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2023

## Review of gynaecological cancer among Aboriginal and/or Torres Strait Islander people in Australia

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### Recommended Citation

Powell, Aime; Morseu-Diop, Ami; Morton Ninomiya, Maya; Yadav, Uday Narayan; Phillips, Emily; Singh, Devendra Raj; Butler, Tamara; Allanson, Emma; and Whop, Lisa J. (2023) "Review of gynaecological cancer among Aboriginal and/or Torres Strait Islander people in Australia," *Journal of the Australian Indigenous HealthInfoNet*: Vol. 4 : Iss. 3 , Article 1.

DOI: <https://doi.org/10.14221/2653-3219.1029>

Available at: <https://ro.ecu.edu.au/aihjournal/vol4/iss3/1>

This Review is posted at Research Online.

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# Review of gynaecological cancer among Aboriginal and/or Torres Strait Islander people in Australia

## Abstract

Gynaecological cancers bear a significant burden on the health of Australians. Whilst Australia has made great strides in reducing the overall gynaecological cancer burden nationally, Aboriginal and/or Torres Strait Islander women continue to experience disproportionately high rates of gynaecological cancers.

This review focuses on the social, cultural, and historical contexts that contribute to inequitable gynaecological cancer rates among Aboriginal and/or Torres Strait Islander women. An in-depth discussion on cervical cancer, ovarian cancer, and uterine cancer are described; including the incidence, mortality, survival, and management of these diseases for Aboriginal and/or Torres Strait Islander women.

It highlights both the persistent barriers and facilitators relating to Aboriginal and/or Torres Strait Islander women's uptake of preventative measures and treatments, including their use of services and programs relating to the management of gynaecological cancers.

This review summarises past and current policies and strategies implemented by the Australian Government and other cancer related peak bodies that aim to address this health issue.

It recommends that critical attention be given to risk reduction, participation in cancer screening programs, and improved access to culturally appropriate, high quality primary health care and tertiary specialist services. This would address inequitable differences faced by Aboriginal and/or Torres Strait Islander people and reduce the overall burden of gynaecological cancers.

## Acknowledgements

LW is supported by a National Health and Medical Research Council Investigator Grant (#2009380).

TB is supported by a National Health and Medical Research Council Investigator Grant (#2008097).

Special thanks are extended to the anonymous peer reviewer whose comments assisted in the finalisation of this review, staff at the Australian Indigenous Health *InfoNet* for their assistance and support and the Australian Government Department of Health and Aged Care for its ongoing support of the work of the Australian Indigenous Health *InfoNet*.

## Keywords

Aboriginal and/or Torres Strait Islander, Aboriginal and/or Torres Strait Islander culture, gynaecological cancer, cervical cancer, ovarian cancer, endometrial cancer, uterine cancer, cancer of the uterus, Aboriginal and/or Torres Strait Islander health, preventative healthcare, primary health care, community health, healthcare practitioners, public health, population health, policies, strategies

## About this review

The purpose of this review is to provide a comprehensive synthesis of key information and evidence on gynaecological cancer among Aboriginal and/or Torres Strait Islander people in Australia to:

- inform those involved, or interested in Aboriginal and/or Torres Strait Islander health
- guide policy, strategies and program development and delivery.

The review focuses on the most common gynaecological cancers among Aboriginal and/or Torres Strait Islander people; cervical, uterine, and ovarian cancers. It provides general information on the social and cultural context of Aboriginal and/or Torres Strait Islander women and gynaecological cancer, and the historical, behavioural, and biomedical factors that contribute to gynaecological cancer among this population.

This review provides detailed information on the extent of gynaecological cancer (cervical, ovarian, and uterine) among Aboriginal and/or Torres Strait Islander people, including incidence, mortality, survival and burden of disease. This review discusses the prevention and management of gynaecological cancer, experience of gynaecological cancer and provides information on relevant programs, services, policies and strategies that address the health issue of gynaecological cancer among Aboriginal and/or Torres Strait Islander people. This review concludes by suggesting possible future directions for addressing gynaecological cancer disparities for Aboriginal and/or Torres Strait Islander women.

This review includes information gathered from journal articles, research reports, government reports, national data collections and national surveys that are available and can be accessed through the Australian Indigenous Health *InfoNet*'s publication database <https://healthinfonet.ecu.edu.au/key-resources/publications/>.

To classify gynaecological cancer, this report utilises the *International Classification of Disease-10* cancer codes and those cancers are classified as 'C51–C58'. These include malignant neoplasm of vulva (C51), vagina (C52), cervix (C53), corpus uteri (C54), uterus - part unspecified (C55), ovary (C56), other and unspecified female genital organs (C57) and placenta (C58) (Australian Institute of Health and Welfare [AIHW], 2021a).

The Health *InfoNet*, consistent with its nomenclature guide, prefers the term 'Aboriginal and/or Torres Strait Islander' rather than 'Indigenous Australian' for its publications. Also, some sources may only use the terms 'Aboriginal only' or 'Torres Strait Islander only'. However, when referencing information from other sources, authors may use the terms from the original source. As a result, readers may see these terms used interchangeably in some instances and if there are any concerns readers are advised to contact the Health *InfoNet* for further information.

## Introduction

Gynaecological cancers are cancers that develop in the female reproductive system. They include vaginal, vulval, placenta, cervical, ovarian and uterine cancers. This review provides detailed information about three common gynaecological cancers (cervical, ovarian, and uterine cancers) that Aboriginal and/or Torres Strait Islander women are most likely to be diagnosed with and die from in Australia (AIHW, 2022b).

*In this report, we have used the term “woman/en”. However, we recognise that not all people with ovaries, cervix, or a uterus identify as women or wish to be referred to by medical terms. We encourage readers to consider transpeople and gender nonbinary people as part of this larger group, as they are also impacted by gynaecological cancers.*

In 2021, it was estimated that in Australia 6,576 new gynaecological cancers would be diagnosed, and Australian women would have a 4.4% (1 in 23) risk of this cancer type by the age of 85 (Cancer Australia, 2022c). The greatest burden of gynaecological cancer is among Aboriginal and/or Torres Strait Islander women who in 2004-2008 were 1.7 times more likely than non-Indigenous women to be diagnosed with, and 2.0 times more likely to die from this disease (AIHW, 2012). Aboriginal and/or Torres Strait Islander women continue to experience a disproportionate burden of these diseases due to complex and multifaceted factors. A key barrier that continues to exist, is the ongoing oppression of Aboriginal and/or Torres Strait Islander people that has resulted in a distrust of health services and institutions (Butler et al., 2020). This leads to a profound impact for Aboriginal and/or Torres Strait Islander women who experience a higher burden of comorbidities (Diaz et al., 2018; Moore et al., 2014), are diagnosed with more advanced diseases (AIHW, 2021a; Condon et al., 2014), have less access to optimal care, and overall receive less cancer treatment (Whop et al., 2017). It is important to share how Australia’s history of colonisation, one of the most detrimental determinants of health, continues to negatively impact Aboriginal and/or Torres Strait Islander people. Historical, contemporary and other contextual factors are essential to understand, if we want to advocate for, and develop future policies that enable Aboriginal and/or Torres Strait Islander women to have autonomy over their health decisions and deliver responsive initiatives that are culturally safe.

