



Australian Government  
Cancer Australia

# National Framework for Gynaecological Cancer Control



*National Framework for Gynaecological Cancer Control* was prepared and produced by:

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# Preface

As the Government's lead national agency in cancer, Cancer Australia works to reduce the impact of cancer and improve the wellbeing of people affected by cancer.

As a group, gynaecological cancers represent the third most common cancers diagnosed in women in Australia. However they represent a heterogeneous range of cancers with respect to incidence, risk factors, treatments and outcomes. For women affected, there are some common issues related to the impact of treatments on fertility, sexuality and supportive care needs.

*The National Framework for Gynaecological Cancer Control* (the 'National Framework') guides future directions in national gynaecological cancer control to improve outcomes for women affected by gynaecological cancers, their families and carers. The National Framework identifies priority areas for action across the cancer control continuum and provides strategies to guide innovative and sustainable delivery of care, improve outcomes in priority population groups and inform future research initiatives.

The development of the National Framework was guided and supported by an expert gynaecological cancer advisory group and informed by national consultations with key stakeholders and a review of literature and epidemiological data. The National Framework incorporates evidence-based strategies and allows flexibility for jurisdictions and organisations to address each priority within their specific service environment.

We hope that the uptake of the National Framework will guide efforts of health professionals, governments, consumer bodies and researchers to improve outcomes in gynaecological cancer and ensure the provision of best practice, culturally-appropriate care to women across Australia.



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CEO Cancer Australia



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Chair, Cancer Australia's Gynaecological Cancer  
Advisory Group  
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## Statement of acknowledgement

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We acknowledge the traditional owners of country throughout Australia, and their continuing connection to land, sea and community. We pay our respects to them and their cultures, and to elders both past and present.

Cancer Australia acknowledges that there is no single Australian Aboriginal and Torres Strait Islander culture or group and that there are many diverse communities, language groups and kinships throughout Australia. However, when presenting data we will be respectfully using the term Indigenous Australians.

# 1 Introduction

## Purpose

Cancer Australia has developed a National Framework for Gynaecological Cancer Control (the National Framework) to guide future directions in national gynaecological cancer control over the next five years to improve outcomes for women in Australia with gynaecological cancers.

The National Framework addresses the continuum of gynaecological cancer control, including prevention, screening, diagnosis, treatment, follow-up, supportive care and palliative care, as well as research.

The following were considered when developing the National Framework:

- ▶ models of care that are most likely to be effective, sustainable and improve quality of life for women with gynaecological cancer
- ▶ integration of primary and multidisciplinary care across the cancer control continuum for women with gynaecological cancer
- ▶ populations with unwarranted variations in outcomes
- ▶ research directions in gynaecological cancers.

## Background

Gynaecological cancers refer to any cancer that begins in the female reproductive system. Gynaecological cancers are a heterogeneous group of cancers. The main types of gynaecological cancers are cancers of the ovary, uterus, cervix, vagina and vulva. These cancers vary by their aetiology, presentation, availability of effective screening methods, treatments and physical and psychosocial impacts. Therefore, addressing gynaecological cancer control requires a multifaceted approach.

- ▶ In Australia, gynaecological cancer is estimated to be the third most commonly diagnosed cancer among women in 2015.<sup>1</sup>
- ▶ In 2015, an estimated 5,530 women were expected to be diagnosed with a gynaecological cancer in Australia, accounting for 9.7% of all reported cancer cases in women.<sup>1</sup>
- ▶ Between 2015 and 2020, the number of new cases diagnosed for the three major types of gynaecological cancers – uterine (including endometrial), ovarian and cervical cancer – are expected to increase from 4,915 new cases in 2015 to 5,385 new cases in 2020.<sup>2,3</sup>
- ▶ Between the periods 1982-1986 and 2007-2011, five-year relative survival from gynaecological cancers significantly improved (59% to 68%, respectively) and has thus led to an increase in the number of survivors over this period.<sup>1</sup>

The National Framework is designed to complement and enhance national and jurisdictional efforts to improve gynaecological cancer outcomes, including cancer plans and related policies, frameworks and action plans. It sets out priority areas for action, and allows flexibility for jurisdictions and organisations to address these priorities in ways that suit their local context and workforce capacity.

## Development of this Framework

Cancer Australia established an expert gynaecological cancer advisory group, comprising gynaecological, medical and radiation oncologists, other health practitioners, consumers and health care administrators to oversee development of the National Framework. Membership details are at Appendix A.

Consultations were held with individuals involved in the provision of gynaecological cancer care, state and territory governments, consumer organisations, professional colleges, and peak clinical and cancer bodies.

Analyses of epidemiological data, a literature review, and findings from the consultations informed development of the National Framework. The expert gynaecological cancer advisory group subsequently reviewed the findings from reviews and consultations to identify priority areas for strategies and action for the next five years.

Full details of the project methodology are at Appendix B.

## 2 Setting the scene

### Gynaecological cancers in Australia

#### Incidence

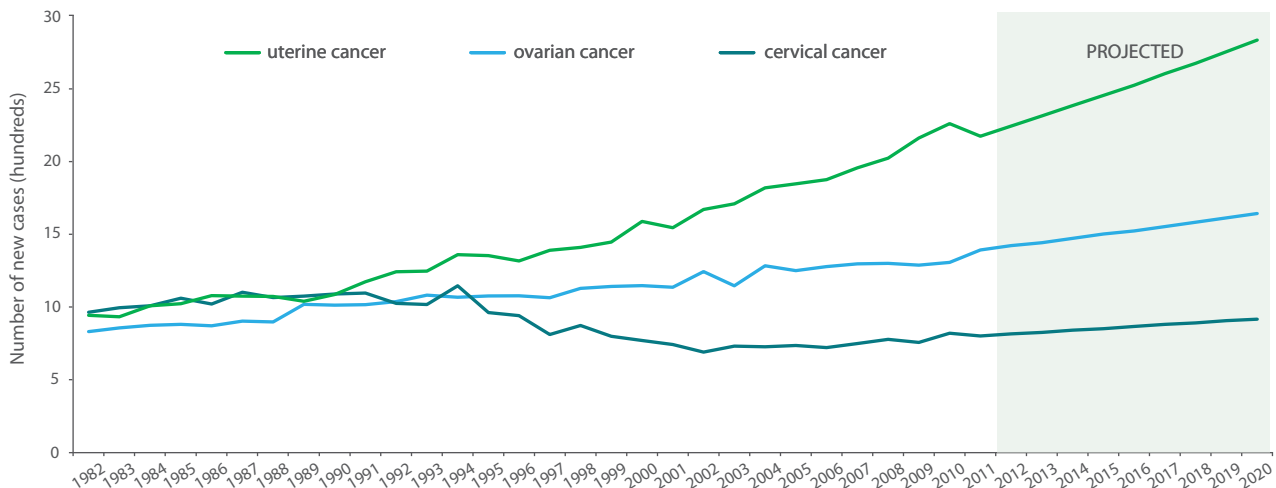
In 2015, an estimated 5,530 women were expected to be diagnosed with a gynaecological cancer<sup>a</sup> in Australia, accounting for 9.7% of all cancer cases in women.<sup>1</sup> The estimated number of new cases diagnosed in 2015 for the three major types of gynaecological cancers is:

- ▶ 2,570 cases of uterine cancer<sup>b</sup> (46.5% of gynaecological cancers diagnosed)<sup>1,2</sup>
- ▶ 1,460 cases of ovarian cancer (26.4% of gynaecological cancers diagnosed)<sup>1,2</sup>
- ▶ 885 cases of cervical cancer (16% of gynaecological cancers diagnosed).<sup>1,2</sup>

Between 1982 and 2011, the number of new cases of uterine and ovarian cancer diagnosed in Australian women increased.<sup>4,5</sup> Between 2011 and 2020, this number is expected to continue to increase <sup>2,3</sup> (Figure 2-1). The number of new cases of cervical cancer has declined since the introduction of the National Cervical Screening Program in 1991 but is expected to increase with expected changes in the population.<sup>6,7</sup> The estimated number of new cases diagnosed in 2020 for the three major types of gynaecological cancers is:

- ▶ 2,830 new cases of uterine cancer (26.5% increase since 2011)<sup>2,3</sup>
- ▶ 1,640 new cases of ovarian cancer (23.3% increase since 2011)<sup>2,3</sup>
- ▶ 915 new cases of cervical cancer (14.2% increase since 2011).<sup>2,3</sup>

Figure 2-1 – Trends in number of new cases of uterine, ovarian and cervical cancers, Australia, 1982-2020



Source: Australian Institute of Health and Welfare. Australian Cancer Incidence and Mortality (ACIM) books. Canberra: AIHW. <http://www.aihw.gov.au/acim-books>. Accessed: July 2015; and Australian Institute of Health and Welfare & Cancer Australia. 2012. Gynaecological cancers in Australia: an overview. Cancer series no. 70. Cat. no. CAN 66. Canberra: AIHW.

#### Impact

Gynaecological cancer incidence, in particular uterine cancer, is projected to increase. There will be a resulting increase in demand for services along the gynaecological cancer control continuum, especially treatment and supportive care.

<sup>a</sup> Gynaecological cancers include cancer of the vulva, vagina, cervix, corpus uteri, uterus (part unspecified), ovary and other and unspecified female genital organs and placenta.  
<sup>b</sup> Uterine cancer includes malignant neoplasms of the endometrium, as well as lower uterine segment, myometrium, fundus uteri, and unspecified areas of the corpus uteri.



## Mortality

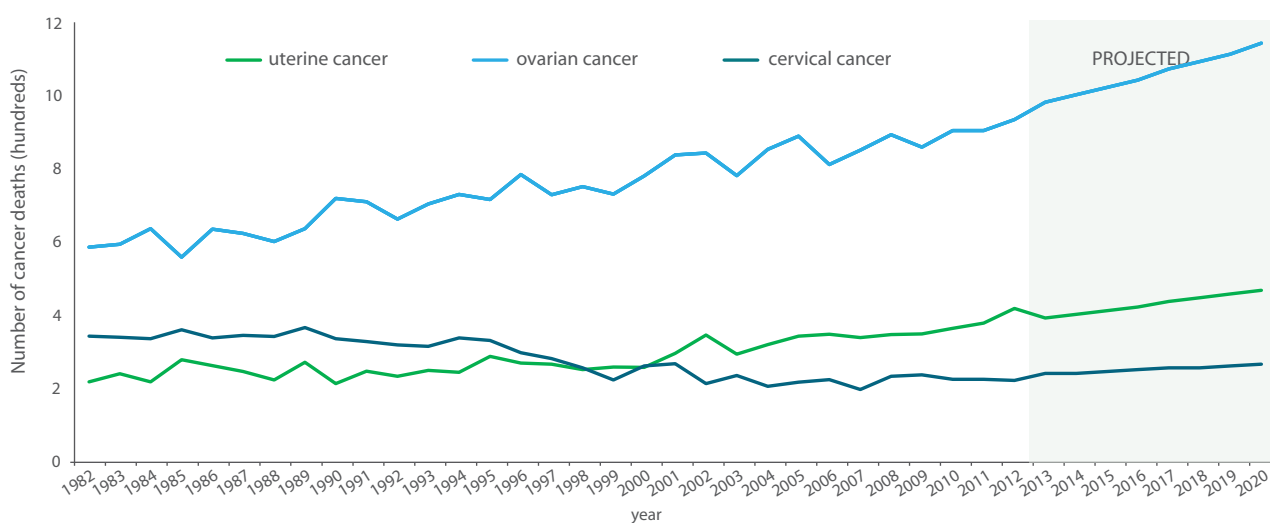
In 2015, an estimated 1,730 women were expected to die from gynaecological cancers in Australia, accounting for 8.6% of all cancer deaths in women.<sup>1</sup> The estimated number of cancer deaths in 2015 for the three major types of gynaecological cancers is:

- ▶ 415 deaths due to uterine cancer<sup>2</sup>
- ▶ 1,020 deaths due to ovarian cancer<sup>2</sup>
- ▶ 250 deaths due to cervical cancer.<sup>2</sup>

Between 1982 and 2012, the number of cancer deaths due to uterine and ovarian cancer in Australian women increased.<sup>4,5</sup> The number of deaths due to cervical cancer decreased over this period due at least in part to the introduction of the National Cervical Cancer Screening Program.<sup>3,7</sup> Between 2012 and 2020, the number of deaths due to the three major types of gynaecological cancers is expected to increase<sup>8</sup> (Figure 2-2). The estimated number of cancer deaths in 2020, for the three major types of gynaecological cancers is:

- ▶ 470 deaths due to uterine cancer (11.6% increase since 2012)<sup>2,8</sup>
- ▶ 1,140 deaths due to ovarian cancer (22.2% increase since 2012)<sup>2,8</sup>
- ▶ 270 deaths due to cervical cancer (19.5% increase since 2012).<sup>2,8</sup>

Figure 2-2 – Trends in number of cancer deaths due to uterine, ovarian and cervical cancers, Australia, 1982-2020



Source: Australian Institute of Health and Welfare. Australian Cancer Incidence and Mortality (ACIM) books. Canberra: AIHW. <http://www.aihw.gov.au/acim-books>. Accessed: July 2015; Australian Institute of Health and Welfare. 2014. Cancer in Australia: an overview 2014. Cancer series No 90. Cat. no. CAN 88. Canberra: AIHW; and Australian Institute of Health and Welfare. National Mortality Database. Cancer mortality projections: 2013 to 2025. <http://www.aihw.gov.au/cancer/mortality-trends-projections>. Accessed: August 2015.

