ensured that the United Nations (UN) Declaration on the Rights of Indigenous Peoples (UNDRIP) (United Nations, 2007) protected the rights of Indigenous women. The UNDRIP specifically calls for measures to ensure that Indigenous women

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can enjoy full protection from and guarantees against all forms of violence and discrimination. Furthermore, the Declaration clearly outlines the right to health without discrimination.

2. Background: Cervical cancer elimination

Cervical cancer can be eliminated as a public health problem, using available and highly effective forms of primary and secondary prevention, and, for early stage disease, treatment. Achieving the WHO elimination threshold of fewer than four new cases of cervical cancer per 100,000 woman-years in all countries, including those with the highest disease burden (incidence rates >25 new cases per 100,000 woman-years), requires scaling up both HPV vaccination of girls and cervical screening in most countries.(Brisson et al., 2020) Preventing deaths in the immediate term also requires scaling up access to cancer treatment.(Canfell et al., 2020) These findings informed the WHO triple-intervention targets (Box 1).(World Health Organization, 2020) Reaching these targets is predicted to reduce global incidence and mortality rates in 2120 by 97% and 99% respectively.(Canfell et al., 2020)

While primary prevention via HPV vaccination has only become possible more recently, secondary prevention through cervical screening has been possible for decades. The wide disparities in cervical cancer incidence between and within countries reflect the wide variability in the use of and access to screening; disparities in mortality additionally reflect variability in access to cancer treatment. The use of and access to screening is impacted by a range of multi-faceted and interconnected barriers. Thus far, modelled analyses of cervical cancer elimination, including those for the WHO, have considered outcomes at a country, regional, or global level.(Brisson et al., 2020; Hall et al., 2019; Burger et al., 2020; Simms et al., 2019b; Xia et al., 2019) The draft WHO elimination strategy acknowledges that tailored approaches are required for vulnerable and under-served populations, and proposes working towards the monitoring of targets that is stratified by population segments.(World Health Organization, 2020) However, the draft strategy fails to specifically mention Indigenous women. The need for equity to be at the heart of the strategy is supported strongly by organisations such as the International Papillomavirus Society (IPVS), whose policy(Lawton et al., 2020) notes the need address the inequitable burden of HPV disease for Indigenous peoples, and outlines fundamental principles to guide an equity-driven approach, including partnerships with Indigenous peoples and communities, Indigenous leadership, co-created strategies and a whole-of-system approach driven by evidence.

There are clear inequities in cervical cancer outcomes between countries and the WHO also highlights within country disparities.(World Health Organisation, 2019) Disparities in cervical cancer have been documented within countries or regions among women with lower socioeconomic status and education levels.(Singh et al., 2004)

Box 1

– WHO 2030 triple-intervention targets towards elimination of cervical cancer.

- 90% of girls fully vaccinated with the HPV vaccine by age 15
- 70% of women are screened with a high-performance test* by 35, and again by 45 years of age (*scaling up to 90% in 2045*)
- 90% of women identified with cervical disease receive treatment
 - 90% of women with pre-cancer treated
 - 90% of women with invasive cancer managed

* A high-performance test refers to a test which would have performance characteristics similar to or better than a HPV test. In the future, however, new technologies may become available.

Furthermore, there are substantial within-country population disparities in cervical cancer morbidity and mortality among women residing in high Human Development Index countries cited as aspirational models for other countries to follow. A previous review of data from New Zealand, Australia (Queensland, Western Australia, and the Northern Territory), Canada (Alberta) and Contract Health Service Delivery Areas of the United States (USA) showed cervical cancer incidence was generally higher among Indigenous women than among non-Indigenous women.(Moore et al., 2015) These inequities must be addressed to ensure that Indigenous women meet cervical cancer elimination goals. Global calls, led by Indigenous women, have urged that elimination targets be equity-driven, and that addressing inequities be central to the elimination agenda within countries to ensure that Indigenous women benefit similarly to other communities and populations globally. Importantly, governments must promulgate specific strategies, actions, and monitoring mechanisms to accelerate cervical cancer elimination for Indigenous women and mitigate further widening of an avoidable gap in balanced healthcare delivery to their citizens.(Whop et al., 2019)

3. Current status of cervical cancer elimination in Indigenous women

In order to have a benchmark starting point and examine whether or not routine monitoring mechanisms were in place, we reviewed data from four high-income colonised countries to assess how each is currently performing in relation to the cervical cancer incidence elimination target and the triple-intervention targets, both nationally and in Indigenous women specifically (Table 1). For cervical cancer incidence, this involved recalculation of age-standardized rates using the standard cervical cancer elimination methodology(Canfell et al., 2020) (in practice requiring age-specific incidence data, which were not always published). For HPV vaccination, we included coverage of completed courses, and coverage with at least one dose. The data review for Table 1 was deliberately focussed on national population-based routinely-published data, provided in enough detail to be compared to the targets, because these data would be required to regularly monitor progress towards achieving elimination, and we wished to identify where they were not yet available and/or regularly updated. In the absence of national or nationally-representative data, we identified data that were representative of one or more jurisdictions.