Aboriginal and/or Torres Strait Islander women seek a holistic and interconnected understanding of their health and wellbeing to enable fulfilment of their family and community roles. Aboriginal and/or Torres Strait Islander women have the right to access healthcare that is free of racism (Whop et al., 2021). It is critical for Aboriginal and/or Torres Strait Islander people to lead, develop and implement culturally safe gynaecological initiatives within their communities (Diaz et al., 2018). A proactive approach that is beyond the healthcare service system is needed to advocate for and enable the effective delivery of preventative health programs. New preventative programs should centre on a holistic health approach and increase community driven awareness of *when, how, and where* women can safely obtain a healthcare provider assessment for their gynaecological health concerns.

*A review of gynaecological cancer among Aboriginal and/or Torres Strait Islander people in Australia* aims to provide insight into national statistics, risk factors, prevention strategies, current policies, and the future directions for three most common types of gynaecological cancers: cervical cancer, uterine cancer, and ovarian cancer to communities, healthcare professionals, policy makers and educators. Once this is achieved and appreciated, we can truly reduce the burden of gynaecological cancer among Aboriginal and/or Torres Strait Islander women.

## Gynaecological cancers defined

As a group, gynaecological cancers represent 9.3% of cancers diagnosed among women in Australia, and uterine cancer is the most common diagnosed gynaecological cancer (Cancer Australia, 2022c). Gynaecological cancer includes cancers of the:

- vagina
- vulva
- placenta
- cervix
- ovaries
- uterus.

The different types of gynaecological cancer are individually associated with different risk factors and have different survival outcomes. Less common types include vaginal cancer, vulval cancer and placenta cancer (a pregnancy-related cancer). This review will focus on the three main types of gynaecological cancer, including cervical cancer (starts in the cells of the cervix), uterine cancer (starts in the lining of the womb [uterus]) and ovarian cancer (starts in one or both ovaries, fallopian tubes and/or the peritoneum) (Cancer Australia, 2018).

## The context of Aboriginal and/or Torres Strait Islander women and gynaecological cancer

In the Australian setting, Aboriginal and/or Torres Strait Islander women continue to experience inequitable gynaecological cancer outcomes and in 2004-2008, were 1.7 times more likely to be diagnosed with, and 2.0 times more likely to die from this disease (AIHW, 2012) compared to other Australian women. An individual's risk of developing a gynaecological cancer is influenced not only by inherited genetics and an individual's behaviour, but also by the continuing legacy of colonialism which impacts on Aboriginal and/or Torres Strait Islander women's health and access to health services. Over more recent years national frameworks and policies (Cancer Australia, 2015, 2016) have been developed that aim to improve awareness of gynaecological cancer prevention and early detection by providing culturally safe and high-quality care services, these are discussed in more detail in the section below.

### Incidence

#### Key message

Aboriginal and/or Torres Strait Islander women are nearly two times more likely than other Australian women to be diagnosed with gynaecological cancer, and this gap is not closing. There is a need to further investigate and identify strategies to reduce women's risk of developing a gynaecological cancer and to identify gynaecological cancers earlier to increase better prognosis and survival for Aboriginal and/or Torres Strait Islander women.

The Australian states and/or territories are mandated by legislation to notify cancer diagnoses; data is available for the years 1982 to 2017. It is estimated that in 2021, 6,576 new cases of gynaecological cancers will be diagnosed, and women have a 1 in 23 risk of being diagnosed with this disease by the age of 85 (AIHW, 2021a). Aboriginal and/or Torres Strait Islander women are nearly two times more likely than other Australian women to be diagnosed with gynaecological cancer (AIHW, 2021a).

#### Cervical cancer

In the Australian setting, national estimates of incidence for cervical cancer greatly vary depending on race and ethnicity (Whop et al., 2021). Australia has successfully reduced cervical cancer incidence since the introduction of the National HPV Vaccination

Program – now integrated into the School Based Immunisation Program and the National Cervical Screening Program (AIHW, 2019a). However, the successful reduction in the incidence of cervical cancer has not occurred for all populations of Australian women (Whop et al., 2021) and it has remained high for Aboriginal and/or Torres Strait Islander women. Over the five-year period between 2012-2016, there were 144 new cases of cervical cancer diagnosed for Aboriginal and/or Torres Strait Islander women aged between 25 to 74 years (AIHW, 2021b). The most recent national estimate of an age-standardised cervical cancer incidence rate for Aboriginal and/or Torres Strait Islander women was 20 per 100,000 women and ranged from 5.8 per 100,000 to 11 per 100,000 across remoteness areas (AIHW, 2021b). The disparity in Aboriginal and/or Torres Strait Islander women's participation in cervical screening is likely to contribute to the increased cervical cancer incidence and mortality rates (AIHW, 2018; Dasgupta et al., 2020; Whop et al., 2016; Wright et al., 2017). This is because cervical screening enables detection of high-risk HPV, thereby enabling timely treatment, which in turn prevents the development of cervical cancer (i.e., ultimately reducing the incidence and mortality from this malignant disease).

### **Uterine cancer**

Uterine cancer, specifically endometrial cancer, is Australia's most commonly diagnosed gynaecological cancer, with the number of cases growing yearly (AIHW, 2021a; Cancer Australia, 2022c). There are two main types of uterine cancer, endometrial cancer (the most common type, accounts for 95% of all cases) and uterine sarcomas. In 2009-2013, Aboriginal and/or Torres Strait Islander women were 1.8 times more likely to be diagnosed with uterine cancer (AIHW, 2018). It is important to note that obesity, nulliparity (not giving birth to a child), and diabetes are all increasing in incidence and are all independently associated with the risk of developing endometrial cancer (Allanson & Ayres, 2022).