<sup>c</sup> Australia introduced the National Human Papilloma Virus (HPV) Vaccination Program in April 2007 to protect young Australian women against infection with HPV and further reduce cervical cancer incidence. The effect of the HPV Vaccination Program on incidence of cervical cancer will not be evident for some time, and is not accounted for in these projections; however, the potential effects should be considered when interpreting these data.<sup>6</sup>

Gynaecological cancers also impose a significant burden of disease on Australian women. In 2012, the number of years of healthy life lost due to gynaecological cancers (known as disability-adjusted life years or 'DALYs') was estimated as:

- ▶ 5,300 for uterine cancer<sup>3</sup>
- ▶ 13,200 for ovarian cancer<sup>3</sup>
- ▶ 4,100 for cervical cancer.<sup>3</sup>

Due to the relatively poor prognosis of cancer compared to other diseases, most DALYs for gynaecological cancers are due to premature mortality (as opposed to disability or morbidity). This is especially the case for ovarian cancer, where 92% of DALYs in 2012 were estimated as being due to premature death.<sup>3</sup>

## Impact

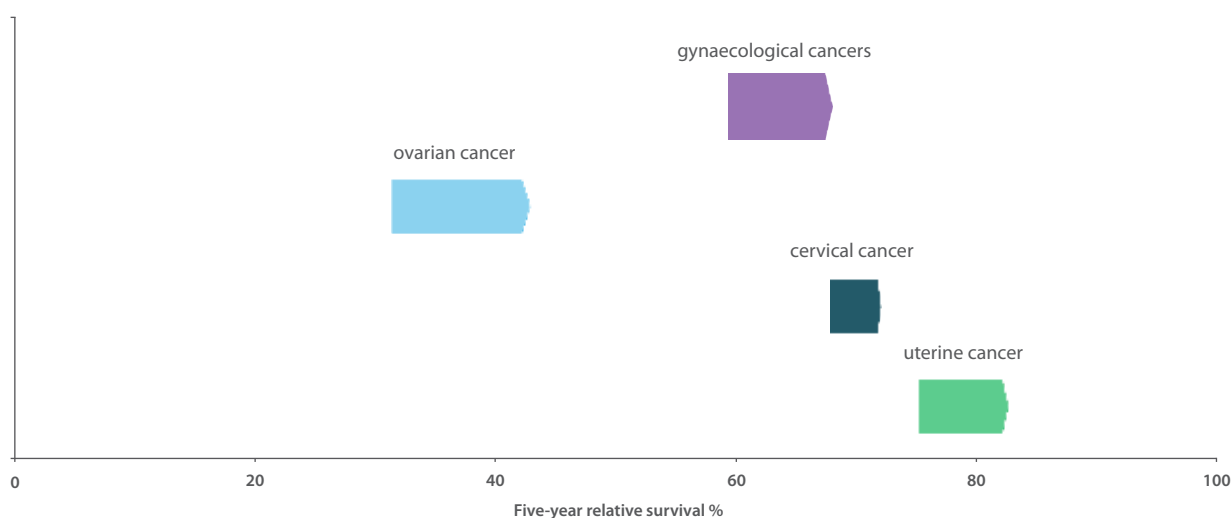
The number of deaths for gynaecological cancers is projected to increase for all gynaecological cancers, in particular for ovarian cancer.

## Survival

In common with other cancers, there are growing numbers of gynaecological cancer survivors. Five-year relative survival for women with gynaecological cancers increased from 59.3% to 67.9% between 1982-1986 and 2007-2011.<sup>1</sup> Survival rates for the three major types of gynaecological cancers have significantly increased over time, although remain poor for ovarian cancer (Figure 2-3).<sup>2</sup> Between 1982-1986 and 2007-2011, five-year relative survival, respectively:

- ▶ increased from 59.3% to 67.9% for gynaecological cancers<sup>1</sup>
- ▶ increased from 74.9% to 82.5% for uterine cancer<sup>2</sup>
- ▶ increased from 31.3% to 43.0% for ovarian cancer<sup>2</sup>
- ▶ increased from 67.7% to 71.9% for cervical cancer.<sup>2</sup>

Figure 2-3 – Trends in survival rates of uterine, ovarian, cervical and gynaecological cancers, Australia, 1982-1986 to 2007-2011



Source: Australian Institute of Health and Welfare. 2014. Cancer in Australia: an overview 2014. Cancer series No 90. Cat. no. CAN 88. Canberra: AIHW; and Cancer Australia. Gynaecological cancers at a glance. <http://canceraustralia.gov.au/affected-cancer/cancer-types/gynaecological-cancers/gynaecological-cancer-statistics>. Accessed: July 2015.

### Impact

Increasing survival rates will increase demand for follow-up and survivorship care for women with gynaecological cancer.

## Gynaecological cancers in Aboriginal and Torres Strait Islander women

Aboriginal and Torres Strait Islander women have a different pattern of gynaecological cancer incidence and mortality compared to non-Indigenous women.<sup>2</sup> In the five years from 2005 to 2009, the age-standardised incidence rate (per 100,000) for cervical and uterine cancer was significantly higher in Indigenous women (Figure 2-4).<sup>2</sup> Compared to non-Indigenous women, Indigenous women in 2005-2009 were:

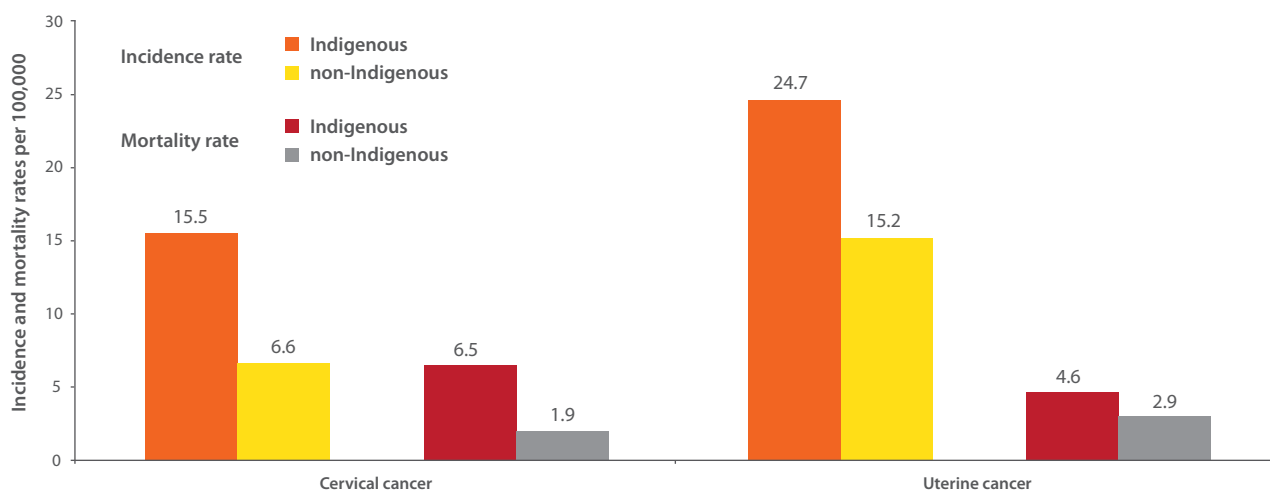
- ▶ 2.3 times more likely to be diagnosed with cervical cancer<sup>2</sup>
- ▶ 1.6 times more likely to be diagnosed with uterine cancer.<sup>2</sup>

In the five years from 2008 to 2012, the age-standardised mortality rate for cervical and uterine cancer was significantly higher in Indigenous women compared to non-Indigenous women (Figure 2-4).<sup>2</sup> Compared to non-Indigenous women, Indigenous women were:

- ▶ 3.4 times more likely to die from for cervical cancer<sup>2</sup>
- ▶ 1.6 times more likely to die from for uterine cancer.<sup>2</sup>

Previous data suggest that the incidence rates and mortality rates of ovarian cancer are comparable between non-Indigenous and Indigenous women.<sup>3</sup>

Figure 2-4 – Age-standardised incidence (2005-2009) and mortality (2008-2012) rates per 100,000 of cervical and uterine cancer, by Indigenous status, Australia



Source: Australian Institute of Health and Welfare. 2014. Cancer in Australia: an overview 2014. Cancer series No 90. Cat. no. CAN 88. Canberra: AIHW.

The five-year crude survival rates for women with ovarian cancer, uterine cancer and all gynaecological cancers combined, did not differ significantly by Aboriginal and Torres Strait Islander status.<sup>3</sup> However, Aboriginal and Torres Strait Islander women diagnosed with cervical cancer had significantly lower 5-year crude survival rates (50.8%) than non-Indigenous women (66.3%).<sup>3</sup> In addition, Aboriginal and Torres Strait Islander people are more likely than other Australians to be diagnosed when cancer is at an advanced stage, limiting their treatment options and contributing to poorer survival.<sup>9-11</sup>

### Impact

Gynaecological cancers impose a comparatively high burden on Aboriginal and Torres Strait Islander women, with a resultant requirement for gynaecological cancer services and systems to deliver good quality, integrated services that meet the needs of Aboriginal and Torres Strait Islander women.

## Risk factors and prevention

There are a number of modifiable risk factors including smoking, overweight/obesity and lack of physical activity, which increase the risk of gynaecological cancers.<sup>12</sup> In addition to other non-gynaecological cancers, the International Agency for Research on Cancer (IARC) has identified that tobacco smoking is a risk factor for cervical and mucinous ovarian cancer.<sup>12,13</sup> There is also convincing evidence that greater body fatness increases the risk of endometrial cancer<sup>14</sup> and is a probable cause of ovarian cancer<sup>15</sup>; and that lack of physical activity and sedentary behaviour increase the risk of endometrial cancer.<sup>12,14-16</sup> This is particularly significant given the increasing prevalence of overweight and obesity in Australia, from 56.3% of adults in 1995 to 62.8% in 2011-12.<sup>12,17</sup>

Infection with the human papilloma virus (HPV) is the most important risk factor for cervical cancer.<sup>12,18,19</sup> In 2007, the Australian Government introduced a world-first National HPV Vaccination Program as a primary prevention program aimed to prevent cervical cancer.<sup>20-23</sup> The vaccination program is delivered through schools, to girls and boys aged 12-13 years.<sup>20-23</sup> Approximately 73% of Australian girls turning 15 in 2014 have been vaccinated with the full three-dose schedule.<sup>20-23</sup> Coverage was lower in Indigenous girls compared to non-Indigenous girls, with 17% fewer Indigenous girls in the Northern Territory starting the course than non-Indigenous girls.<sup>20-23</sup>

Evidence has suggested an association between certain gene mutations and the risk of gynaecological cancer. Having a strong family history of breast and ovarian cancer or carrying a BRCA1 and/or BRCA2 gene mutation are established risk factors for breast and ovarian cancer. Their carrier status may have implications for their subsequent treatment as well as for other members of their family.<sup>24,25</sup> A small proportion of endometrial and ovarian cancers can be attributed to Lynch Syndrome, an autosomal dominant inherited cancer susceptibility syndrome.<sup>26</sup> Genetic risk assessment may be considered for women who are identified to be at risk of Lynch Syndrome by their family history, or their personal history of endometrial cancer in association with other cancers.<sup>25,26</sup> Early identification of women who carry a gene mutation may allow prevention of BRCA1/2 or Lynch-Syndrome-associated malignancies.