HPV vaccination has been offered to girls in all four of these countries for more than 10 years, although the method of delivery, extent of catch-up programs, and vaccine coverage vary. All four countries also now recommend HPV vaccination for boys, also with variations in coverage, delivery method, and timing of introduction. HPV vaccination of boys is not included in WHO elimination targets, but where offered, coverage in boys could compensate for lower coverage in girls (for example the impact of vaccinating 80% of girls and boys is similar to vaccinating 100% of girls, so this could be considered as meeting the 90% of the girls target(Brisson et al., 2016)). The cervical cancer elimination target includes screening 70% of women by age 35 and again by age 45 using a test with comparable or superior performance to an HPV test. Cytology-based screening has been offered in all four of these countries for more than 25 years, but the countries differ in terms of whether or not HPV-based screening is routinely offered. Australia and New Zealand have national organized screening programs. These four countries routinely publish cancer incidence data at the national level, with more variability in the availability of routine vaccination and screening data, and generally limited availability of routine data in relation to treatment for precancer or cancer. A similar pattern is observed for data relating to Indigenous women: data are more likely to be available for cancer incidence, and rarely available for treatment for precancer or cancer. In all four countries there were indicators where routine data was available at the national level, but not for Indigenous populations. A summary of whether or not current performance meets the WHO targets is presented in Table 2.

Table 1
- Benchmark status against WHO elimination targets.

	Cervical cancer incidence ¹		HPV vaccination coverage (female by age 15; any doses/ complete course)		% screened at age 35, 45		% receiving treatment for diagnosed precancer		% receiving treatment for diagnosed cancer		Comments (coverage in males if relevant in setting)
Target	<4 per 100,000		90% by age 15		70% by 2030 ²		90%		90%		
Performance	Indigenous	Overall	Indigenous	Overall	Indigenous	Overall	Indigenous	Overall	Indigenous	Overall	
Australia	15.4	6.4	87.3–95.9/ 66.5–82.6	88.9/ 80.2	50.1	79.7	NA	Not available	76.8	95.9	Coverage in same-age boys = Indigenous: 82.4–94.0/ 61.2–72.6; overall 85.9/75.5
Canada		6.6		74.6 / NA		80.1		NA		NA	Boys offered vaccine all provinces and territories from fall 2017 (some started 2012–2017)
First Nations			40.0/ NA		80.3 (30-39yo); 75.2 (40-49yo)		NA		NA		Uptake in same-age boys = 20.3% (data pre-dates national funding)
Inuit					75.4–83	76–80.1	NA		NA		
Métis					69.0–80.2	67.8–80.1	NA		NA		
New Zealand	10.7	6.1	NA/ 69.4	NA/ 67.1	62.0	74.8	NA	63.2% within 8 weeks	70.3	69.1	Boys offered HPV vaccination from 2017
USA		6.5		69.9/ 53.7		82.8		NA		NA	Coverage in same-age boys = 66.3/ 48.7
Native Alaskans	4.5		80.1/ 58.7		76.9		NA		NA		Coverage in same-age boys 64.7/ 56.5
Native Americans	4.5		80.1/ 58.7		76.9		NA		NA		Coverage in same-age boys 64.7/ 56.5
Native Hawaiians	NA		NA		NA		NA		NA		

Sources: Australia: cancer incidence: Australian Institute of Health & Welfare (AIHW) (NSW, Qld, WA and NT)([Australian Institute of Health and Welfare, 2019](#)); vaccination coverage: National HPV Vaccination Program Register (ACT, NSW, NT, Qld)([Brotherton et al., 2019](#)); screening: Queensland([Whop et al., 2016](#)); treatment: Queensland.([Whop et al., 2017](#))

Canada: cancer incidence: Canadian Cancer Registry (ex Quebec)([Carrière et al., 2012](#); [Statistics Canada, 2020](#)) and 1991 Canadian Census Health and Environment Cohort([Mazereeuw et al., 2018a](#); [Mazereeuw et al., 2018b](#)); vaccination coverage: childhood National Immunization Coverage Survey([Public Health Agency of Canada, 2018](#)) and First Nations Regional Health Survey (FNRHS)([First Nations Information Governance Centre, 2018](#)); screening: FNRHS,([First Nations Information Governance Centre, 2018](#)) Canadian Community Health Surveys and Aboriginal People's Survey([McDonald and Trenholm, 2010](#)) and regional surveys([Tung-asuvvingat Inuit and Cancer Care Ontario, 2017](#); [Martens et al., 2010](#); [Withrow et al., 2014](#)); treatment: NA.

New Zealand: cancer incidence: New Zealand Cancer Register (NZCR)([Ministry of Health, 2019](#)); vaccination coverage: Ministry of Health([New Zealand Ministry of Health, 2018](#)); screening: independent monitoring reports([Smith et al., 2019](#)); treatment: NZCR.([McLeod et al., 2010](#))

US: cancer incidence: SEER([Howlander et al., 2020](#)); vaccination coverage: NIS-TEEN([Centers for Disease Control and Prevention, 2019](#)); screening: National Health Interview Survey([White et al., 2017](#)); treatment: NA.

¹ using WHO recommended elimination method (age-standardisation to World female population 2015 ages 0–99 years; in practice this requires age-specific rates) NA: not available (for cancer incidence, this means age-specific data are not available; rates that are standardized using different standard populations cannot be compared to the WHO target).

² Scaling up to 90% by 2045.