### **Ovarian cancer**

In 2017, ovarian cancer was the ninth (1,615 new cases were diagnosed) most diagnosed cancer in Australia (AIHW, 2022c). In 2009-2013, 103 cases of ovarian cancer were diagnosed among Aboriginal and/or Torres Strait Islander women (an average of 21 cases per year) (AIHW, 2018). For all women, ovarian cancer is mainly a disease that is diagnosed in postmenopausal woman, with 60% of cases diagnosed in women aged over 60 years (AIHW, 2018). It is important to note that ovarian cancer data could be underestimated due to the lack of reliable national historical data (McCluggage et al., 2015). Consequently, the incidence time series is likely to be of very poor quality and was omitted from this report (AIHW, 2022c).

## **Mortality**

### **Key message**

Aboriginal and/or Torres Strait Islander women continue to experience inequitable gynaecological cancer outcomes and are two times more likely to die from this disease. If we are to close persistent gaps in gynaecological cancer care and outcomes for Aboriginal and/or Torres Strait Islander women, a coordinated focus across gynaecological cancers that is grounded in the lived experiences of Aboriginal and/or Torres Strait Islander women is urgently needed.

The Australian states and/or territories are mandated by legislation for the notification of all deaths, including the cause of death. In 2021, it was estimated that 2,139 (9.9%) women died from gynaecological cancer (AIHW, 2021a). The mortality rates for the major three types of gynaecological cancer are presented below.

### **Cervical cancer**

Australia is reported to have one of the lowest cervical cancer mortality rates in the world (Sung et al., 2021), however, this significant reduction has not been observed for Aboriginal and/or Torres Strait Islander women. Aboriginal and/or Torres Strait Islander women aged between 25 to 74 years are three times more likely to die from cervical cancer. Between 2015-2019, 61 (8.1 deaths per 100,000 women) Aboriginal and/or Torres Strait Islander women died from cervical cancer (AIHW, 2021b). It is important to note, that mortality rates for cervical cancer could be underestimated due to poor identification of Aboriginal and/or Torres Strait Islander people. The mortality data were only analysed for five jurisdictions in Australia (New South Wales, Queensland, Western Australia, South Australia, and the Northern Territory) (AIHW, 2021b).

### **Uterine cancer**

Uterine cancer was the 10<sup>th</sup> most common cause of cancer death among Australian women in 2018 (Cancer Australia, 2022). In 2018, the age-standardised mortality rate for uterine cancer for all populations was 2.1 deaths per 100,000 females (Cancer Australia, 2018). For the period 2011-2015, 36 Aboriginal and/or Torres Strait Islander women died from uterine cancer, approximately seven deaths per year (AIHW, 2018).

### **Ovarian cancer**

Ovarian cancer is the leading cause of death among gynaecological cancer types worldwide and in Australia. For the five-year period between 2011-2015, there were 40 Aboriginal and/or Torres Strait Islander women who died from ovarian cancer (an average of eight deaths per year) (AIHW, 2018). The age-standardised mortality rate was 6.2 deaths per 100,000 Aboriginal and/or Torres Strait Islander women. Ovarian cancer continues to have a high mortality rate because there is no screening test to detect early-stage cellular changes, and the disease is very aggressive. Ovarian cancer usually remains undetected until it has metastasised (spread) to other parts of the body.

## **Relative survival**

### **Survival**

Survival after a gynaecological diagnosis is associated with a range of factors, including characteristics of when a woman was diagnosed with the cancer (i.e., age, existing additional illnesses, and lifestyle), the tumour characteristics (i.e., stage and grade at time of diagnosis, and the histology type), and access to a health-care system (i.e., diagnostic and treatment facilities, individualised follow-up services). The relative survival estimates reported are based on the cancer outcomes for a group of women with diverse gynaecological cancer diagnoses and their own personal characteristics. They provide an indication of the average survival experience for each of the gynaecological cancer types. The relative survival estimates (the ratio of observed survival to expected survival) are reported for each of the gynaecological cancer types.

### **Cervical cancer**

In Australia, the cervical cancer relative survival significantly increased from 68% in 1982-1987 to 71% in 1988-1992, and was most recently reported to be 74% in 2013-2017 (AIHW, 2022c). However, semi-national and national analyses have consistently reported Aboriginal and/or Torres Strait Islander women's five-year relative survival to be significantly lower at 56% (AIHW, 2018; Condon et al., 2014; Diaz et al., 2018). The association of comorbidities and a lowered survival rate for Aboriginal and/or Torres Strait Islander women has been investigated, however, a comorbidity survival gradient was not clearly identified (Diaz et al., 2018). The major limitation of previously conducted studies, includes the lack of information about known predictors of survival, including stage of cancer at diagnosis and the cancer treatment performed. This lack of information limits the ability to truly investigate survival outcomes across different population groups (Condon et al., 2014; Diaz et al., 2018). Further investigations into cervical cancer care, diagnosis, treatment and support services that aim to improve Aboriginal and/or Torres Strait Islander women's survival is still greatly needed (Diaz et al., 2018).

### **Uterine cancer**

Between 1986-1990 and 2011-2015, the relative five-year survival for all Australian women with uterine cancer increased from 77% to 83% (AIHW, 2019). Between 2007-2014, the crude uterine cancer survival rate for Aboriginal and/or Torres Strait Islander women was 78% (AIHW, 2018). Despite the increasing number of uterine cancer cases, there is not a statistically significant increase or decrease in the uterine cancer mortality trend rate for Aboriginal and/or Torres Strait Islander women from 1998 to 2015 (AIHW, 2019).

### **Ovarian cancer**

There has been no substantial improvement in ovarian cancer survival rates for the last two decades and the chance of surviving at least five years after diagnosis is less than 50% (AIHW, 2022c). Between 2007-2014, Aboriginal and/or Torres Strait Islander women had a five-year relative survival rate of 45% (AIHW, 2018). The reasons that contribute to a low five-year survival rate for women diagnosed with ovarian cancer include a lack of effective tests available for population-based screening, non-specific nature of the symptoms of this cancer, and a high proportion of diagnoses occurring at an advanced stage.