### Impact

Some gynaecological cancers may be prevented by addressing modifiable risk factors, increasing the uptake of HPV vaccination and identifying women at high risk.

## Screening and early detection

The availability of effective population-based screening methods differs across various gynaecological cancers. The introduction of the National Cervical Screening Program in 1991 has reduced the burden of cervical cancer in Australia, with the incidence rate halving from 13.3 per 100,000 women in 1991 to 6.8 per 100,000 women in 2015.<sup>3</sup> In 2009, 80% of Victorian women with invasive cervical cancer had never been screened or had not had regular screening tests.<sup>27</sup> Conversely, there is no population-based screening for ovarian or uterine cancer. The lack of effective screening and early detection approaches for ovarian cancer contributes to the high proportion of women with ovarian cancer being diagnosed with advanced disease.<sup>28</sup>

The current National Cervical Screening Program encourages women to have biennial Pap smears facilitating the detection of pre-cancerous lesions.<sup>27,29</sup> National planning is currently underway for renewal of the National Cervical Screening Program (the 'Renewal Program'). From May 2017, the recommendations for women aged between 25-74 years will change from a two-yearly Pap test to a five-yearly HPV test.<sup>29</sup> The HPV test uses the same procedure as the Pap test and is predicted to be more effective at reducing incidence and mortality from cervical cancer compared to conventional cytology.<sup>27</sup>

### Impact

The implementation of the Renewal of the National Cervical Screening Program presents an opportunity to enhance outcomes for cervical cancer and to improve general community understanding of gynaecological cancers.

## Treatment

Management principles for gynaecological cancers vary according to the site and cell type of the primary disease.<sup>30</sup> Treatment options also vary according to the stage of the disease, the histological subtype and comorbidities of patients.<sup>30</sup> The incidence of comorbidities due to the increasing prevalence of obesity<sup>31</sup> and diabetes mellitus<sup>31</sup> has led to growing case complexity amongst women with gynaecological cancer. Case complexity has an impact on the risk of complications related to gynaecological cancer treatment, and as such, influences treatment decisions made by clinicians.

The emergence of personalised medicine, with treatment approaches varying according to molecular subtype of disease, has implications for delivery of care, including equitable access and cost.

There are some areas where consensus regarding the best-practice treatment of gynaecological cancers is yet to be achieved. This includes best practice treatment for recurrent ovarian cancer, the role of adjuvant radiotherapy and chemotherapy in endometrial cancer, and appropriate models of follow-up care for endometrial cancer.<sup>32,33</sup>

Gynaecological cancers require specialised multidisciplinary care. Case volumes of gynaecological cancers are relatively low compared to other cancers experienced by Australian women, such as breast cancer.<sup>2</sup> This has an impact on the delivery of specialised care for women with gynaecological cancer and the availability of appropriate experience and expertise.

The complexities of treatment and supportive care for women with gynaecological cancer require coordinated multidisciplinary input. Multidisciplinary care for gynaecological cancer cases ideally involves gynaecological oncologists, medical oncologists, radiation oncologists, nurses with specialist gynaecological expertise, pathologists, radiologists, general practitioners (GPs), gynaecologists, specialist allied health professionals

(including social workers, psychologists and physiotherapists), palliative care providers, sexual health counsellors, Aboriginal and Torres Strait Islander Health Workers, geneticists, dieticians, and genetic counsellors.<sup>28</sup>

Planning and treatment for most gynaecological cancers in Australia is coordinated and delivered by sixteen gynaecological cancer units (as at June 2015) based at teaching hospitals around the country. There are multiple gynaecological cancer units in four states: New South Wales (5 units, 6 locations), Victoria (3 units), Queensland (2 units, 3 locations), and South Australia (2 units). Western Australia and Tasmania each have only one gynaecological cancer unit. Neither the Australian Capital Territory nor the Northern Territory has a gynaecological cancer unit (See Appendix C, Table C-1).

Only two of the gynaecological cancer units have locations outside a capital city – John Hunter Hospital in Newcastle in New South Wales, and the Gold Coast Hospital in Queensland. Regional centres may not have enough service volume from their catchment area to establish their own gynaecological cancer units, particularly for surgical and radiation oncology treatment components.

### Impact

There are emerging issues related to understanding the best-practice use and cost of personalised medicine; and there are gaps in identifying effective approaches for treatment and follow-up care of gynaecological cancers.

## Psychosocial well-being and supportive care

Diagnosis and treatment affects the psychosocial and psychosexual well-being of women with gynaecological cancer. A holistic approach to treating gynaecological cancers requires supportive care and, where appropriate, palliative care.

In addition to the many common experiences of people with a cancer diagnosis (such as pain, fatigue, anxiety, coping with hair loss, financial stress, and managing treatment regimes)<sup>34</sup> women with gynaecological cancer may face more specific problems associated with:

- ▶ lower leg lymphoedema (which can affect mobility)
- ▶ surgically- or chemically-induced menopause
- ▶ sexual dysfunction, including vaginal dryness, bleeding and stenosis, and pain during intercourse
- ▶ emotional and psychological issues including body image concerns, relationship or interpersonal problems and sexuality concerns
- ▶ bowel dysfunction, faecal and urinary incontinence
- ▶ loss of fertility.<sup>72</sup>

### Impact

Women with gynaecological cancers have specific needs for psychosocial and supportive care across all stages of the gynaecological cancer care continuum.

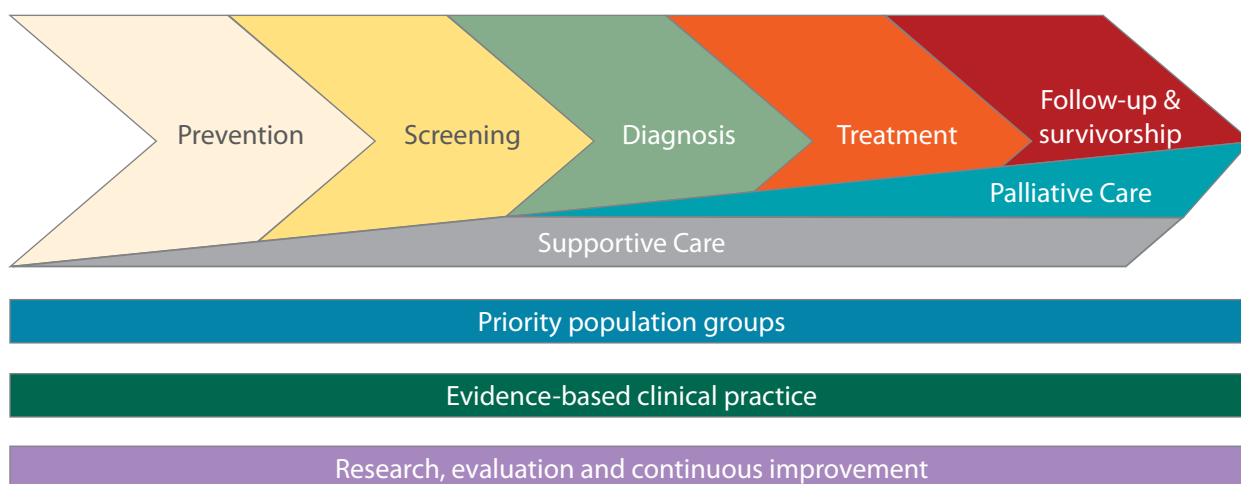
## Informing the response - Gynaecological cancer control

Examination of the literature and consultation findings informed the development of a logic structure to guide the National Framework (referred to as the 'guiding structure'). The structure has the following elements:

- ▶ The continuum of gynaecological cancer control: delivery of cancer control for gynaecological cancers is provided in the areas of prevention, screening, diagnosis, treatment, follow-up and survivorship, supportive care, and palliative care.
- ▶ Priority population groups: within the overall population, there are specific groups that need additional attention because of higher incidence or characteristics that affect their capacity to access services.
- ▶ Evidence-based clinical practice involves interaction between funders, service provider organisations, clinicians and other direct and indirect care staff, and patients, carers and their families.
- ▶ Research, evaluation and continuous improvement build knowledge and inform the design of programs, services and clinical interventions, as well as monitor patient outcomes.

The relationship between these structural elements is shown in Figure 2-5.

Figure 2-5 – The guiding structure for gynaecological cancer control



The guiding structure has informed analysis of the issues in gynaecological cancer control that were identified when developing the National Framework. Priority areas for investment and underlying strategies were categorised according to the elements of the guiding structure.

Chapter 3 provides details of the priority areas and strategies.

### Cancer control continuum

Cancer control focuses on addressing the impact of cancer by reducing cancer incidence and mortality and improving quality of life for people affected by cancer. This is achieved through the systematic implementation of evidence-based strategies across the cancer control continuum.<sup>35,36</sup>

The cancer control continuum refers to the broad range of areas in which cancer-related services are provided, including: prevention, screening, early detection, diagnosis, treatment, supportive care, follow-up care, survivorship and palliative care.<sup>37</sup>



## 3 Priorities

### Priority areas and strategies

Cancer Australia's expert gynaecological cancer advisory group reviewed the findings from the project's situation analysis, literature scan and consultations. Based on this analysis, the expert group identified six priority areas where action is needed to address gynaecological cancer control in Australia over the next five years. These are:

#### Priority Area One

Enhancing the centralised model of treatment planning

#### Priority Area Two

Improving outcomes for Aboriginal and Torres Strait Islander women

#### Priority Area Three

Promoting a holistic approach to person-centred care

#### Priority Area Four

Developing sustainable models of care

#### Priority Area Five

Enhancing health promotion and public awareness

#### Priority Area Six

Targeting research funding

Within each priority area, the expert gynaecological cancer advisory group identified a series of strategies of specific relevance to gynaecological cancer control.

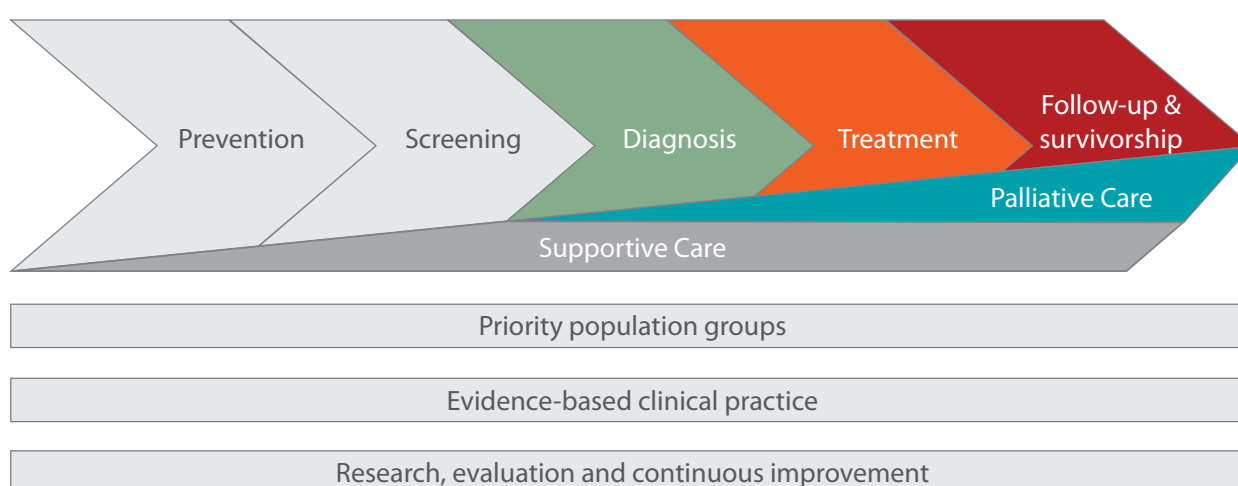
## Priority Area One: Enhancing the Centralised Model of Treatment Planning

The centralised model of treatment planning is currently a major feature of gynaecological cancer care in Australia. This model involves referral of women by general practitioners or gynaecologists to a specialist multidisciplinary gynaecological cancer unit, where they receive their diagnosis, treatment planning, initial treatment and initial follow-up care.

Planning and treatment for most gynaecological cancers in Australia is currently coordinated and delivered by sixteen gynaecological cancer units based at teaching hospitals around the country (as at June 2015). Use of the centralised model of treatment planning is a clinical and organisational response to the relatively low incidence of gynaecological cancer, together with specialised care needs for women with these diseases. Variants of the centralised model of treatment planning have been operational in Australia for over three decades in some jurisdictions.