3.1. Australia

3.1.1. Incidence target

Nationally, 6.4 per 100,000 women; predicted to fall below the elimination threshold within 15 years in the context of current interventions.([Hall et al., 2019](#); [Australian Institute of Health and Welfare, n.d.](#)) Incidence in Indigenous Australian women is more than twice as high (15.4 per 100,000 women)([Australian Institute of Health and Welfare, n.d.](#)) as than the national rate. Modelled predictions of the time to elimination are not yet available but achieving elimination will require a 74% reduction in incidence.

3.1.2. Vaccine coverage target

Coverage in Indigenous girls by age 15 is close to 90% for dose 1, but varies from 66.5%–82.6% by jurisdiction for complete courses (national data are not available).(Brotherton et al., 2019) Coverage in boys similarly varies by state/territory but is around 5–15 percentage points

lower than in girls.

3.1.3. Screening target

HPV-based screening is the universal standard of care provided in Australia. National coverage data are not available for Indigenous Australian women, an information gap that has persisted even after the recent transition to a National Cancer Screening Register in conjunction with the transition to primary HPV screening. State-specific data demonstrate very substantial differences in screening of at least 20 percentage points, that have persisted over at least a 10-year period. ([Whop et al., 2016](#))

3.1.4. Treatment target

National data are not available for precancer or cancer treatment, neither for all women nor Indigenous women. Data from Queensland suggests 76.8% of Indigenous women receive optimal cancer treatment, which was less than non-Indigenous women.([Whop et al., 2017](#)) Five-

Table 2

Summary report card: current status in Indigenous women compared to WHO elimination targets.

Target	Percent reduction required in cervical cancer incidence	HPV vaccination coverage (F)	HPV-based screening available?	% screened at age 35, 45	% receiving treatment for diagnosed precancer	% receiving treatment for diagnosed cancer
	<4 per 100,000	90% by age 15		70% by 2030	90%	90%
Australia	74%	Met ¹	Yes	Not met	?	Not met
Canada - First Nations	?	Not met	Varies	Coverage met ²	?	?
Canada - Métis	?	?	Varies	Coverage met ²	?	?
Canada - Inuit	?	?	Varies	Coverage met ²	?	?
New Zealand	63%	Not met	No	Not met	?	Not met
USA - Native Americans	?	Not met	Varies	Coverage met ²	?	?
USA - Native Alaskans	?	Not met	Varies	Coverage met ²	?	?
USA - Native Hawaiians	?	?	Varies	?	?	?

¹ Based on data from 4 of 8 jurisdictions (representing 71% of indigenous population) and taking into account coverage in boys in some jurisdictions

² Coverage met, but target not fully met as requires HPV testing or equivalent (World Health Organization, 2020)

year relative survival is poorer for Indigenous women (Australian Institute of Health and Welfare, 2019) and mortality is around four times higher in Indigenous women (7.3 per 100,000 vs 1.8 per 100,000 for Australia overall). (Australian Institute of Health and Welfare, 2019)

3.2. Canada

3.2.1. Incidence target

Nationally, 6.6 per 100,000 women. Cervical cancer data are not published in sufficient detail to compare incidence in First Nations, Métis, and Inuit women against the WHO elimination threshold. Studies that have compared incidence within specific regions or large cohorts suggest incidence rates are around twice as high in First Nations, Métis, and Inuit women compared to non-Indigenous women. (Mazereeuw et al., 2018a; Mazereeuw et al., 2018b; Carrière et al., 2012; Statistics Canada, 2020)

3.2.2. Vaccine coverage target

Data are available nationally and to a limited extent for First Nations girls but were not identified for Métis or Inuit girls. Coverage as low as 40% has been reported among First Nations girls aged 12–14 years, which is well below the WHO target and that in 13–14 years old girls in Canada overall (75%). (First Nations Information Governance Centre, 2018; Public Health Agency of Canada, 2018)

3.2.3. Screening target

Data for First Nations women are available from a repeated national First Nations-controlled survey. (First Nations Information Governance Centre, 2018) Routine data on screening are limited, but studies suggest that screening rates are similar in Indigenous and non-Indigenous populations in Canada, with around 75–80% being screened in the recommended time period (3 years). (First Nations Information Governance Centre, 2018; McDonald and Trenholm, 2010; Milosevic, 2019) One province is transitioning to primary HPV screening; some others are in the process of decision-making, planning or undertaking pilots. (Chao et al., 2019)

3.2.4. Treatment target

No treatment data are available at the national level, or for Indigenous women. Some data suggest poorer survival in Indigenous women than in non-Indigenous women. (Withrow et al., 2017) Cancer mortality data for Indigenous women are very limited, but suggest that rates are around twice as high as in the general population. (Milosevic, 2019; Bramley et al., 2004)

3.3. New Zealand

3.3.1. Incidence target

Nationally, 6.1 per 100,000 women; 10.7 per 100,000 among Māori women. (Ministry of Health, 2019) Achieving cervical cancer elimination in Māori women will require a 63% reduction in incidence compared to current rates.

3.3.2. Vaccine coverage target

69% in Māori girls by age 15 (New Zealand Ministry of Health, 2018); coverage in boys (offered HPV vaccination since 2017) has not yet been published.