### **Risk factors**

A risk factor is anything that is known to increase the likelihood of a person developing a health condition, including a gynaecological cancer. Risk factors may be modifiable (e.g., smoking) while others are non-modifiable (e.g., a person's age or family history). The presence of one (or more) of these risk factors, does not mean a gynaecological cancer has developed, or will develop. The primary causes of all gynaecological cancers are still not fully understood. However, researchers have identified several factors that may increase the risk of developing one (or more) gynaecological cancers. These include family history, gene mutations, reproductive history, viral infection, and socio-environmental factors such as smoking and/or obesity (Avgerinos et al., 2019; Crosbie et al., 2010; Faber et al., 2013; Momenimovahed et al., 2019; Plummer et al., 2003; Raglan et al., 2019). The specific risk factors (i.e., legacy of colonisation, discriminatory policies, smoking, limited knowledge of food systems and colonial history) are discussed separately for cervical cancer, uterine cancer and ovarian cancer.

### **The legacy of colonisation as a substantive health risk for gynaecological cancer**

The ongoing process of colonisation has been identified as a core social determinant of Indigenous health (Allan & Smylie, 2015). The health disparities experienced by Aboriginal and/or Torres Strait Islander people, as well as other Indigenous Peoples worldwide, are rooted in colonial histories and systems (Griffiths et al., 2016). Colonisation and racism have made it difficult to assess the status of gynaecological cancer for Aboriginal and/or Torres Strait Islander women, manifesting in exposure to risk factors and challenges in accessing culturally safe non-discriminatory care.

### **Discriminatory policies and/or experiences**

As a result of colonial and racist policies and experiences, Indigenous Peoples have reported not feeling comfortable self-identifying as Indigenous in the health care system for fear of discriminatory treatment (Allan & Smylie, 2015). The identification of Aboriginal and/or Torres Strait Islander people in datasets requires an understanding and consideration of historical and contemporary contexts (Griffiths et al., 2016). As Griffiths et al. (2016, p. 91) argue 'this includes how Aboriginal and/or Torres Strait Islander people have been defined and by whom, as well as how identification is operationalised in official data collections'. A formal assessment of data quality in the Northern Territory conducted between 1991 and 2001, found that the Aboriginal and/or Torres Strait Islander people's cancer incidence was underestimated by 15-20% (Wakewich et al., 2016). To effectively respond to the disparities in Aboriginal and/or Torres Strait Islander people's cancer care in Australia, comprehensive data on incidence and mortality is warranted.

### **Smoking**

Aboriginal and/or Torres Strait Islander people are also more likely to be exposed to risk factors related to cancer such as smoking as a direct result of colonialism (Salmon et



al., 2018). Currently, adult daily smoking prevalence is 40% among Aboriginal and/or Torres Strait Islander people, which is 2.8 times the prevalence of the general population across Australia (Thomas et al., 2019; Thurber et al., 2021). The disproportionately high smoking prevalence among Aboriginal and/or Torres Strait Islander people is directly attributed to commercial tobacco originally introduced by colonisers in exchange for labour, or as government or employer rations (Colonna et al., 2020).

#### **Food systems and ecological knowledge**

With 19% of Aboriginal and/or Torres Strait Islander people living in very remote and/or remote communities, there is limited access to affordable fresh and healthy foods (Markham & Kerins, 2020). Additionally, the intentional severing of intergenerational transmission of knowledge on traditional food security and preparation as well as the displacement of Aboriginal and/or Torres Strait Islander people, make it difficult to access healthy foods today (Markham & Kerins, 2020). Poor nutrition, high body mass and obesity are significant risk factors for cancer (AIHW, 2021a). Between 2018-19 around 71% of Aboriginal and/or Torres Strait Islander people aged 15 and over had a BMI in the overweight (29%) and obese (43%) range and around 25% had a BMI in the normal weight range (Australian Institute of Health and Welfare & National Indigenous Australians Agency, 2023). Accordingly, Aboriginal and/or Torres Strait Islander people aged 15 and over were 1.5 times more likely to be obese than other Australians. Increasing food sovereignty, particularly in remote communities, to re-strengthen Indigenous food systems and ecological knowledge is another important part of the decolonisation process (Markham & Kerins, 2020).

#### **Colonial history and parallels shared experiences in other countries**

The colonial history of Aboriginal and/or Torres Strait Islander people has significant parallels with the experience of Indigenous Peoples in Canada; therefore, we can learn from their shared experiences (Lavallee & Poole, 2009). Women and health care professionals in an Indigenous community in Ontario, Canada, raised several specific impacts that colonialism had on their experience with cervical cancer (Wakewich et al., 2016). Societally, colonialism has resulted in a disruption of gender roles, reducing women's status in what was once a matrilineal society (Wakewich et al., 2016). Structurally, because of past and present colonialism and racism, distrust of health authorities and institutions serve as barriers to Indigenous people accessing health care services, such as cervical cancer screening (Wakewich et al., 2016). Finally, at the individual level, the experience of residential/boarding schools has impacted women's experience of their body and their sexuality as well as interrupted the intergenerational knowledge sharing about sexual health (Wakewich et al., 2016). Women have shared how this impacted their own mothers' ability to talk openly about sexual health impacts and how this influenced the next generation's knowledge of gynaecological health, including cervical cancer (Wakewich et al., 2016).

### **The most common gynaecological cancer specific risk factors**

#### **Cervical cancer**

The main risk factor for cervical cancer is a chronic infection with the human papillomavirus (HPV), specifically high-risk HPV types 16 and/or 18 (Cohen et al., 2019; Walboomers et al., 1999). The virus is spread by skin-to-skin or skin-to-mucosal contact during sexual activity, including the vagina and cervix (Crosbie et al., 2013). Exposure to HPV is extremely common and it is estimated that up to 80% of sexually active people will be infected with HPV in their genital tract before the age of 50 (Manhart et al., 2006; Workowski et al., 2021). Many women will not be aware of infection with HPV and will clear the infection prior to development of cervical dysplasia (pre-cancerous lesions). While genital tract infection with HPV is extremely common, the development of cervical dysplasia is less common and the progression to cervical cancer only occurs in a small proportion of women over a long-time frame (up to 10 years) (Crosbie et al., 2013). Although high-risk HPV types (16 and/or 18) is the primary risk factor for cervical cancer, in 2020, the World Health Organisation (WHO) updated the *Female genital tumors classification*, and it is now recognised that a proportion (~5%) of cervical cancers are not associated with HPV infection (Fernandes et al., 2022; McCluggage et al., 2022; WHO Classification of Tumours

Editorial Board, 2020). The specific risk factors for HPV-associated and non-HPV-associated cervical cancers are presented below.