Figure 3-1 illustrates the relevant elements of the guiding structure for gynaecological cancer control for Priority Area One.

**Figure 3-1 – The guiding structure for gynaecological cancer control: Enhancing the Centralised Model of Treatment Planning**



During consultations undertaken to inform development of the National Framework, service providers at gynaecological cancer units expressed strong support for continuing this centralised approach. However, increased demand in the next five to ten years is likely to put pressure on existing service delivery capacity under the centralised model. In response, ways of enhancing and optimising treatment based on this centralised approach require exploration.

## Issues for consideration

### Initial diagnosis and treatment by gynaecological cancer units with appropriate breadth of expertise

There are potential benefits to women for initial planning and treatment of gynaecological cancer care and management of recurrent cancer within a specialist multidisciplinary gynaecological cancer unit. This centralised approach includes access to multidisciplinary teams with specialist knowledge, including gynaecological oncologists, medical oncologists, radiation oncologists and diagnostic pathologists with expertise in gynaecological cancers,<sup>28</sup> and a range of specialised supportive care staff including palliative care specialists, specialist nursing and allied health services.<sup>28,30</sup>

Several measures have been used to assess the impact of specialised multidisciplinary care for women with gynaecological cancer on treatment outcomes. Studies report that:

- ▶ women with gynaecological cancer who received treatment from specialised centres or hospitals had longer survival than those managed elsewhere.<sup>30</sup> The evidence was stronger for ovarian cancers than other gynaecological cancers<sup>30</sup>
- ▶ survival for women with ovarian cancer improved when the initial surgery had been done by a gynaecological oncologist<sup>38</sup>
- ▶ outcomes for women with ovarian cancer are improved if they are managed under the guidance of a multidisciplinary care team.<sup>38</sup>

### Strategies

- ▶ Ensure appropriate and timely referral to specialist gynaecological multidisciplinary teams at critical points of the cancer control continuum – including at diagnosis, treatment and recurrence.
- ▶ Ensure the right expertise is available, across all relevant treatment options, to inform the delivery of clinical and psychosocial care.

## Promoting multidisciplinary care across different settings and sectors

The centralised nature of treatment planning and initial treatment means women in regional, rural and remote areas often need to travel to access specialist treatment for their gynaecological cancer, requiring them to leave their family and incur substantial travel costs.<sup>28,39,40</sup> This may delay timely diagnosis, care planning and treatment, leading to poorer outcomes.

There are opportunities to provide flexible approaches to treatment planning more broadly, such as the increased use of communication technology to connect multidisciplinary team members and patients across different sites.<sup>40</sup> This approach has been described as a networked model.<sup>40</sup> Under this model, the central multidisciplinary team is able to lead case planning and monitor patients from regional, rural and remote areas.<sup>40</sup> This will allow specialist clinicians and supportive care staff in a range of settings and primary care clinicians to participate in multidisciplinary team meetings, enabling them to locally manage and deliver care.<sup>40</sup>

Most states and territories have embarked on significant cancer reform agendas to enhance cancer services.<sup>28</sup> There has been a significant investment by the Commonwealth to support the development of regional cancer centres which offer an opportunity to enhance the centralised model of treatment planning for people outside metropolitan areas based on shared care arrangements.<sup>28</sup> This can include the provision of chemotherapy, follow-up care, and supportive care.<sup>41</sup> This initiative will result in increased capacity within regional centres and may facilitate better local access to quality services for women with gynaecological cancer.<sup>28</sup>

### Strategies

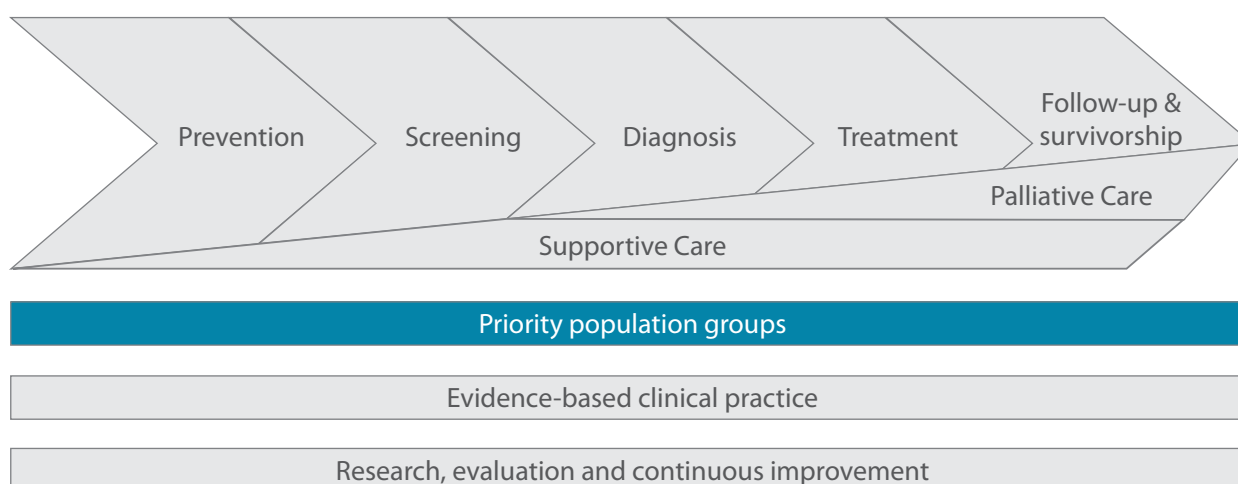
- ▶ Develop models of care, which incorporate and support evidence-based and coordinated multidisciplinary care across different settings.
- ▶ Multidisciplinary teams should provide timely and adequate communication between all members of the multidisciplinary team, including the patient's general practitioner and primary care team.

## Priority Area Two: Improving Outcomes for Aboriginal and Torres Strait Islander Women

There are significant disparities in outcomes for Aboriginal and Torres Strait Islander women with gynaecological cancer. Incidence and mortality for all gynaecological cancers combined occur at a significantly higher rate compared to non-Indigenous women.<sup>3</sup> In particular, age-standardised incidence rates and mortality rates for cervical and uterine cancer are significantly higher in Indigenous women.<sup>3</sup> This disparity is likely due to higher rates of known risk factors such as obesity, lower participation in cervical cancer screening and diagnosis at a more advanced stage of development.

Figure 3-2 illustrates the relevant elements of the guiding structure for gynaecological cancer control for Priority Area Two.

**Figure 3-2 – The guiding structure for gynaecological cancer control: Improving Outcomes for Aboriginal and Torres Strait Islander Women**



Efforts to address the poorer gynaecological cancer outcomes for Aboriginal and Torres Strait Islander women must consider the diversity of the Aboriginal and Torres Strait Islander population and understand the underlying causes, including the impact of social and cultural determinants of health. It is important to consider the following key concepts that are fundamental to Aboriginal and Torres Strait Islander health, including cancer control:

- ▶ **A holistic approach to health and well-being:** Aboriginal and Torres Strait Islander concepts of health extend beyond physical well-being of an individual, to the social, emotional and cultural well-being of the whole community, in which each individual is able to achieve their full potential as a human being.<sup>42,43</sup>
- ▶ **The diversity of Aboriginal and Torres Strait Islander people:** This diversity encompasses gender, age, language, geographic location, sexual orientation, religious beliefs, family responsibilities, marriage status, life and work experiences, personality and educational levels.<sup>43,44</sup>

- ▶ **The social and cultural determinants of health:** Aboriginal and Torres Strait Islander health is significantly affected by the social and cultural determinants of health. Aspects of the broader social and cultural environments can influence (in a negative or positive way) the capacity of individuals, families and communities to engage with health care and manage their own health.<sup>43,45-50</sup> For Aboriginal and Torres Strait Islander people, these social determinants of health may include support from family, community and church groups, connection to culture and country, a sense of empowerment or self-efficacy, education and literacy levels, poverty, marginalisation from the dominant culture, racism, poor housing, poor nutrition, smoking and other high risk behaviours, and living in remote areas.<sup>43,46-50</sup>
- ▶ **Involvement throughout the planning, design and delivery of cancer services:** Evidence shows that services and programs for Aboriginal and Torres Strait Islander people are most likely to be effective when Aboriginal and Torres Strait Islander people are integrally involved throughout the process of development and implementation.<sup>49,51</sup> This applies to services across the cancer continuum including physical infrastructure and service environments.<sup>43</sup>

## Issues for consideration

### Understanding the views of Aboriginal and Torres Strait Islander people

Studies of Aboriginal and Torres Strait Islander people's knowledge and beliefs about cancer have found that cancer is generally not discussed and is often misunderstood.<sup>52-54</sup> Furthermore, there is limited specific research on how Aboriginal and Torres Strait Islander women view gynaecological cancer, and how this may differ by community.

Misconceptions about cancer may influence how Aboriginal and Torres Strait Islander people engage with cancer screening, diagnostic or treatment services.<sup>55</sup> The impact of treatment (such as debilitating side effects), living away from family and communication difficulties with health care staff can add to these misconceptions and may lead to poor adherence to treatment and follow-up.

#### Strategies

- ▶ Undertake research to identify the views of Aboriginal and Torres Strait Islander people about gynaecological cancers and identify barriers to screening, early detection and treatment, and access to services.

## Raising awareness of risks and symptoms

Aboriginal and Torres Strait Islander people have higher levels of modifiable risk factors for cancer including smoking, risky alcohol consumption, obesity, poor diet, low levels of physical activity and high levels of infections such as HPV which may contribute to the higher gynaecological cancer incidence and mortality rates.<sup>56</sup>

Aboriginal and Torres Strait Islander people are more likely than non-Indigenous Australians to be diagnosed with cancer that has progressed to an advanced stage, contributing to higher mortality.<sup>43,57,58</sup> Delayed presentation following the onset of symptoms may contribute to the diagnosis of later-stage gynaecological cancer. Barriers to timely diagnosis include: comorbidities masking cancer symptoms; lack of knowledge about cancer, its symptoms and survivability amongst Aboriginal and Torres Strait Islander communities; fear of the potential effects of treatment and mistrust of the medical system; and the general barriers that Aboriginal and Torres Strait Islander people may experience in accessing health services.<sup>43,59</sup>

### Strategies

- ▶ Raise awareness in Aboriginal and Torres Strait Islander communities of risk factors and symptoms of gynaecological cancer, to support prevention and early detection.

## Increasing cervical cancer screening participation

Many potentially preventable or screen-detectable cancers are more common among Aboriginal and Torres Strait Islander people than non-Indigenous Australians.<sup>43,60</sup> Indigenous Australians have lower participation in screening programs than non-Indigenous Australians, which is particularly relevant to cervical cancer, where an effective national screening program has been in place in Australia since 1991.<sup>43,56</sup>

It is likely that lower participation by Aboriginal and Torres Strait Islander people in cervical cancer screening contributes to its higher incidence and poorer outcomes in Indigenous women.<sup>43,61</sup> In addition, Aboriginal and Torres Strait Islander women may experience difficulty in accessing colposcopy services.

Available evidence shows that participation in screening programs by Aboriginal and Torres Strait Islander women is approximately 18 percent lower than that of non-Indigenous women (based on data from 1997-2004 and 1991-2001 from Northern Territory and Queensland, respectively).<sup>63,64</sup>

### Strategies

- ▶ Increase participation of Aboriginal and Torres Strait Islander women in the National Cervical Screening Program.
- ▶ Improve national recording of Indigenous status in pathology requests and reports.

## Improving the cultural appropriateness of services

Aboriginal and Torres Strait Islander people can experience significant cultural and social barriers in engaging with mainstream services that can contribute to lower participation in screening, treatment and follow-up care.<sup>52</sup>

Consultations with gynaecological cancer units identified that the low incidence of gynaecological cancers means individual services only see small numbers of Aboriginal and Torres Strait Islander women with these diseases. This has limited their capacity to develop appropriately tailored cultural support.

A culturally appropriate approach to cancer care is required for Aboriginal and Torres Strait Islander people, in order to strengthen the provision of culturally safe services and a culturally competent workforce.<sup>43</sup> Enabling the Aboriginal and Torres Strait Islander health workforce (including Aboriginal and Torres Strait Islander Health Workers) to support the delivery of culturally appropriate and evidence-based cancer care is important. Quality cancer care for Aboriginal and Torres Strait Islander people requires effective cross-cultural communication skills, supported by organisations in which cultural competence is embedded as integral to quality and safety.<sup>35,59</sup>

### Strategies

- ▶ Strengthen the capacity of cancer related services and systems to deliver culturally appropriate, integrated services that meet the needs of Aboriginal and Torres Strait Islander people across the cancer control continuum.