3.3.3. Screening target

Routinely-published national data indicate that 62% of Māori women were screened in the recommended time period (3 years). (Smith et al., 2019) Women in New Zealand do not yet have routine access to primary HPV screening. (Ministry of Health, 2020)

3.3.4. Treatment target

Precancer treatment data are routinely reported, but not yet by ethnicity, and performance is measured against a quality indicator relating to a relatively short timeframe so does not give a full picture of how many women are treated. Cancer treatment data are not routinely published, however an analysis of national data indicated 70.3% of Māori women were treated within 12 months, comparable to the national rate (69.1%). (McLeod et al., 2010) Cancer mortality is more than twice as high in Māori women (3.6 per 100,000 vs 1.6 per 100,000 in New Zealand overall). (Ministry of Health, 2019)

3.4. USA

Data typically groups Native Americans and Native Alaskans together, and groups Native Hawaiians with Asian/ Pacific Islander women (and Native Hawaiians comprise a relatively small proportion of the Asian/ Pacific Islander population).

3.4.1. Incidence target

Nationally, 6.5 per 100,000 women (Howlader et al., 2020); this is predicted to fall below the elimination threshold between 2038 and 2046. (Burger et al., 2020) Cervical cancer data are not published in sufficient detail to compare Native Americans, Native Hawaiians, or Native Alaskans against the WHO elimination threshold separately. Incidence among Native American/Native Alaskan women combined is 4.5 per 100,000, based on detailed Surveillance, Epidemiology, and End Results (SEER) data, but linkage studies have found substantial

misclassification of race on cancer registers (Watson et al., 2014) and reported higher incidence.

3.4.2. Vaccine coverage target

Vaccine coverage by age 15 is not one of the routine reporting indicators, but 80% of Native American/Native Alaskans girls aged 13–17 years have received at least one dose, compared to 70% of girls this age nationally. (Centers for Disease Control and Prevention, 2019) Coverage of completed courses in girls this age is less than 60%, both in Native Americans/ Native Alaskans and nationally, suggesting a lower completion rate in Native American/Native Alaskan girls. Coverage (completed courses) in same-age boys is 56% in Native Americans/ Native Alaskans and 49% nationally.

3.4.3. Screening target

Based on the self-reported National Health Interview Survey, 76.9% of eligible Native American/ Native Alaskans women were screened as recommended (Pap in the past three years or an HPV test in the past five years), compared to 82.8% of women nationally. HPV-based screening is available but not universally used (cytology-only screening is one of the standards of care, and used by a sizeable minority (Watson et al., 2018)).

3.4.4. Treatment target

Data were not identified for the proportion of women receiving treatment for precancer or cancer. SEER data suggest lower cervical cancer mortality among Native American/ Native Alaskan women (1.7 per 100,000 vs 2.3 per 100,000 nationally), (Howlader et al., 2020) but misclassification of race on death certificates contributes to underestimates of cancer mortality in the Native American/Native Alaskan population. Linkage studies that aimed to improve identification have found mortality is approximately twice as high in Native American/ Native Alaskan women as in non-Hispanic white women. (Watson et al., 2014)

4. Meeting cervical cancer elimination targets in Indigenous women

There are multiple barriers to reaching elimination targets for Indigenous women (Table 3). Globally, Indigenous women experience barriers spanning HPV vaccination, cervical screening, and treatment, that relate to knowledge, information and beliefs; access; data and systems; healthcare provider factors; health care system factors; and the impacts of colonisation. Some enablers to overcome these are described in the following sections.

4.1. HPV vaccination

HPV vaccination has the potential to be an equitable approach. Publicly-funded school-based vaccine delivery tends to result in the most equitable coverage. (Brotherton et al., 2019; Musto et al., 2013; Borena et al., 2016; Hughes et al., 2014; Kumar and Whynes, 2011; Lefevre et al., 2015; Barbaro and Brotherton, 2014; Poole et al., 2012) HPV vaccination is delivered through schools in Australia, the only one of the four countries that is achieving the WHO vaccination target in Indigenous girls, vaccination is delivered through schools. Vaccine coverage in New Zealand and the USA does not meet WHO targets, but coverage in Indigenous girls is similar to national coverage. Enablers specific to HPV vaccination include family and community collective involvement in decision-making and health promotion. For Indigenous peoples, the family often extends past the nuclear and encompasses a broad collective of extended family members and wider kin and tribal networks. Indigenous parents may want to consult this collective on whether their child should be vaccinated (Rose et al., 2010) and collectively make decisions about the content and delivery of HPV vaccine education, including the important role of Elders and female family members for sexual health education and broader traditional teachings

about healthy relationships. (Henderson et al., 2018; Schmidt-Grimminger et al., 2013) Including the multi-generational collective in this decision-making has been suggested (Toffolon-Weiss et al., 2008) and successfully demonstrated to increase HPV vaccination among Indigenous youth. (Winer et al., 2016) For example, coverage in Native Americans and Native Alaskans was increased following education for and outreach to tribal leaders, community groups, providers and parents that were both tailored and recognised multigenerational family involvement in decision-making. (Centers for Disease Control and Prevention, 2017; Smallenberg et al., 2010; Jacobs-Wingo et al., 2017) Additionally, policy, funding and program design can explicitly incorporate and promote equity – for instance, in New Zealand the vaccination program was planned, designed and implemented with specific equity-based objectives and levers (Box 2).

Vaccination is a long-term approach to reducing cervical cancer incidence; achieving faster reductions and improving equity in the near term requires scaled-up screening and treatment. (Brisson et al., 2020; Canfell et al., 2020; Burger et al., 2020; Simms et al., 2019b; Smith et al., 2018)

4.2. Screening

HPV-based screening can help to reduce disparities because it can be done less frequently than cytology, (Smith et al., 2018) and on a self-collected sample (and/or using point-of-care tests, potentially enabling see-and-treat approaches in some circumstances) - but only if detected precancer is treated. Increasing treatment of invasive cancer is the fastest way to save lives. (Canfell et al., 2020) Understanding the barriers and enabling factors to cervical screening for Indigenous women is critical.