**HPV-dependent cervical cancers:**

- early onset of sexual activity (International Collaboration of Epidemiological Studies of Cervical Cancer [ICESCC], 2007)
- multiple sexual partners (ICESCC, 2007)
- history of vulvar and/or vaginal squamous intraepithelial lesion (Buchanan et al., 2019)
- immunosuppression (e.g., HIV infection) (Mapanga et al., 2018)
- history of sexually transmitted infections (Abebe et al., 2021; King et al., 2011; Mapanga et al., 2018; Smith et al., 2002).

**Non-HPV associated cervical cancers:**

- low socioeconomic status, specifically patients in the USA who live in communities of higher poverty (Yoo et al., 2017; Yu et al., 2019)
- oral contraceptive use (i.e., ≥5 years of use) (Appleby et al., 2007; Gierisch et al., 2013; Green et al., 2003)
- tobacco smoking (ICESCC, Appleby et al., 2007; 2007).

**Uterine cancer**

Uterine cancer is associated with both modifiable and non-modifiable risk factors. Factors such as increasing age (aged 60 or above), obesity, physical inactivity and dietary factors were found to be the most common risk factors associated with endometrial cancer among Aboriginal and/or Torres Strait Islander women. A summary of risk factors is presented in Table 1 (AIHW, 2019b; AIHW & Cancer Australia, 2013).

**Table 1. An overview of potentially modifiable and non-modifiable risk factors associated with uterine cancer.**

Non-modifiable or environmental risks factors	Potentially modifiable risk factors
<ul style="list-style-type: none"> <li>• increasing age (women aged 60 or above)</li> <li>• family history of endometrial, ovarian or bowel cancer</li> <li>• having polycystic ovary syndrome</li> <li>• never having children or being infertile</li> <li>• genetic changes (overexpression of pro-tumorigenic KRAS oncogene and mismatch-repair in DNA)</li> <li>• polyps (postmenopausal women and women with abnormal uterine bleeding).</li> </ul>	<ul style="list-style-type: none"> <li>• being overweight or obese</li> <li>• having high blood pressure (hypertension) and/or diabetes</li> <li>• sedentary behaviour</li> <li>• taking tamoxifen to treat breast cancer</li> <li>• smoking and alcohol consumption</li> <li>• taking oestrogen hormone replacement therapy without progesterone (menopausal hormone therapy).</li> </ul>

**Ovarian cancer**

Little is known regarding the early aspects of ovarian cancer. Consequently, the identification of women who are at a higher risk for the disease is based primarily on clinical grounds, with family history being the most important risk factor (Mok et al., 2007). A summary of the known risk factors that are associated with developing ovarian cancer overall are provided below (Hunn & Rodriguez, 2012; Permuth-Wey & Sellers, 2009; Riman et al., 2004).

**Older age:**

All women are at risk of developing ovarian cancer regardless of age, however, ovarian cancer rates are highest among women aged over 50 years (AIHW, 2021a).

#### **Inherited gene changes:**

- A small percentage of ovarian cancers are caused by inherited genes. For example, two genes called BReast CAncer 1 and BReast CAncer 2 (known as BRCA1 and BRCA2, respectively) are present for 10-20% of ovary, fallopian tube, and primary peritoneal cancers (Rosenthal et al., 2013). When certain changes occur in BRCA1 and BRCA2, called pathogenic or mutations, ovarian cancer can develop.

#### **Personal history of endometriosis:**

- Endometriosis is a disorder in which tissue that normally lines the inside of the uterus - the endometrium - grows outside of the uterus.
- Endometriosis most commonly involves the ovaries, fallopian tubes and the tissue lining the pelvis.
- Endometriosis appears to be associated with an increased risk of two ovarian cancer histological subtypes (endometrioid and clear-cell carcinomas) (Merritt et al., 2013; Merritt et al., 2008).

#### **Personal history of cancer:**

- Women who have had cancer of the breast, uterus or colon have a higher risk of ovarian cancer (Metcalf et al., 2005; Shin et al., 2018; Stewart et al., 2018).

#### **Family history of breast or ovarian cancer:**

- A family history of breast or ovarian cancer, usually in the mother or sister, is associated with an increased risk for ovarian cancer (Chiaffarino et al., 2007; Kurian et al., 2005; Modugno et al., 2001).

#### **Hormone replacement therapy:**

- Menopausal hormone therapy may increase the risk of ovarian cancer, especially for serous and endometrioid tumours (Liu et al., 2019; Urban et al., 2015).

#### **Obesity:**

- Several studies have identified obesity as a possible risk factor for the development of postmenopausal ovarian cancer (Leitzmann et al., 2009; Olsen et al., 2013).

### **Burden of disease**

Gynaecological cancer imposes a significant burden of disease on Aboriginal and/or Torres Strait Islander women. In 2018, the number of healthy life years lost due to gynaecological cancers (known as disability-adjusted life years or 'DALYs') were estimated to be (AIHW, 2022a; 2022b):

- Cervical cancer: 526 DALY, equivalent to 1.0 per 1,000 population (decreased by 14% since 2011).
- Endometrial cancer: 289 DALY, equivalent to 0.6 per 1,000 population (increased by 18% since 2011).
- Ovarian cancer: 332 DALY, equivalent to 0.6 per 1,000 population (decreased by 38% since 2011).

### **Prevention and early detection**

All women are at risk of gynaecological cancer and historically, gynaecological cancer had a reputation of being 'undetectable' and 'silent'. They were known as the cancer types that were not preventable and were only diagnosed at advanced stages. The advancements in screening, modern testing, and genetic discovery have now led to an increased opportunity for the earlier detection of many types of gynaecological cancer. The recommendations below provide a summation of interventions that may assist in the prevention and/or detection of gynaecological cancer at an earlier stage.

**Vaccination against HPV infection (Australian Government Department of Health and Aged Care [AGDHAC], 2019):**

- Cervical, vaginal and vulva cancers may commonly be caused by infection with HPV. The HPV vaccine protects against the types of HPV that most often cause these types of cancers.
- The most effective time for HPV vaccination is before a person becomes sexually active.
- Anyone over nine years of age can talk to their doctor about getting immunised.
- In Australia, the HPV vaccination is provided free by the National Immunisation Program (NIP) to school children aged 12 to 13 years, or for people aged over nine years who have a weakened immune system.
- HPV protection is provided by administering a course of injections. It is important to complete the full course of HPV injections.