## Improving knowledge of the patterns of care

Aboriginal and Torres Strait Islander women are less likely to access treatment for gynaecological cancer, especially those women living in rural and remote areas. This may be due to discomfort in travelling away from their local community and land, and limited access to financial resources, making it difficult to cover travel costs and costs of daily living.

There is limited evidence regarding the patterns of care followed by Aboriginal and Torres Strait Islander women across the gynaecological cancer care continuum. In particular, more information is required about the extent that Aboriginal and Torres Strait Islander women:

- ▶ may be considered 'at risk' of having a gynaecological malignancy but are not referred to a gynaecological cancer unit for comprehensive diagnosis
- ▶ delay presentation with symptomatic advanced disease
- ▶ commence and complete treatment
- ▶ attend follow-up care.

Better information on these patterns of care could inform the design of alternative programs and clinical support to promote the engagement of Aboriginal and Torres Strait Islander women across the gynaecological cancer care continuum.

### Strategies

- ▶ Identify the patterns of care for Aboriginal and Torres Strait Islander women with gynaecological cancers including in areas such as referral, treatment and follow-up care.

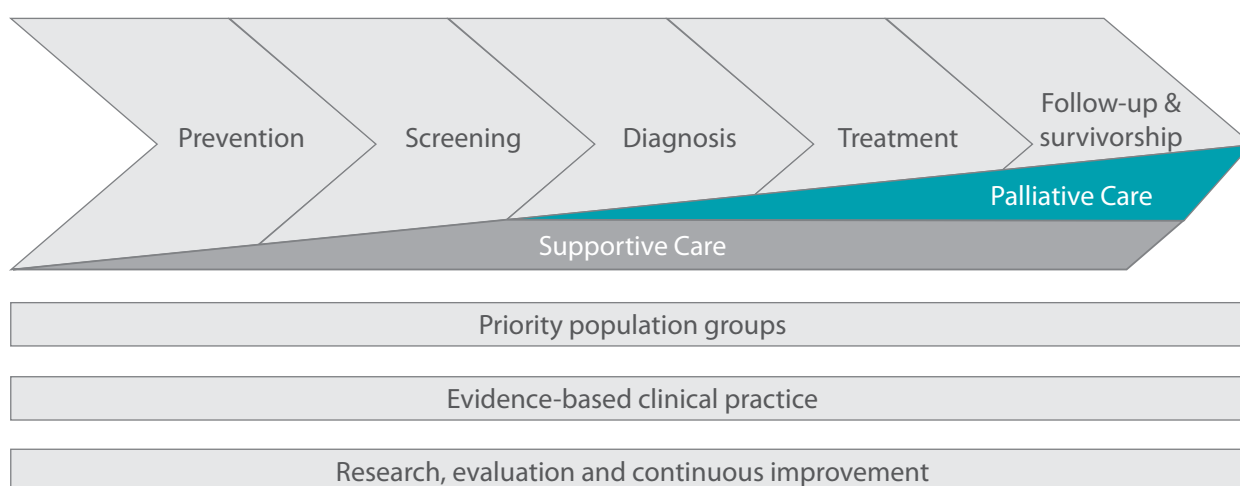


## Priority Area Three: Promoting a Holistic Approach to Person-Centred Care

Women with gynaecological cancer have broad psychosocial, psychosexual and other supportive care needs related to their disease and treatment. These can have physical, practical, psychological, social, cultural, and spiritual dimensions.<sup>65</sup> Addressing the varied needs of women with gynaecological cancer requires the use of a holistic model of care, which takes a 'whole person' and 'person-centred' approach. Holistic care recognises that changes to the mind, body or spirit can affect the overall health and quality of life of an individual and their family.<sup>66</sup>

Figure 3-3 illustrates the relevant elements of the guiding structure for gynaecological cancer control for Priority Area Three.

**Figure 3-3 – The guiding structure for gynaecological cancer control: Promoting a Holistic Approach to Person-Centred Care**



Delivery of a holistic approach to care requires the provision of supportive care and palliative care defined by the National Cancer Institute as the care given to improve the quality of life of patients who have a serious or life-threatening disease.<sup>67,68</sup>

The goal of supportive care is to prevent or treat as early as possible the symptoms of a disease, side effects caused by treatment of a disease, and psychological, social, and spiritual problems related to a disease or its treatment.<sup>67</sup> Adequate supportive care applies throughout the whole cancer care continuum, irrespective of the setting where care is delivered, and is not just a response to the particular stage of disease<sup>69</sup> such as end-of-life care.

Palliative care has traditionally focused on the assessment and management of physical, psychosocial, cultural and spiritual distress of patients living with advanced cancer,<sup>70</sup> especially care of the whole person and their family at the end of life. However, many of the principles and skills of palliative care can be delivered as supportive care at any stage of illness, even when the prognosis is good.

## Issues for consideration

### Specific psychosocial and psychosexual needs of women with gynaecological cancer

At diagnosis, approximately half of all cancer patients experience levels of anxiety and depression, sufficient to affect their quality of life adversely.<sup>34,69</sup> About one quarter continue to be affected in the next six months.<sup>69</sup> Anxiety and depression rise to 50% among those patients experiencing recurrence of disease.<sup>69</sup> Cancer patients with anxiety, depression and other psychosocial issues (including problems with personal relationships, sexual difficulties, and alcohol and drug-related problems) can benefit from psychological support services.<sup>34,71</sup>

Women with gynaecological cancer may face specific problems associated with their disease and treatment, such as:

- ▶ lower leg lymphoedema (which can affect mobility)
- ▶ surgically or chemically-induced menopause
- ▶ sexual dysfunction, including vaginal dryness, bleeding and stenosis, and pain during intercourse
- ▶ emotional and psychological issues including body image concerns, relationship or interpersonal problems and sexuality concerns
- ▶ bowel dysfunction, faecal and urinary incontinence
- ▶ risk of malnutrition
- ▶ loss of fertility.<sup>72</sup>

These are in addition to the many common experiences of people with a cancer diagnosis such as pain, fatigue, anxiety, coping with hair loss, financial stress, and managing treatment regimes, including potential isolation from normal support networks, particularly for rural women who are staying away from home for treatment.<sup>34</sup>

### Strategies

- ▶ Alert health professionals, including general practitioners, to the specific psychosocial, psychosexual and other supportive care needs of women undergoing or following treatment for gynaecological cancers.

## Need for supportive care assessment

Clinicians working in the field of gynaecological cancer recognise that an important aspect of their work is enabling a woman living with cancer to access good supportive care. The supportive care needs of patients with gynaecological cancer and their families require assessment at key points along the gynaecological cancer care pathway, particularly at times of increased vulnerability. These may include:

- ▶ initial presentation or diagnosis
- ▶ the beginning of treatment or a new phase of treatment
- ▶ change in treatment
- ▶ change in prognosis
- ▶ end of treatment
- ▶ survivorship
- ▶ recurrence
- ▶ change in or development of new symptoms
- ▶ palliative care
- ▶ end-of-life care.<sup>72</sup>

A systematic approach to the delivery of supportive care screening is required to ensure that the holistic needs of patients, as well as their family and carers, are identified.<sup>69</sup> Comprehensive assessment addresses all the domains of supportive care: physical, social, cultural and occupational needs, psychological and spiritual well-being and information provision.<sup>65,66,72</sup> An assessment may result in the development of a care or action plan where required, including referring patients to relevant resources, information and support services.

Not all patients diagnosed with cancer require psychological support, but there is increased use of research-based approaches to identify those patients who will benefit from psychosocial interventions.<sup>73</sup> These interventions may include psychosocial education, counselling and psychotherapy (structured therapeutic interventions aimed at improving psychological wellbeing).<sup>73</sup>

### Strategies

- ▶ Assess patient needs systematically and ensure timely referral to appropriate counselling, psychosocial and support services where required.

## Survivorship care

Gynaecological cancer survivors experience a number of unmet needs, which impact upon their quality of life. Unmet needs may include, fear about the cancer spreading, concerns about the worries of those close to them, uncertainty about the future, lack of energy/tiredness, and not being able to do things they used to do as well as psychosocial and psychosexual needs specific to women with gynaecological cancer.<sup>74</sup>

As a result, high quality information and support are needed to assist women to self-manage and implement well-being strategies.

Management of modifiable risk factors including promoting healthy lifestyles and weight management is a key aspect of survivorship care. Obesity is a risk factor for the development of endometrial cancer<sup>12</sup> and is also a risk factor for poor outcomes for both ovarian and endometrial cancer.<sup>75</sup> Studies have shown that a lifestyle intervention program for obese endometrial cancer survivors is feasible and can result in sustained behaviour change and weight loss over a one-year period.<sup>76</sup>

### Strategies

- ▶ Include a focus on quality of life and secondary prevention as part of survivorship care in order to support women to live well after cancer treatment.

## Improve knowledge of psychosocial-cultural care

Supportive care includes cultural dimensions,<sup>69</sup> so that holistic and person-centred care also includes greater sensitivity and understanding of the concerns and needs of Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse (CALD) backgrounds, and their families.

More work is required to better understand the specific psychological and psychosexual needs of women with gynaecological cancer.<sup>73</sup> In particular, research is needed to identify effective supportive psychosocial-cultural care for Aboriginal and Torres Strait Islander women and CALD women with gynaecological cancer.

### Strategies

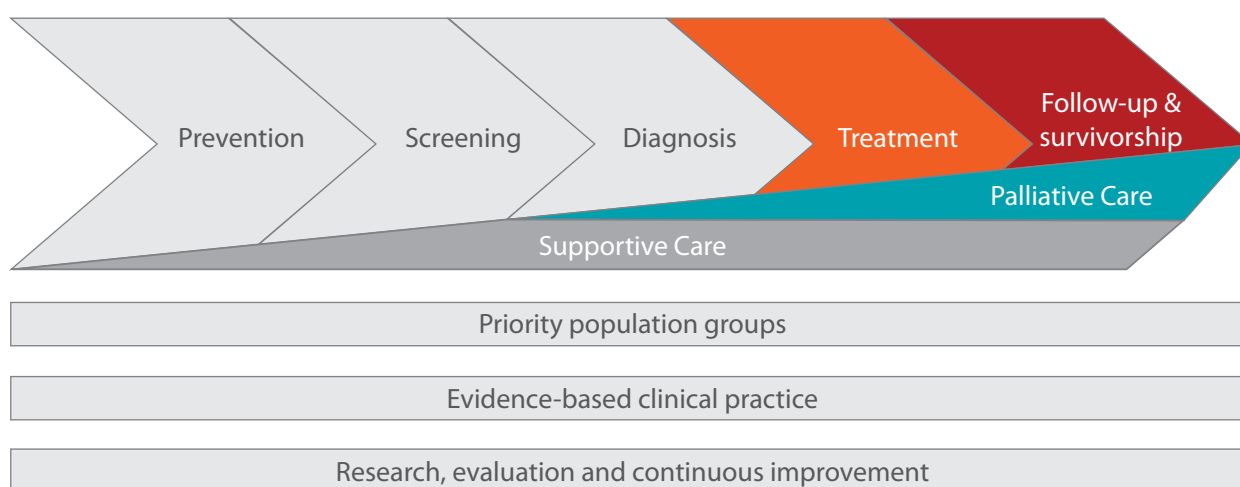
- ▶ Increase knowledge of effective psychosocial-cultural care for women with gynaecological cancer to improve outcomes, particularly for Aboriginal and Torres Strait Islander women and culturally and linguistically diverse women.

## Priority Area Four: Developing Sustainable Models of Care

The community has ongoing expectations that high quality, comprehensive care will be available to any woman diagnosed with gynaecological cancer, from diagnosis through to survivorship care. The projected incidence of gynaecological cancers, along with improved survival, will result in an increase in the number of gynaecological cancer survivors. In the current fiscal environment, health investment decisions will need to deliver optimal outcomes as well as value for the health system through sustainable models of care.<sup>77</sup>

Figure 3-4 illustrates the relevant elements of the guiding structure for gynaecological cancer control for Priority Area Four.