Indigenous women in Australia who participate in cervical screening reported that screening can be a means of empowerment and control. (Butler et al., 2020) Several facilitators that can overcome barriers to screen include openly talking about screening, trusting relationships with health professionals, and overcoming logistical barriers and privacy concerns (especially for women employed at health centres). (Butler et al., 2020) Importantly, women who screen still describe needing to overcome fears, shame or past negative experiences. (Butler et al., 2020) Other enablers include access to female health professionals (including Indigenous health workers), and locally-devised health plans that aim to improve access, GP knowledge, recall systems, targeted culturally-relevant health promotion, and population registers. (Coe et al., 2007; Reath and Carey, 2008; Adcock et al., 2018; Robson et al., 2010; Sadler et al., 2004) Enacting these enablers is important to sustain long term improvements in cervical screening, but the unacceptable inequities call for additional and innovative strategies focused at addressing or overcoming persisting barriers. Such strategies could be, for example, the use of Patient Navigators and self-sampling for HPV testing. The use of patient navigators, community members, or Indigenous Liaison Officers can help women to navigate through screening and treatment pathways – making appointments, attending appointments, organising transportation, being a support person, and facilitating consultations with healthcare providers. (Kirk et al., 1998; Liddell et al., 2018; Marcusson-Rababi et al., 2019; Slater et al., 2013; Walker et al., 2008; Whop et al., 2012) Trust, credibility, and accountability are key, therefore health providers involved in cervical screening services and interventions with Indigenous women need to provide culturally safe care. (Lovell et al., 2007; Ristevski et al., 2020; Zehbe et al., 2011; Wakewich et al., 2016) Maar et al. developed ‘Seven Ways to promote Cervical Cancer Screening in First Nations Women’, including: education about cervical cancer, community-based strategies for promoting health, culturally specific community events, healthcare provider professional development/training, integration of services to be more flexible/mobile, awareness promotion, and the incorporation of First Nations gender perspectives on body and health. (Maar et al., 2016) These are intended to “shape individual behaviour by influencing the beliefs and actions of

Table 3
- Barriers to reaching triple-intervention targets.

	Knowledge, information, and beliefs	Access to health care – Physical and financial	Data and systems	Health care provider factors	Health care system factors	Colonial legacy	Other issues
HPV vaccination	<p>Low awareness of vaccine and its benefits (prevention of cancer & warts) (Toffolon-Weiss et al., 2008; Jacobs-Wingo et al., 2017; Hodge et al., 2011; Cerigo et al., 2012)</p> <p>Misunderstandings about HPV and vaccine (Schmidt-Grimminger et al., 2013)</p> <p>Stigma about HPV infection (Schmidt-Grimminger et al., 2013)</p> <p>Stigma related to sexually transmitted nature of infection (Jacobs-Wingo et al., 2017)</p> <p>Need for increased information availability (Schmidt-Grimminger et al., 2013; Toffolon-Weiss et al., 2008)</p> <p>Generally limited sexual education (Henderson et al., 2018)</p> <p>Cultural taboo on talking about sex with parents (Henderson et al., 2018; Hodge et al., 2011)</p> <p>Concerns about vaccine efficacy, safety/side effects (Jacobs-Wingo et al., 2017; Hodge et al., 2011; Kemberling et al., 2011)</p>	<p>Cost of the vaccine, especially for countries where a school-based program not implemented and where insurance does not cover (Hodge et al., 2011)</p> <p>Access to clinic (Jacobs-Wingo et al., 2017; Hodge et al., 2011)</p>	<p>Missing vaccination data (Jacobs-Wingo et al., 2017)</p>			<p>Distrust and avoidance of government, pharmaceutical companies and health institutions due to past mistreatment (Henderson et al., 2018; Toffolon-Weiss et al., 2008; Hodge et al., 2011)</p> <p>Intergenerational impacts of trauma leading to prioritising immediate needs of housing and food over vaccine (Henderson et al., 2018)</p> <p>Preference traditional medicine due to loss of cultural practice (Hodge et al., 2011)</p>	<p>Mistrust of vaccines (Schmidt-Grimminger et al., 2013; Toffolon-Weiss et al., 2008)</p> <p>Concerns that the needle will hurt (Hodge et al., 2011; Kemberling et al., 2011)</p> <p>Where school-based, lower rates of school attendance and difficulty obtaining parental consent (Brotherton et al., 2013)</p>
Cervical screening	<p>Low awareness levels about screening and benefits for prevention of cancer (Maar et al., 2016; Maar et al., 2013)</p> <p>Seeking health care reserved for when symptomatic (O'Brien et al., 2008)</p> <p>Embarrassment and fear, (O'Brien et al., 2008)</p> <p>whakamā, (Lovell et al., 2007; Adcock et al., 2019)</p> <p>shame, (Shahid et al., 2009a)</p> <p>negative body perception (Maar et al., 2016)</p> <p>Exposing body compromises sacredness of women's bodies (Lovell et al., 2007; Adcock et al., 2019)</p> <p>Need for culturally-relevant</p>	<p>Limited access to appropriate health services (Maar et al., 2013)</p> <p>Limited transport options, especially for women living on reserve and/or rural areas (Butler et al., 2020; Maar et al., 2013; Adcock et al., 2019; Kirk et al., 1998)</p> <p>Limited clinic opening hours and appointment times, especially for women who are working and/or have caring responsibilities (Butler et al., 2020; Maar et al., 2013)</p>	<p>Lack of recall systems, especially when opportunistic screening programs rely on primary health care providers to remind women to screen (Maar et al., 2013)</p> <p>Lack of national participation data for Indigenous women (Whop et al., 2014)</p> <p>Under-ascertainment of Indigenous status (Shahid and Thompson, 2009; Whop et al., 2014)</p>	<p>Limited availability of female practitioners (Maar et al., 2013)</p> <p>Previous negative experiences with health professionals or health services (Maar et al., 2016)</p>		<p>Impacts from ongoing colonisation and oppression including racist policies leading to distrust of health care services (Maar et al., 2016; Maar et al., 2013)</p>	