**Participation in cervical screening (AGDHAC, 2022):**

- Cervical screening is very effective at finding cervical disease early, this is important because:
  - Pre-cancerous lesions and early cervical cancer is frequently asymptomatic (has no symptoms) and is the reason it is so important for women to routinely participate in cervical screening.
  - Women should have a cervical screening test, even if they had the HPV vaccine.
  - Routine screening can help detect a high-risk HPV infection and cervical changes, that if left untreated may progress to cervical cancer.
  - The cervical screening test should be done every five years, from the age of 25 to 74 years.
  - All women can now request to perform their own cervical screening test (self-collection).

**Genetic testing:**

- By sharing a family's health history, specifically breast and ovarian cancer, a doctor may recommend seeking genetic counselling and testing.
- Genetic risk assessment testing may be considered for women who are identified to be at risk of BRCA or Lynch Syndrome (an inherited condition due to mismatch repair genes that can lead to cancer) by their personal (or family) history of ovarian, breast, endometrial cancer or in association with other cancers.
- Early identification of women who carry a gene mutation may allow prevention of BRCA1 and/or 2 or Lynch-Syndrome-associated malignancies (Ryan et al., 2021).

## **Clinical investigations**

### **Investigating signs/symptoms**

If a woman presents to her doctor with gynaecological symptoms, they may arrange for further testing to be performed (Cancer Australia, 2021, 2022a, 2022b). A summary of the main types of investigations is provided below:

**Physical examination:**

- feeling the abdomen and checking for swelling
- internal vaginal examination, including looking (colposcopic assessment) at the cervix.

**Blood tests:**

- can be performed to check a woman's overall health.

### **Internal scoping tests:**

Using a device like a telescope so the doctor can have a closer look at the affected area(s). A biopsy may also be performed (i.e., a small piece of tissue is taken and sent to pathology for assessment). Examples can include:

- colposcopic assessment - to view the cervix, vulva and/or vagina
- hysteroscopic assessment - to look inside the womb (uterus)
- laparoscopic assessment - to look inside the stomach.

### **Imaging tests:**

Imaging tests take pictures of the area of the body that is affected by symptoms and/or to check other areas for signs of cancer. Examples of imaging can include X-rays, computerised tomography (CT) scans, magnetic resonance imaging (MRI), or positron emission tomography (PET).

### **Overview of treatments**

The treatment recommendations that will be offered for gynaecological cancer are dependent on a variety of factors including the type of gynaecological cancer, the stage (including how far it has spread), the woman's general health, and treatment preference. Women with gynaecologic cancer can often receive a combination of treatments, including:

- surgery - removal of the cancer tissue during an operation
- chemotherapy - using a special medicine to target and shrink/kill the cancer (the medicine can be administered with pills or through a drip into the veins)
- hormonal therapies - intrauterine or oral hormones may be used as primary treatment or in conjunction with other treatments (e.g., surgery) in some gynaecological malignancies
- radiation - using high-energy rays to kill the cancer
- complementary and alternative medicine - medicines or health practices that are not standard treatment and should occur alongside conventional treatment (women must talk to a doctor about the benefits/risks before starting any type of alternative medicine).

### **The experience of gynaecological cancer**

This report has identified significant differences in the incidence, survival and burden of gynaecological cancer for Aboriginal and/or Torres Strait Islander women. The pathway for patients undergoing diagnosis and treatment across the cancer continuum is complex. It will usually involve multiple healthcare providers across a range of settings, both public and private. Although clinical aspects of cancer treatment are the same for all people, the health services still have a responsibility and need to provide care that is culturally safe and inclusive. Despite long standing policy priorities (Cancer Australia, 2015, 2016), the disparities in gynaecological cancer outcomes continue to persist for Aboriginal and/or Torres Strait Islander women (AIHW, 2022a, 2022b, 2022c; Cancer Australia, 2022c). The factors that underpin and drive these inequitable outcomes are complex and cumulatively inhibit Aboriginal and/or Torres Strait Islander people in their readiness and ability to engage with cancer care services (Butler et al., 2019; Jaenke et al., 2021; Marcusson-Rababi et al., 2019; Reath & Carey, 2008).

It is important to understand Aboriginal and/or Torres Strait Islander women's experiences of cancer care and factors that may impact on accessibility (Marcusson-Rababi et al., 2019). In 2019, the first (and currently only study) investigated study of gynaecological care was meeting the needs of Aboriginal and/or Torres Strait Islander women who had attended a major metropolitan hospital in Queensland. Although it was a small cohort of participants, the study identified a combination of factors that were negatively impacting on the gynaecological cancer experience. Aboriginal and/or Torres Strait Islander women were left feeling at 'breaking point' and had very limited access to information and/or support (Marcusson-Rababi et al., 2019). The challenges experienced

included delayed referrals, overall lack of information, logistical difficulties accessing and complying with treatment recommendations, and cultural insensitivities within the healthcare system (Marcusson-Rababi et al., 2019). Future studies are needed to investigate and gain further understanding of how cancer care health services can better meet the needs of Aboriginal and/or Torres Strait Islander women.

### **Australian Government programs and services**

There are a range of mainstream Australian Government Department of Health and Aged Care programs and services that contribute to the prevention, diagnosis, and management of gynaecological cancers among Aboriginal and/or Torres Strait Islander women. A summary of these include:

1. The Medicare Benefits Schedule (MBS):
  - A Medicare health assessment for adult Aboriginal and/or Torres Strait Islander people must be performed by a medical practitioner and is an overall check of a person's health, including cervical screening.
  - Medicare funds genetic testing for gene mutations for women with ovarian cancer who have a high probability of having a faulty gene. This can allow for follow-up care including taking specific measures such as increasing the frequency of screening or early intervention measures to reduce risk.
2. The National Cervical Screening Program (NCSP)
  - aims to prevent cervical cancer through regular testing and early detection of human papillomavirus (HPV)
  - Since 1 July 2022, the NCSP allows for eligible screeners to collect their own cervical screening test sample, an approach which is acceptable to Aboriginal and/or Torres Strait Islander women.
3. The National Cancer Screening Register:
  - supports the NCSP by providing a single electronic record for each person in Australia.
4. The Practice Incentives Program (PIP):
  - aims to encourage GPs to screen under-screened women for cervical cancer, and to increase overall screening rates.
5. The Pharmaceutical Benefits Scheme (PBS):
  - provides subsidies for medicines used in the treatment of gynaecological cancers.
6. The National Immunisation Program (NIP):
  - provides free HPV vaccination for school aged children 12 to 13 years
  - It also covers free catch-up vaccinations if they were missed during childhood for people aged less than 20 years old. Immunisation against HPV is highly effective at protecting against up to nine types of HPV, including those that cause cervical cancers.
7. The Indigenous Australian's Health Programme (IAHP)
  - provides funding for Primary Health Networks and Aboriginal Community Controlled Health Organisations (ACCHOs) for Indigenous led, culturally appropriate initiatives to increase access to health care for Aboriginal and/or Torres Strait Islander people.
8. The provision of funding and development of the *Australian cancer plan 2023-2033*.