Figure 3-4 – The guiding structure for gynaecological cancer control: Developing Sustainable Models of Care



During consultations undertaken to inform development of the National Framework, the following issues were raised:

- ▶ rising gynaecological cancer incidence rates and prevalence of women living with gynaecological cancers will increase the need for diagnostic and treatment services from specialist gynaecological cancer teams, putting pressure on their ability to deliver services across the continuum of care
- ▶ there is limited available evidence regarding the ideal models of care for follow-up, survivorship and palliative care for women with gynaecological cancer
- ▶ availability of staff within gynaecological cancer teams with specialist supportive care skills is limited. Consultations identified that patients would benefit from greater access to the supportive care skills of psychologists, social workers, occupational therapists, and palliative care staff (both physicians and nurses).

Whilst diagnosis and initial treatment planning for women with gynaecological cancer occurs through gynaecological cancer units, with flexibility across settings where appropriate, opportunities for developing more sustainable models of care exist for delivery of follow-up, survivorship and palliative care.

## Issues for consideration

### Models of care for follow-up and survivorship

In Australia, follow-up and survivorship care are predominantly carried out in tertiary settings by specialist clinicians. In the context of growing numbers of cancer survivors and limited resources, some of these approaches may be unsustainable.<sup>77,78</sup> A new approach to follow-up care is required in which available resources are optimised, and service provision requirements are based on stratification of risk as well as on individual patient need.<sup>77-81</sup>

The evidence on appropriate models of follow-up care for women with gynaecological cancer is limited.<sup>77,79</sup> Current models of practice vary by health service, clinician preference and cancer type, and tend to be locally designed rather than based on demonstrations of effectiveness. While the optimal method of follow-up is not yet established for women with gynaecological cancer,<sup>79,82,83</sup> possible options for follow-up and their implications should be discussed with the woman at the completion of primary treatment.<sup>84</sup>

A Cancer Australia clinical practice guideline, *Follow-up of women with epithelial ovarian cancer*, identifies that alternate models of follow-up care for women with ovarian cancer, such as GP or nurse-led follow-up, telephone follow-up and patient initiated care are an area for future research.<sup>84</sup> Some of the issues that would need to be addressed in any future studies include patient and clinician preferences, the effectiveness and cost effectiveness of alternate models, and the ability of health services to support them.<sup>84</sup>

In the Australian context, new approaches would ideally aim to retain the benefits of specialist gynaecological multidisciplinary teams in the planning, coordination and management of treatment at critical points along the cancer care continuum, while supporting the management of follow-up and supportive care services in a primary care or community setting.

Critical elements of follow-up and survivorship care include person-centred care, the promotion of secondary prevention and the identification of new or recurrent disease. Relevant patient-centred programs and services are available in the community, such as support groups, psycho-educational programs, nutritional counselling, smoking cessation programs, and physical rehabilitation programs.<sup>85</sup>

### Models of palliative care

Research findings on specific models of palliative care for women with gynaecological cancer are limited.

Studies from the United States show that timely palliative care consultations reduce costs,<sup>86-88</sup> improve quality of care<sup>86-88</sup> and in some cases, improve survival leading to increased demand for palliative care specialists.<sup>87</sup> Findings in the literature promote a workforce model whereby all clinicians and specialists can assist with basic symptom management and psychosocial support, leaving more complex cases to palliative care specialists.<sup>87,89</sup>

General practitioners play an essential role in delivering palliative care in the community.<sup>89</sup> Formally integrating general practitioners in the multidisciplinary care of individual patients with advanced illness may be an effective way to make use of existing health system resources.<sup>89</sup>

A Cochrane Review on the effectiveness of home-based palliative care found home palliative care improved the chance of dying at home, and reduced symptom burden for patients with cancer without adversely impacting carers.<sup>90</sup>

### Strategies

- ▶ Explore sustainable models of care, which deliver safe, effective person-centred care for women with gynaecological cancer, particularly in follow-up, survivorship and palliative care.

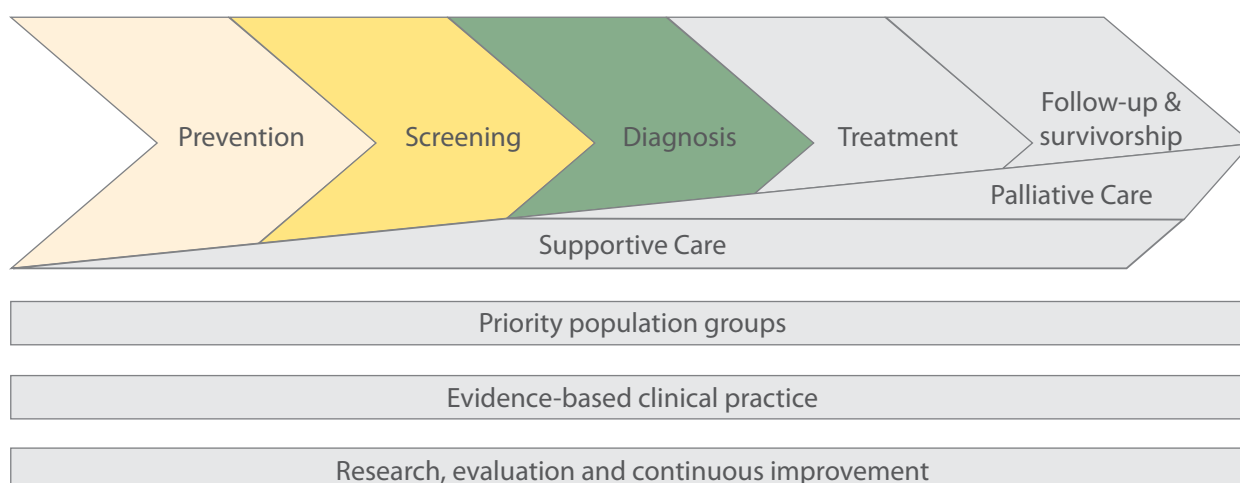
## Priority Area Five: Enhancing Health Promotion and Public Awareness

Modifiable and non-modifiable risk factors contribute to the development of some gynaecological cancers. Increasing awareness of these risk factors and encouraging people to adopt healthy lifestyle behaviours is therefore an important aspect of gynaecological cancer control.

Greater community and health practitioner awareness of gynaecological cancer risk factors, as well as increasing awareness and uptake of cervical cancer screening will improve prevention of gynaecological cancer. Evidence suggests that factors influencing time to diagnosis are affected by patient and clinician behaviours.<sup>91</sup> Greater awareness of symptoms of gynaecological cancer and timely investigation and referral of a woman who may have symptoms of gynaecological cancer, may improve earlier detection, enabling more timely treatment and improving the chances of long-term survival.

Figure 3-5 illustrates the relevant elements of the guiding structure for gynaecological cancer control for Priority Area Five.

**Figure 3-5 – The guiding structure for gynaecological cancer control: Enhancing Health Promotion and Public Awareness**



## Issues for consideration

### Understanding risk factors

There is a general lack of awareness among the community of modifiable risk factors for developing cancer, including for some gynaecological cancers.<sup>91</sup> An Australian study (NSW) found that 46% of survey respondents were unable to identify the common uterine cancer risk factors of obesity, diabetes and hypertension.<sup>92</sup> However, there is convincing evidence that obesity increases the risk of endometrial cancer and has been identified as a cause of 39% of endometrial cancer cases.<sup>12</sup> In addition, obesity is a probable cause of ovarian cancer.<sup>12</sup>

The link between persistent HPV infection and cervical cancer is not well understood by many Australian women: one survey found that 14.9% of Australian women did not know that HPV can cause cervical cancer.<sup>93</sup> Women in Australia had lower general awareness of HPV (72%) compared to the United States (88%).<sup>93</sup> An Ovarian Cancer Australia survey found a third of the respondents incorrectly believed that the HPV vaccine protects against ovarian cancer; and only 10% of respondents knew that the oral contraceptive pill reduces the risk of ovarian cancer.<sup>94</sup> This suggests cancer prevention campaigns need to promote a better understanding of modifiable risk factors for gynaecological cancers.

Having a strong family history of breast and ovarian cancer or carrying a BRCA1 and/or BRCA2 gene mutation are established risk factors for breast and ovarian cancer. Up to 15% of epithelial ovarian cancers can be explained by an inherited gene fault.<sup>95</sup> Australian guidelines have been developed regarding testing for such mutations in women diagnosed with epithelial ovarian cancer who are 70 years and younger. Their carrier status may have implications for their subsequent treatment as well as for other members of their family.<sup>24,25</sup>

A small proportion of endometrial and ovarian cancers can be attributed to Lynch Syndrome, an autosomal dominant inherited cancer susceptibility syndrome caused by defects in the mismatch repair system.<sup>26</sup> Lynch Syndrome is associated with a high risk of developing bowel, endometrial and ovarian cancer, as well as an increased risk of developing other cancers.<sup>26</sup> Genetic risk assessment may be considered for women who are identified to be at risk of Lynch Syndrome by their family history, or their personal history of endometrial cancer in association with other cancers.<sup>25,26</sup> Special tumour testing (immunohistochemistry for mismatch repair proteins) can identify patients who may have Lynch Syndrome and is appropriate for women diagnosed with endometrial cancer under 60 years of age.<sup>96</sup> Early identification of mutation carriers may allow prevention of Lynch Syndrome-associated malignancies.

### Specific messaging to support participation in cervical cancer screening

Australia's National Cervical Screening Program<sup>97</sup> is an effective population screening program for cervical cancer, which has reduced the burden of cervical cancer since its introduction in 1991. By encouraging women to have biennial Pap smears, it facilitates detection of pre-cancerous lesions thus preventing cervical cancer.<sup>27,29</sup>

National planning is currently underway for changes to the National Cervical Screening Program (the 'Renewal Program'). From May 2017, the recommendations for women aged between 25-74 years will change from a two-yearly Pap test to a five-yearly HPV test.<sup>29</sup> Implementation of the Renewal Program will require effective communication strategies. As a public health program, it presents an opportunity to improve outcomes for cervical cancer and to improve general community understanding of gynaecological cancers.

Specific messaging in relation to cervical cancer screening is required for groups with poorer outcomes. For example, participation rates by Aboriginal and Torres Strait Islander women in the National Cervical Screening Program is approximately 18 percent lower than that of non-Indigenous women.<sup>63,64</sup> Improving knowledge and attitudes towards cancer requires evidence-based public awareness and health promotion strategies that specifically address the concerns and needs of Aboriginal and Torres Strait Islander people in formats and languages that are accessible and culturally appropriate.



Research findings are limited on the experience of women from CALD communities in Australia participating in cervical cancer screening. Apart from the challenges of language barriers and lack of familiarity with the Australian health system, many people from CALD communities hold attitudes and beliefs about cancer which may influence the level of trust in health professionals and health systems.<sup>98</sup>

### Priority messaging on symptoms of gynaecological cancers

There is evidence that greater awareness of gynaecological cancer symptoms is required, both in the community and among health practitioners to facilitate earlier detection and diagnosis.