(continued on next page)

Table 3 (continued)

	Knowledge, information, and beliefs	Access to health care – Physical and financial	Data and systems	Health care provider factors	Health care system factors	Colonial legacy	Other issues
Treatment	<p>and acceptable information (Maar et al., 2016)</p> <p>Beliefs about cancer including fatalistic views and stigma (Shahid et al., 2009a; Shahid and Thompson, 2009)</p> <p>Generally low levels of knowledge about cancer in communities, (Tranberg et al., 2016; Horrill et al., 2019)</p> <p>Shame and stigma surrounding cancer and treatment (Kirk et al., 1998; Tranberg et al., 2016; Horrill et al., 2019)</p>	<p>Having to travel long distances to specialist and treatment appointments, especially for rural/remote living women (Kirk et al., 1998; Liddell et al., 2018; Horrill et al., 2019)</p> <p>Financial costs of travel, attending appointments, treatment, medication and childcare (Marcusson-Rababi et al., 2019; Walker et al., 2008; Shahid et al., 2009b) often not covered by insurance (Liddell et al., 2018; Adcock et al., 2019; Maar et al., 2013; Horrill et al., 2019)</p> <p>Emotional and social burden of having to leave family and community support networks while travelling for treatment, (Kirk et al., 1998; Slater et al., 2013; Tranberg et al., 2016; Horrill et al., 2019; Shahid et al., 2009b)</p> <p>Concerns about leaving family duties and responsibilities (Marcusson-Rababi et al., 2019)</p>		<p>Male health care provider can be a source of embarrassment/ shame for in treating cancers that are viewed as Women’s Business (Liddell et al., 2018; Marcusson-Rababi et al., 2019)</p> <p>Lack of clear and consistent communication and information about diagnosis and treatment (Kirk et al., 1998; Liddell et al., 2018; Marcusson-Rababi et al., 2019; Slater et al., 2013; Walker et al., 2008; Tranberg et al., 2016)</p> <p>Use of medical jargon (Kirk et al., 1998; Marcusson-Rababi et al., 2019)</p> <p>Lack of empathy (Walker et al., 2008; Tranberg et al., 2016)</p> <p>Disrespectful and insensitive communication (Liddell et al., 2018)</p> <p>Lack of rapport and relationship building with patient and family (Slater et al., 2013; Tranberg et al., 2016)</p> <p>Language barriers (Kirk et al., 1998; Marcusson-Rababi et al., 2019; Horrill et al., 2019)</p> <p>Poor coordination of care between multiple HCPs and services (Horrill et al., 2019)</p>	<p>Difficulty navigating an unfamiliar and complex hospital and health system (Marcusson-Rababi et al., 2019; Tranberg et al., 2016; Horrill et al., 2019; Shahid et al., 2009b)</p>	<p>Fear and mistrust of healthcare system due to historical traumas and abuse (Horrill et al., 2019)</p> <p>Experiences of racism and discrimination (Horrill et al., 2019)</p> <p>Feelings of disempowerment and lack of control in decision-making about treatment (Kirk et al., 1998; Marcusson-Rababi et al., 2019)</p> <p>Concerns are overlooked in health care provision (Liddell et al., 2018; Horrill et al., 2019)</p> <p>Options for treatment generally do not accommodate Indigenous peoples’ holistic views of health (Walker et al., 2008)</p>	

Box 2

– Example of successful equity design – HPV vaccination in New Zealand.

When designing the introduction of the HPV vaccine for females in New Zealand, particular focus was placed on identifying and incorporating strategies and tactics to foster equal opportunity for Māori and Pacific young women* the design included:

- Explicit prioritisation of Māori and Pacific young women
- Engagement with Māori and Pacific stakeholders nationally and regionally
- Māori and Pacific equity advisory groups guided the design and roll out of the program to district health boards (responsible for delivery)
- Service delivery processes that had been shown to be most effective for Māori and Pacific young women and their whanau, using the existing evidence-base
- Funding to specifically target Māori and Pacific young women and their whanau
- Ongoing monitoring of uptake by Māori and Pacific young women, and sought to resolve monitoring issues relating to the National Immunization Register's ethnicity data

* <https://www.health.govt.nz/system/files/documents/publications/hpv-immunisation-programme-evaluation-v2.pdf>

individuals and their support system of family, friends, and health care providers”, providing a framework for a more collective approach to screening promotion.