### **Role of primary health care services**

Primary health care services play a key role in the early diagnosis of gynaecological cancers, improving patient outcomes and survival. For primary healthcare services to be successful, it is essential that Aboriginal and/or Torres Strait Islander people are involved

in the delivery of cancer care and there is a provision of culturally appropriate support for patients throughout their cancer journey. For example, the ACCHOs play a vital role in the delivery of primary healthcare to Aboriginal and/or Torres Strait Islander people. There are ACCHOs located across all jurisdictions, funded by federal and state or territory governments. ACCHOs are primary healthcare services governed and operated by the local community, providing holistic, comprehensive, and culturally appropriate healthcare to the communities in which they serve. A holistic approach to healthcare encompasses physical, social, emotional and cultural wellbeing of Aboriginal and/or Torres Strait Islander peoples. ACCHOs provide a range of services, including but not limited to, cervical screening, women's wellness checks, dental, drug and alcohol, specialist care, and mental and public health.

## **Policies and strategies**

There are a number of initiatives, frameworks, plans, and strategies that focus on addressing cancer disparities experienced by Aboriginal and/or Torres Strait Islander people (Garvey & Cunningham, 2018). However, there are few national policies and strategies that focus specifically on gynaecological cancer for Aboriginal and/or Torres Strait Islander people. This lack of attention has been identified as a key barrier to decreasing the cancer burden among Aboriginal and/or Torres Strait Islander people (Garvey & Cunningham, 2018). Below summarises the most relevant national and international policies and strategies aimed at preventing, managing, and reducing gynaecological cancers and cancer in general among Aboriginal and/or Torres Strait Islander women.

### **Policies and strategies developed for Aboriginal and/or Torres Strait Islander women with gynaecological cancer**

- The *National framework for gynaecological cancer control* (Cancer Australia, 2016) was developed in 2012 to address future directions of gynaecological cancer control to reduce the burden of gynaecological cancers among women in Australia:
  - One priority area focused on improving the outcomes for Aboriginal and/or Torres Strait Islander women.
  - Strategies aimed to improve the participation of Aboriginal and/or Torres Strait Islander women in the NCSP, national data collection (including the inclusion of Indigenous status in pathology requests and reports), cultural appropriateness of cancer related services, and undertaking further research to understand Aboriginal and/or Torres Strait Islander people's views and beliefs about gynaecological cancers.
  - Despite this framework being developed over a decade ago, there is currently no evidence of an implementation or evaluation plan being undertaken or completed.
- The *National gynaecological cancers service delivery and resource framework* was developed in 2011 to provide and inform health professionals and service providers of the best practice requirements of services to support women with a gynaecological cancer:
  - Part 1 of the framework covers service delivery elements and models.
  - Part 2 focuses on developing a skilled and supported workforce, including for Aboriginal and Torres Strait Islander Health Workers.
- The *Optimal care pathways (OCPs)* were developed in 2014-15 to provide a standard of care and best practice framework(s) for the delivery of consistent, safe, high-quality, and evidence-based care for people with cancer:
  - The OCPs address key considerations around prevention, early detection, and recovery, living with chronic diseases and palliative care.

- Currently, there is no specific OCP that covers gynaecological cancer as a group, but there is tumour specific OCPs for cervical cancer, endometrial cancer and ovarian cancer.
- In addition to the tumour specific OCPs, there is also the *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer* which aims to provide Aboriginal and/or Torres Strait Islander people access to healthcare that is culturally safe:
  - This specific OCP provides recommendations (i.e., cross cultural communication and holistic approach to health) for consideration and adoption by healthcare services and healthcare providers to ensure they are responsive to the needs of Aboriginal and/or Torres Strait Islander people's needs.
  - To date, no evaluation has been conducted to investigate if the recommendations have been adopted and adhered to.
- In 2018, *A handbook for Aboriginal and Torres Strait Islander health workers and health practitioners* (Cancer Australia, 2018) was developed:
  - It aimed to assist health professionals in their provision of information and support to Aboriginal and/or Torres Strait Islander women about gynaecological cancers.
  - The handbook recommends that Aboriginal and Torres Strait Islander Health Workers should promote healthy lifestyles with a focus on risk reduction, raise awareness around symptoms and early detection, explain tests and medical information, ensure culturally appropriate care, and to support women, families, and communities during and following treatment.
- The *Ovarian cancer national action plan* for 2015-2020 and 2020-2025 (Ovarian Cancer Australia et al., 2020) aims to reduce the incidence, increase the survival rate, and improve follow-up care and quality of life for women and people with a cervix diagnosed with ovarian cancer:
  - The current plan does not present specific targets for Aboriginal and/or Torres Strait Islander women, however, does mention the need for improving equity around access to information about ovarian cancer including using consistent messaging about screening, risk factors, participating in clinical trials, advances in treatment, and how/where to access optimal care.
  - The plan also highlights the need for prevention research about genetic and modifiable risk factors, patterns of disease, and experiences that are common among Aboriginal and/or Torres Strait Islander women. It also emphasises a need for resources that are culturally and linguistically appropriate for Aboriginal and/or Torres Strait Islander women but does not offer any specific strategies or measures to achieve this.
- In 2018, the WHO made a global call for action to eliminate cervical cancer and the *Global Strategy to Accelerate the Elimination of Cervical Cancer as a Public Health Problem* initiative was adopted by the World Health Assembly in 2020:
  - It is recommended that an incidence rate of below 4 per 100 000 women in all countries is required to eliminate cervical cancer.
  - The strategy sets out three clear targets that each country should meet to achieve this:
    - 90% of girls should be fully vaccinated with the human papilloma virus (HPV) vaccine
    - by 15 years of age; 70% of women should be screened at 35 years of age and again by 45 years of age
    - 90% of women with pre-cancer should be treated and 90% of women with invasive cancer managed.