Patients may be less likely to delay presentation to a health practitioner for a gynaecological cancer if they experience a symptom perceived to be more serious such as pain or unusual bleeding. However, lack of awareness of symptom-seriousness is an important patient-mediated factor resulting in late diagnosis of gynaecological cancers.<sup>91</sup> This may be particularly relevant for ovarian cancer where patients may experience vague and non-specific symptoms such as abdominal bloating.<sup>94</sup> For example, an Ovarian Cancer Australia survey identified broad gaps in community knowledge about ovarian cancer: nearly half of the respondents did not know that ovarian cancer has symptoms while half the respondents incorrectly believed that Pap smears can be used to detect ovarian cancer.<sup>99</sup>

General practitioners and primary healthcare practitioners play key roles along the cancer control continuum, from prevention and diagnosis through to follow-up and palliative care. General practitioners have an important part in reinforcing messaging of community awareness campaigns, especially for those women who may be at higher risk of developing cancer.<sup>100</sup> Reducing diagnostic delays through appropriate and timely investigation and referral of a woman who has symptoms which may be due to gynaecological cancers, may lead to earlier stage diagnosis and improved outcomes.<sup>100</sup>

#### Strategies

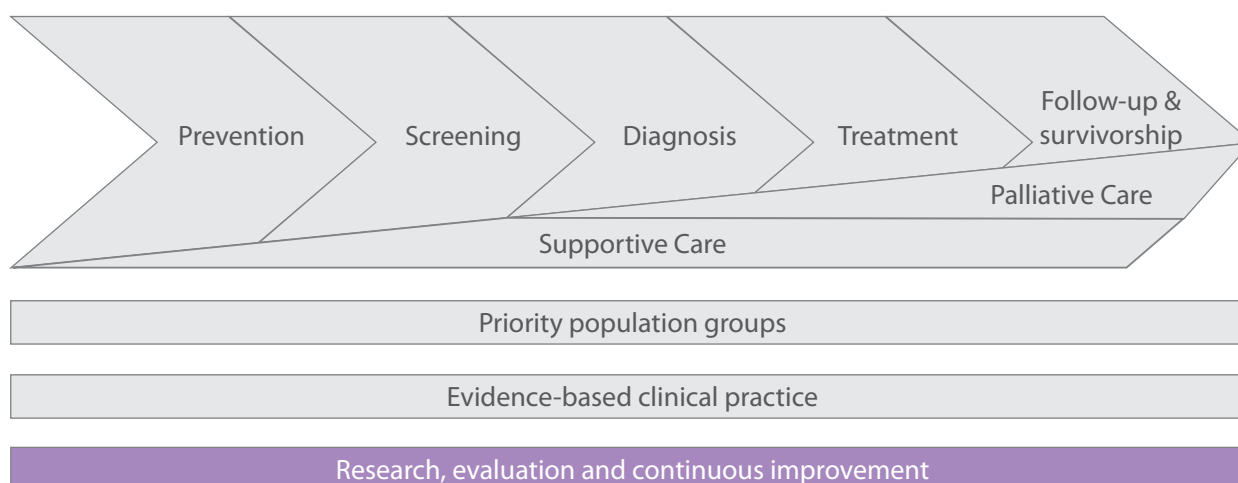
- ▶ Develop and promote consistent evidence-informed messages about prevention, screening and symptom awareness of gynaecological cancers for the community, specific groups with poorer outcomes and health practitioners.
- ▶ Engage general practitioners and primary healthcare practitioners about the importance of their role in screening, prevention and appropriate investigation of women with symptoms, which may be due to gynaecological cancers.

## Priority Area Six: Targeting Research Funding

Quality research and evaluation, including clinical trial data, underpins evidence-based policy and best-practice care, and drives improvements in cancer outcomes. Development of the National Framework has highlighted gaps in peer-reviewed published research on aspects of gynaecological cancer control. In particular, there is a lack of published research on approaches to improving gynaecological cancer outcomes for Aboriginal and Torres Strait Islander women, innovative models of follow-up and survivorship care, and communication about gynaecological cancers symptom recognition and risk factor reduction.

Figure 3-6 illustrates the relevant elements of the guiding structure for gynaecological cancer control for Priority Area Six.

**Figure 3-6 – The guiding structure for gynaecological cancer control: Targeting Research Funding**



While the investment in funding to gynaecological cancer research projects and research programs has increased in the period 2003-05 to 2009-11, the amount of research funding and the pattern of funding across the research continuum varies for different gynaecological cancer types.<sup>101</sup>

- ▶ Funding for gynaecological cancer research projects and programs increased by 43% from 2006-2008 to the 2009-2011 triennium, which was broadly in line with the growth in funding for all cancer research projects and programs over the same period (an increase of 44.3% from \$413m to \$596m).<sup>101,102</sup>
- ▶ The allocation of \$19.3m in research funding in 2009-11 for gynaecological cancers was approximately 3.2% of all cancer research funding identified in that triennium.<sup>101</sup> This was broadly in line with the proportion of gynaecological cancers diagnosed in women i.e. about 4% of all newly diagnosed cancers.<sup>1,2</sup> However only around 15% of this funding was allocated to research examining cancer control, survivorship and outcomes.<sup>101</sup>

## Issues for consideration

Development of the National Framework has identified several areas of gynaecological cancer research where there is a lack of evidence. These areas include:

- ▶ health services research including assessing effectiveness of models of follow-up and survivorship care
- ▶ effective approaches to improving gynaecological cancer outcomes for Aboriginal and Torres Strait Islander women, including addressing perceptions of gynaecological cancer; promoting participation in cervical cancer screening; and raising awareness of symptoms of gynaecological cancer to facilitate early detection; and
- ▶ identifying the needs and outcomes for women from CALD backgrounds with gynaecological cancer.

The National Framework has also identified the need for effective communication strategies about symptom recognition and risk factors for gynaecological cancers.

Given the majority (90%) of gynaecological cancer research projects and research programs in Australia are funded by single funders,<sup>102</sup> opportunities to partner and leverage investments may help to strategically maximise funding for gynaecological cancer research in the future. Furthermore, ongoing reviews of the pattern of funding to gynaecological cancer and specific gynaecological cancer types provides the opportunity to identify future priority areas for cancer research investment.

### Strategies

- ▶ Use the evidence to invest in priority areas of gynaecological cancer research and form partnerships to leverage investment for research, including in identified gaps.

## Increasing knowledge about outcomes of care

The ongoing collection of data on treatment and outcomes for women with gynaecological cancer is required to measure the impact of different patterns of gynaecological cancer care on patient outcomes. Australia's national gynaecological cancer data set specification (DSS) has been developed to support the standardised collection of clinical data so that data collected is consistent and reliable. The scope of the gynaecological cancer DSS encompasses the period from when a person is first referred for the investigation of symptoms and includes the entire duration of their illness, so that treatment and outcomes are captured. The data elements in the DSS provide a framework for:

- ▶ providing a systematic foundation for, and promoting the delivery of, evidence-based care to patients with gynaecological cancer;
- ▶ informing treatment guidelines and professional education;
- ▶ informing quality assurance;
- ▶ guiding resource planning and the evaluation of cancer control activities.<sup>103</sup>

### Strategies

- ▶ Encourage consistent uptake of standardised data collection as the evidence base to inform future work in gynaecological cancer control at both the national and local level.

# APPENDIX A

## Acknowledgments

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Clinical Oncology Society of Australia (COSA)

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# APPENDIX B

## Project methodology

Healthcare Management Advisors (HMA) was engaged to provide technical advice to Cancer Australia for this project. The project was undertaken in seven stages, described below.

1. **Situation Analysis:** HMA completed a situation analysis, a scan of the relevant literature, and reviewed and synthesised other documentation related to the project, including previous Cancer Australia reports.
2. **Consultations:** HMA scheduled and conducted consultations with key stakeholders, including:
  - ▶ peak bodies
  - ▶ consumer organisations
  - ▶ multidisciplinary team members at gynaecological cancer units across Australia.
3. **Formulate directions:** findings from the consultations were presented to the expert gynaecological cancer advisory group at a meeting on 16 April 2015. HMA formulated a preliminary draft National Framework, based on feedback received in this meeting.
4. **Review by expert gynaecological cancer advisory group:** the draft version of the National Framework was circulated to members of the expert gynaecological cancer advisory group for comment.
5. **Review by nominated state/territory/health department nominees**
6. **Prepare Final Framework:** the National Framework for Gynaecological Cancer Control (this document) was prepared, reflecting feedback from the expert gynaecological cancer advisory group and Cancer Australia.

# APPENDIX C

## Current service delivery arrangements

### Models of care

Women with or at risk of gynaecological cancer are treated by a variety of different service providers. Where a woman is treated may depend on her location of residence, the type of treatment required and whether she has private health insurance.

Throughout the patient pathway, women may receive care from multiple service providers depending on their care needs. Figure C-1 provides a summary of the types of gynaecological cancer service providers as summarised in the National Gynaecological Cancers Service Delivery Framework.<sup>28</sup>

Figure C-1 Gynaecological cancer service providers

#### Gynaecological cancer units

These units provide care to a large number of women with gynaecological cancers, have strong multidisciplinary teams and processes, offer the full range of treatment modalities on site or in close location and have good access to clinical trials and research and to specialist nursing and supportive care service providers.

#### Other metropolitan services

These may provide some but not all aspects of care to smaller numbers of women. Services may be supported by individual gynaecological oncologists and some may have their own multidisciplinary processes or are linked in with a centralised multidisciplinary team. However, a more linear model of multidisciplinary care with sequential referral to other service providers may occur with more limited formal multidisciplinary treatment planning. There is more limited access to nursing and supportive care providers with specialist knowledge of gynaecological cancer.

#### Private services

These may provide services to varying numbers of women and have variable access to multidisciplinary treatment planning. A more linear or informal model of multidisciplinary care may occur. Lack of access to supportive care providers within private services may result in some private patients being treated in the public sector to ensure access to the full range of required services.

#### Regional services

These may have a range of different approaches including:

- ▶ mixed centralised and local service models where some treatment or care is provided in a metropolitan service and some in regional services by local providers such as medical oncologists
- ▶ visiting specialist service models where a specialist or subspecialist may visit a regional centre to provide aspects of care.

Source: Cancer Australia and the Royal Australian College of Obstetricians and Gynaecologists. 2011. National Gynaecological Cancers Service Delivery and Resource Framework, Cancer Australia. Canberra.

It is common practice in developed countries for gynaecological cancer services to be centralised, whereby women with gynaecological cancer are treated in a gynaecological cancer unit.

In Australia there are sixteen gynaecological cancer units, as shown in Table C-1.

**Table C-1 Gynaecological cancer units as at June 2015**

State	Hospital	Location
NSW	Royal Hospital for Women	Sydney
	Westmead Hospital	Sydney
	Royal North Shore Hospital	Sydney
	Chris O'Brien Lifehouse at RPA	Sydney
	Liverpool Hospital	Sydney
	John Hunter Hospital	Regional NSW
VIC	Mercy Hospital for Women, Melbourne	Melbourne
	Royal Women's Hospital	Melbourne
	Monash Medical Centre	Melbourne
QLD	Royal Brisbane & Women's Hospital	Brisbane
	Mater Hospital Brisbane	Brisbane
	Gold Coast University Hospital	Gold Coast
SA	Flinders Medical Centre	Adelaide
	Royal Adelaide Hospital	Adelaide
WA	King Edward Memorial Hospital for Women	Perth
TAS	Royal Hobart Hospital	Tasmania

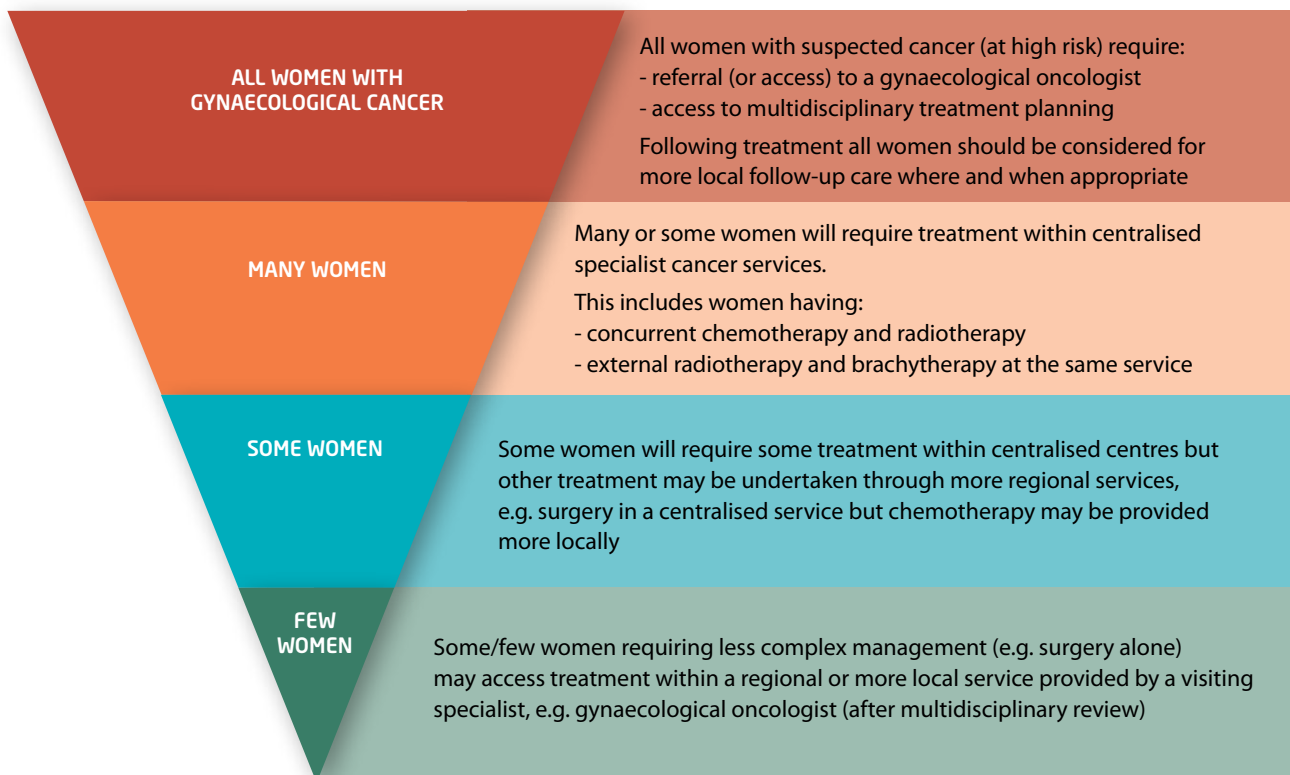


## A centralised model of care

In Australia, gynaecological cancer services follow a centralised model of care where patients primarily receive surgery and multidisciplinary team treatment planning through a gynaecological cancer unit. This centralised model of care also involves the delivery of radiation oncology (where required) and chemotherapy.