4.3. Self-sampling

As most countries move from cytology to HPV-based screening, one promising advantage is the ability to perform HPV testing on a self-collected vaginal sample. Women report that “self-testing” is empowering as a *term* as well a screening method. HPV testing is as sensitive for detecting cervical pre-cancer on self-collected and clinician-collected samples (when PCR-based assays are used), and is effective at increasing participation among under-screened women.(Arbyn et al., 2018) Several studies have offered self-testing to Indigenous women and explored acceptability and preferences. These studies have consistently found self-testing to be highly acceptable, feasible, and effective at overcoming multiple barriers to clinician-collected samples via a pelvic examination.(Winer et al., 2016; Zehbe et al., 2011; Styffe et al., 2020; Adcock et al., 2019; University of Melbourne, Victorian Cytology Service, 2017; Dutton et al., 2020; Brewer et al., 2019a) Women described it as simple, convenient, private, and giving them control and bodily autonomy.(Winer et al., 2016; Styffe et al., 2020; University of Melbourne, Victorian Cytology Service, 2017; Dutton et al., 2020) Flexibility in delivery was important at all steps in the pathway, including how self-testing was accessed (via post/ clinic/ pharmacy), where it was done (at home/ clinic), how it was returned (via post, or dropped off to a clinic or pharmacy), and how results were delivered (text, phone, email, clinic visit, letter).(Winer et al., 2016; Styffe et al., 2020; Adcock et al., 2019) Providing appropriate support both before the test, when delivering the results, and in the decision-making regarding treatment was also important.(Winer et al., 2016; Adcock et al., 2019; Dutton et al., 2020) Studies that have directly reported the impact on screening uptake are much more limited. Results from two randomised studies have indicated uptake was 1.3- to 3-fold higher when women were offered self-testing compared to a clinician-collected Pap test (Zehbe et al., 2016; MacDonald et al., 2021), and small pilot studies have reported high uptake among Indigenous women.(University of Melbourne, Victorian Cytology Service, 2017; Dutton et al., 2020) Further research is warranted, and findings from work still in progress will be important to add to the evidence base.(Brewer et al., 2019b) Healthcare providers generally also support self-sampling for women(Adcock et al., 2019; University of Melbourne, Victorian Cytology Service, 2017) which would allow women to be in control of the timing and place of testing and remedy concerns women have in relation to privacy and discomfort (Wakewich et al., 2016). Studies of self-sampling also provide examples of consultation and co-design (e.g. Kaupapa Māori (by, with, for Māori) design,(Adcock et al., 2019) or prioritising consultation with First Nations community leaders and Chiefs(Zehbe et al., 2012)); local research

capacity-building (training community-based research assistants(Zehbe et al., 2012)); and innovative designs such as a distributed research model where community-based researchers, who ran focus groups, assisted some interested participants to help collect survey data from peers.(Adcock et al., 2019)

Addressing shared barriers across the triple-intervention targets is critical and urgent. The use of a patient navigator in the absence of culturally safe screening and treatment services can help to guide women through the full screening pathway in a supportive way; as does specifically providing an alternative pathway for women who are under-/never-screened. Making self-testing widely available and free or low-cost for Indigenous women will address longstanding barriers. Involvement of family and community in decision-making and health promotion materials is critical.

Encapsulating these strategies with adequate monitoring and reporting systems is an essential enabler to ensure that progress is on track for Indigenous women, and elimination is reached.

5. Inclusion and identification

Indigenous peoples should have the power to determine who they are, what data are collected about them and why, and who has access to that data,(Snipp, 2016; Rodriguez-Lonebear, 2016) for “Indigenous peoples have always been data collectors and protectors”.(Lovett et al., 2019; Health and Disability System Review, 2020) The absence of Indigenous peoples in the production of data about Indigenous peoples contributes to deficit statistical narratives that are used to justify inequities in health.(Walter and Suina, 2019) The collection and reporting of Indigenous data too often focuses on ‘the five Ds’ of ‘non-wellbeing’: disparity, deprivation, disadvantage, dysfunction, and difference.(Walter, 2016) There needs to be a focus on wellbeing, with Indigenous data sovereignty upheld. Indigenous data sovereignty pertains to “the rights of Indigenous peoples to own, control, access and possess data that derive from us” and “the desire for data to be used in ways that support and enhance the collective wellbeing and self-determination of Indigenous peoples”.(Kukutai, 2019) Groups in Canada (OCAP), Australia (MaiaM nayri Wingara), Aotearoa New Zealand (Te Mana Raraunga) and the USA (USIDSN), as well as the Research Data Alliance International Indigenous Data Sovereignty Interest Group have been set up to advance Indigenous data sovereignty goals.(Lovett et al., 2019)

5.1. Data

The burden of cancer-related diseases for Indigenous peoples, especially in less-resourced regions, may be substantially under-estimated due to limited resourcing, methodological issues in data collection (such as identification, numerator-denominator bias, data linkage issues, and statistical considerations), and the heterogeneity of Indigenous

groups.(Sarfati et al., 2018; Sarfati and Robson, 2015) Recent research assessing the quality of Indigenous status data in cancer registries in 25 settler colonial nation states found that a lack of data collection, lack of transfer of Indigenous status information, inadequate information systems, and legislative limitations are barriers to the collection of Indigenous status data.(Diaz et al., 2020) As noted earlier, race misclassification appears to have led to SEER data underestimating cervical cancer incidence and mortality in Native Alaskans and Native Americans,(Watson et al., 2014) and this may be the case in some other countries. Health information systems, such as national cervical screening registries, must be strengthened and include Indigenous leadership and governance.(Diaz et al., 2020)