- As of November 2021, the Australian Centre for the Prevention of Cervical Cancer (APCC) has been developing a National Cervical Cancer Elimination Strategy:
  - The project will inform future activities undertaken by the Australian Government Department of Health and Aged Care to eliminate cervical cancer in Australia by 2035.
  - The strategy is a collaborative effort and includes input from a diverse range of health sector stakeholders, representatives of priority communities, and other interested groups to inform the development of the strategy.
  - Australia is currently on track to reaching this elimination target and globally, is leading the way to reaching the WHO elimination targets by 2030.
- Currently, there are no specific strategies that could be located that provide a comprehensive framework and aim to address the increasing burden of uterine cancer for Aboriginal and/or Torres Strait Islander women.

**The Australian strategies/initiatives that are relevant to gynaecological cancer, include:**

1. The National HPV Vaccine Program:

- In the Australian setting, protection against HPV is available to anyone through this program and can be accessed through a vaccination provider.
- The HPV vaccine is free under the National Immunisation Program, offered via the school-based programs.
- It is recommended that adolescents aged 9 to 18 years (which includes Aboriginal and/or Torres Strait Islander adolescents) have the HPV vaccine administered.
- The World Health Organization Strategic Advisory Group of Immunization (SAGE) reviewed new evidence in April 2022, on the efficacy of a single dose HPV vaccine schedule (World Health Organization [WHO], 2022). SAGE have advised that countries now have the option to offer a one or two-dose schedule for people aged 9-14 years and a two-dose schedule for people aged 21 years and above (WHO, 2022). The schedule remains unchanged in Australia but the WHO will hold a stakeholder consultation on these potential policy changes.
- The HPV vaccination coverage rates among Aboriginal and/or Torres Strait Islander adolescents have recently become available (Patel et al., 2022). Compared to other Australian adolescents, by age 15 (80% of females and 77% of males), Aboriginal and/or Torres Strait Islander adolescents have lower full course completion rates (females 72%, males 65%) and equal completion rates for dose one coverage (84% Aboriginal and/or Torres Strait Islander, 85% non-Indigenous) (Patel et al., 2022). New South Wales, Northern Territory, and Victoria are the only regions with over 90% dose one coverage among Aboriginal and/or Torres Strait Islander females (Patel et al., 2022).

2. The National Cervical Screening Program (NCSP):

- The NCSP was introduced by the Australian Government in 1991 and is focused on reducing morbidity and mortality from cervical cancer (AGDHAC, 2022). The NCSP policy recommends:
  - Women aged 25 to 74 years of age are invited to have a cervical screening test every five years through their healthcare provider.
  - Women are now able to perform a self-collected cervical screening test (CST).
  - The option for women to perform a CST is a critical step in addressing common barriers experienced by many women by providing an alternative screening process for under screened populations. This is particularly pertinent for Aboriginal and/or Torres Strait Islander women or from

culturally and linguistically diverse backgrounds who are largely under-screened (Whop et al., 2021).

- There is a lack of reliable and available national cancer data reporting Aboriginal and/or Torres Strait Islander people (Zhang et al., 2011), including their participation in cervical screening (Whop et al., 2021):
  - Localised studies have indicated that Aboriginal and/or Torres Strait Islander women's participation in screening is significantly lower in comparison to other Australian women (Whop et al., 2016).
- The Cancer Council Australia recommends five key cervical screening strategies to increase cervical screening participation for Aboriginal and/or Torres Strait Islander women (Cancer Council Australia, 2018). They include:
  - Aboriginal and/or Torres Strait Islander women should be encouraged to participate in the NCSP and invited to a five-yearly HPV test.
  - Invitations should be culturally appropriate and tailored to women's specific needs to maximise delivery of services.
  - Cervical screening services including diagnostic and treatment services should be accessible and culturally safe.
  - Self-collected vaginal samples or clinician-collected samples should be offered as a choice for all Aboriginal and/or Torres Strait Islander women.
  - Aboriginal and/or Torres Strait Islander status should be confirmed by healthcare professionals and recorded on clinical records to improve and maintain accurate data of screening participation among Aboriginal and/or Torres Strait Islander women, particularly for inclusion in the National Cervical Cancer Registry. In some cases, Aboriginal and/or Torres Strait Islander status may influence clinical management of tests.

### **Key message**

The development of a specific strategy to address the burden of gynaecological cancer for Aboriginal and/or Torres Strait Islander women that is resourced and has a specific focus on implementation, monitoring and evaluation is critical to addressing inequitable disparities.

### **Future directions**

National strategies and policies have clearly highlighted the need to improve awareness of cancer prevention and early detection through the provision of culturally safe and high-quality care. Despite this, little progress has been made and the disparities in gynaecological cancer outcomes persist. Aboriginal and/or Torres Strait Islander led research across the cancer care continuum is urgently needed to fill these knowledge gaps and identify solutions from which to assist in addressing gynaecological cancer disparities for Aboriginal and/or Torres Strait Islander women. Alongside rigorous research is the urgent need to focus on implementation, monitoring and evaluation of strategies and plans to hold the entire health system accountable to providing culturally safe care, free of racism and that is patient centred. With the *Australian cancer plan*, *National Aboriginal and Torres Strait Islander cancer plan* and the National Strategy to Eliminate Cervical Cancer under development it is critical that they are accompanied and resourced to be implemented, monitored, and evaluated. This will work towards ensuring tangible outcomes in the prevention, diagnosis, treatment and care of Aboriginal and/or Torres Strait Islander women for gynaecological cancer.

## **Concluding comments**

Aboriginal and/or Torres Strait Islander women are disproportionately burdened by gynaecological cancers, impacted by increased exposure to risk factors as a direct result of colonisation. The prevention and early diagnosis of gynaecological cancers is important to decrease the incidence of and survival from gynaecological cancers. Providing effective cancer prevention by risk reduction and participation in cancer screening programs for Aboriginal and/or Torres Strait Islander people requires improved access to both high quality primary health care services and tertiary specialist services. This will also enable earlier diagnosis, management, and care for Aboriginal and/or Torres Strait Islander women at all stages of the cancer continuum. Culturally safe, accessible and patient centred care are key components to decreasing the burden of gynaecological cancers on Aboriginal and/or Torres Strait Islander women and their communities. Without equitable resourcing to implement effective prevention, management and care of gynaecological cancers, Aboriginal and/or Torres Strait Islander women will continue to suffer.

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