Addressing inequities in cancer outcomes for Indigenous peoples requires Indigenous peoples being included in research as participants, research leaders, and in the governance of data.(Henare et al., 2019) Planning and prioritisation must be equity focused.(Gurney et al., 2020) The colonial legacy of marginalization and negative experiences of the health system, as experienced by many Indigenous women, needs to be acknowledged.(Lovell et al., 2007; Wakewich et al., 2016)

6. Conclusions and recommendations

Indigenous women suffer increased cervical cancer incidence and mortality compared to their non-Indigenous peers despite no increased risk of early-stage disease.(Vasilevska et al., 2012) The drivers of cervical cancer inequities need to be addressed, including differences in determinants of health, access to care, quality of care, and data monitoring, that are impacted by institutionalised racism and health system structures.(Sarfati and Robson, 2015; Gurney et al., 2020) Improved data collection, accuracy, and completeness are key components in achieving this; failing to improve them fails to keep the system that is intended to care for women accountable, and in turn is a way of silencing Indigenous women.

The WHO targets call for global action towards elimination of cervical cancer to address the unjust differential burden of cervical cancer between low, middle- and high-income countries. Currently the WHO targets do not support or advocate for the rights of Indigenous peoples to have these targets met and eliminate within country inequity. It is likely, as history has demonstrated, these targets will be met for whole of population but not for Indigenous women. To achieve equitable health outcomes for Indigenous peoples, strategies need to centre Indigenous leadership, knowledge, and solutions with ongoing community engagement. This requires a culture shift, where the prioritisation of research questions, methods, and solutions are Indigenous-led, ensuring that solutions are acceptable, appropriate and sustainable.(Cochran et al., 2008)

Large inequities exist for Indigenous peoples in Australia, Canada, New Zealand and the USA, and elimination is not on track in these countries for Indigenous women. These countries must urgently address their systemic failure to care and provide health for Indigenous women. We have summarised the pressing barriers to reaching the triple-intervention targets for Indigenous women – but also enablers to overcome these barriers, with examples of community-focused interventions. Like the WHO, we also call for global action – use these enablers to remove these inequities and eliminate cervical cancer in Indigenous women.

The international community and countries should consider the following principles in their approach:

- Relationships with Indigenous communities must be based on respect, reciprocity and responsibility.(Salmon et al., 2018) Earning trust takes time and reciprocity. It involves being respectful, becoming known, humility, and ensuring that the status and wellness of the community is always the priority.(Anderson et al., 2016; Butler et al., 2019) This relationship ethic speaks to the importance of collective accountability, working together, mutual learning, and

accepting that some knowledge is sacred or not for the public domain.(United Nations, 2015) Health policy and strategies have a responsibility to involve ongoing partnership in an authentic relationship with Indigenous communities.(Burns et al., 2010)

- Further research needs to avoid the pitfalls of scientific colonialism, that by its nature supports political colonialism.(Cram, 2009; Nobles, 1976) Although Article 24 of the UNDRIP asserts Indigenous peoples' right to achieve the highest attainable health, it lacks guidance on how the data used to measure this are governed.(Walker et al., 2017) Research that is Indigenous led, focusing on eliminating system inequities, supported by informed policy decisions with adequate resourcing, should be priorities above research that reproduces person/population deficit narratives. Indigenous peoples' concerns must be addressed.(Walker et al., 2017)
- Complete and accurate data collection and reporting, e.g., health staff training to identify and record Indigenous status, through a standard census question and ethnicity data protocols(Ministry of Health, 2017); financial investment in information systems that can transfer information both locally and in organized programmes; the development and capacity building of cancer registries; and Indigenous leadership and governance.(Diaz et al., 2020) High quality data collection and reporting enables ongoing monitoring and evaluation, measures progress against elimination targets, identifies where resources are most needed, and measures which interventions work and do not work.
- Indigenous leadership includes family collectives, tribes, Elders, and knowledge holders, as well as professionals. Family and cultural connections are important supports for Indigenous peoples on their cancer journey.(Ristevski et al., 2020) Indigenous leadership must be central to directing where to focus efforts, planning, policy, monitoring and evaluation; intervention design and implementation; and supporting the programme and women.
- Indigenous peoples must define their cancer research agenda – as participants and in leadership and governance positions.(Letendre et al., 2020; Garvey and Cunningham, 2018) Indigenous peoples, such as Māori in Aotearoa New Zealand,(Scott et al., 2020) have experienced breaches of trust that discourage participation in research.(Henare et al., 2019) Henare and colleagues (2019) call for cancer researchers to honestly assess their practices to benefit Indigenous peoples, such as through road maps that assess investigator, advisory and governance factors.(Henare et al., 2019)
- Indigenous peoples should have equal rights to health and be provided with the appropriate resourcing for this. Equitable investment is urgently needed.

Current increased global attention on the lives of Black and Indigenous peoples highlights how critically important it is that action to eliminate cervical cancer does not leave Indigenous women behind, in its process or its outcomes. We urge the international community to hold individual countries to account for not *only* meeting their elimination targets, but meeting them for *all women*.

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