The National Gynaecological Cancers Service Delivery and Resource Framework<sup>28</sup> advocates a tiered approach where women receive care as shown in Figure C-2.

**Figure C-2** The tiered approach to service levels for providing care for women with suspected or confirmed gynaecological cancer



Source: Cancer Australia and the Royal Australian College of Obstetricians and Gynaecologists. 2011. National Gynaecological Cancers Service Delivery and Resource Framework, Cancer Australia. Canberra.

Depending on the jurisdiction this tiered approach operates in three main ways, described below.

- 1. No gynaecological cancer unit:** In these jurisdictions (Northern Territory and Australian Capital Territory) patients often receive services at a metropolitan, private or regional service of another jurisdiction. In some cases services within the jurisdiction may have access to visiting gynaecological oncologist and/or formal referral pathways to a gynaecological cancer unit in another jurisdiction.
- 2. Jurisdictions with one gynaecological cancer unit:** Under this model there is only one centralised referral pathway for all patients seen in metropolitan, private or regional services. Western Australia and Tasmania have this arrangement.
- 3. Jurisdictions with multiple gynaecological cancer units:** This model operates in New South Wales, Victoria, Queensland, and South Australia. There are generally informal catchment areas or 'custom and practice' around referral pathways to the different units.

# Abbreviations

ABS	Australian Bureau of Statistics
ACRRM	Australian Council for Rural and Remote Medicine
ACT	Australian Capital Territory
AIHW	Australian Institute of Health and Welfare
ANZGOG	Australia New Zealand Gynaecological Oncology Group
ASGO	Australian Society of Gynaecologic Oncologists
ASR	Age-standardised rate
CALD	Culturally and Linguistically Diverse
CNSA	Cancer Nurses Society of Australia
COSA	Clinical Oncology Society of Australia
DSS	Data Set Specification
GP	General practitioner
HMA	Healthcare Management Advisors
HPV	Human papilloma virus
IARC	International Agency for Research on Cancer
MOGA	Medical Oncology Group of Australia
NSW	New South Wales
NT	Northern Territory
OCA	Ovarian Cancer Australia
OT	Occupational Therapy
QLD	Queensland
RACGP	Royal Australian College of General Practitioners
RANZCOG	The Royal Australian and New Zealand College of Obstetricians and Gynaecologists
RANZCR	Royal Australian and New Zealand College of Radiologists
SA	South Australia
TAS	Tasmania
VIC	Victoria
WA	Western Australia

# Glossary

Term	Description
Acute services	Describes a hospital where patients receive treatment for an episode of illness
Adjuvant radiotherapy	Radiotherapy given after the primary treatment (such as surgery) which is aimed at killing any remaining cancer cells
Advanced disease	This term typically refers to cancer that has spread beyond the organ or tissues where it originated and is unlikely to be curable
Allied health providers	This group includes healthcare professionals – other than doctors and nurses – such as occupational therapists, dietitians, physiotherapists, social workers and others directly involved in the provision of health care
Brachytherapy	A form of radiotherapy where radioactive seeds or sources are placed inside or next to the area requiring treatment. Can be used alone or in combination with surgery, chemotherapy or other treatments
Cancer control	All actions that reduce the burden of cancer in the community. It includes every aspect of care, from prevention and early detection to curative treatment and palliative care, all underpinned by the best scientific evidence available
Cancer continuum	The full spectrum of cancer control services from prevention and early detection efforts, through diagnosis and treatment, to rehabilitation and support services for people living with cancer and/or palliative care
Cervical cancer	Cancer that forms in tissues of the cervix (the organ connecting the uterus and vagina). It is usually a slow-growing cancer that may not have symptoms but can be found with regular Pap tests (a procedure in which cells are scraped from the cervix and looked at under a microscope). Cervical cancer is almost always caused by human papilloma virus infection
Cervical cancer screening	The organised program of regular testing of women using Pap tests – also known as Pap smears – to detect early pre-cancerous changes in the cervix before cervical cancer develops. Cells are collected from the surface of the cervix and sent to a laboratory where they are tested for cellular abnormalities. Cervical screening can also detect if cervical cancer is present
Chemotherapy	The use of chemical agents (drugs) to kill cancer cells
Cochrane Review	A systematic review on a health-related topic undertaken by a global independent network of researchers
Colposcopy	A medical diagnostic procedure using a colposcope – an illuminated binocular microscope that magnifies the view of the cervix, vagina and vulva – to identify abnormal tissue
Co-morbidities	Co-existing medical conditions
Culturally and linguistically diverse (CALD)	People from a CALD background have a specific cultural or linguistic affiliation due to their country of birth, ethnic origin, language(s) and/or family traditions
Cytology	The study of cells using a microscope

Dietitian	Dietitians – or dieticians – specialise in the study of nutrition and its contribution to maintaining or restoring health
Endometrial cancer	Cancer that forms in the tissue lining the uterus (the small, hollow, pear-shaped organ in a woman’s pelvis in which a fetus develops). Most endometrial cancers are adenocarcinomas (cancers that begin in cells that make and release mucus and other fluids)
Epithelial ovarian cancer	Cancer that forms in the tissue covering the ovary (one of a pair of female reproductive glands in which eggs are made). Most ovarian cancers are epithelial ovarian cancers. Many epithelial ovarian cancers may originate in the fallopian tubes, which connect the ovaries to the uterus. Fallopian tube cancer and primary peritoneal cancer are similar to epithelial ovarian cancer and are staged and treated the same way. Also called ovarian epithelial cancer
Follow-up care	Monitoring a person’s health over time after treatment. This includes keeping track of the health of people who participate in a clinical study or clinical trial for a period of time, both during the study and after the study ends
Geneticist and genetic counsellor	Geneticists study genes, heredity and genetic causes of human variations. Genetic counsellors offer information and testing to help determine the diagnosis, risk, carrier and pre-symptomatic status of genetic conditions
Gynaecological cancer	This term refers to cancers that originate in a woman’s reproductive system, including cancers of the ovary, fallopian tube, uterus, cervix, vagina, vulva and placenta
Gynaecological oncologist	Gynaecological oncologists are gynaecologists who have undertaken additional specialist training in the diagnosis and management of women with gynaecological cancers
Gynaecological cancer nurse (or nurse coordinator/consultant)	A specialist cancer nurse who has specific expertise in supporting women with gynaecological cancer
Gynaecologist	Gynaecologists are specialist doctors in the field of women’s reproductive systems. Gynaecologists investigate, diagnose and treat diseases of the reproductive system
Human papilloma virus (HPV) vaccine	This vaccine prevents infection with some types of HPV, including types 16 and 18 which are responsible for the majority (70% internationally; 80% in Australia) of cervical cancers and a significant proportion of some other genital cancers
Lymphoedema	Swelling caused by a build-up of lymph fluid. This happens when lymph nodes do not drain properly, usually after lymph glands are removed
Medical oncologist	Specialist doctors with training in the management of cancer using chemotherapy as the main treatment modality
Menopause	The time in a woman’s life when the menstrual cycle ends
Multidisciplinary care	An integrated team approach to health care in which medical, nursing and allied healthcare professionals consider all relevant treatment options and collaboratively develop an individual treatment plan for each patient

Palliative care nurse	These nurses have specialist training in multidimensional symptom assessment and management, advanced care planning and coordination of palliative care services. They may provide inpatient, consultancy or specialist community-based support to patients
Nurse practitioner	These nurses have undertaken further (master's level) training, and are authorised to function autonomously and collaboratively in an advanced and extended clinical role
Occupational therapist	A health professional trained to help people who are ill or disabled learn to manage their daily activities
Ovarian cancer	Cancer that forms in tissues of the ovary (one of a pair of female reproductive glands in which the ova, or eggs, are formed). Most ovarian cancers are either epithelial ovarian cancers (cancer that begins in the cells on the surface of the ovary) or malignant germ cell tumours (cancer that begins in egg cells). Fallopian tube cancer and primary peritoneal cancer are similar to ovarian epithelial cancer and are staged and treated the same way
Palliative care (or specialist palliative care)	Specialised health care focusing on relieving and preventing the suffering of patients with life-threatening illness, including those with curable illnesses, chronic disease and those nearing the end of life
Pastoral care	Spiritual support and guidance provided by chaplains and other care workers who have a broad understanding of the spiritual beliefs of people from diverse cultures
Pathologist	Pathologists examine changes in the structure and composition of organs and tissues that occur as a result of disease
Person-centred care	Person-centred care considers patients' cultural traditions, their personal preferences and values, their family situations, and their lifestyles. It makes patients and their families an integral part of the care team who collaborate with health care professionals in making clinical decisions. Person-centred care provides an opportunity for patients to decide important aspects of self-care and monitoring. Person-centred care ensures that transitions between providers, departments, and health care settings are respectful, coordinated, and efficient. When care is person centred, unneeded and unwanted services can be reduced
Primary services	The patient's first point of contact with the healthcare system before referral to specialist services. Primary services providers include GPs, nurses and pharmacists
Psychiatrist	A physician with specialist training in mental illness. Psychiatrists can apply a range of modalities to diagnose, manage, treat and prevent mental and emotional illnesses
Psychologist	Psychologists have specific training in the biological, cognitive and social causes of human behaviour, and apply this knowledge to help people overcome emotional and behavioural problems
Psychosexual care	Care that relates to psychosexual experiences and needs of women / couples affected by gynaecological cancers

Psychosocial care	Care that relates to one's practical, social and psychological needs with the aim of helping to control symptoms or distress and increase satisfaction with life. It can include practical advice, motivational, social and vocational training, structured counselling, support and guidance. The term psychosocial care may be used interchangeably with supportive care, although does not include physical aspects of care
Radiation oncologist	A medical doctor who specialises in treating cancer patients using radiation therapy as the main treatment modality
Radiologist	A doctor who specializes in creating and interpreting pictures of areas inside the body. The pictures are produced with x-rays, sound waves, or other types of energy
Radiotherapy	The use of high-energy radiation from x-rays, gamma rays, neutrons, protons, and other sources to kill cancer cells and shrink tumours. Radiation may come from a machine outside the body (external-beam radiation therapy), or it may come from radioactive material placed in the body near cancer cells (internal radiation therapy). Systemic radiotherapy uses a radioactive substance, such as a radiolabeled monoclonal antibody, that travels in the blood to tissues throughout the body. Also called irradiation and radiation therapy
Shared care	Cooperation between different groups of clinicians to provide agreed aspects of care given to patients
Supportive care providers	These include social workers, psychologists, psychiatrists, sexual counsellors, pastoral care providers and other allied health providers who address a range of social, practical, psychological, spiritual and physical needs
Surgical oncologist	A doctor who specialises in the surgical treatment of cancer
Survivorship care	In cancer, survivorship focuses on the health and life of a person with cancer post treatment until the end of life. It covers the physical, psychosocial, and economic issues of cancer, beyond the diagnosis and treatment phases. Survivorship includes issues related to the ability to get health care and follow-up treatment, late effects of treatment, second cancers, and quality of life. Family members, friends, and caregivers are also considered part of the survivorship experience
Treatment plan	A written document outlining the commencement, approach, goals and progression of therapy
Uterine cancer	Includes malignant neoplasms of the endometrium, as well as lower uterine segment, myometrium, fundus uteri, and unspecified areas of the corpus uteri
Vaginal cancer	Cancer that forms in the tissues of the vagina (birth canal). The vagina leads from the cervix (the opening of the uterus) to the outside of the body. The most common type of vaginal cancer is squamous cell carcinoma, which starts in the thin, flat cells lining the vagina. Another type of vaginal cancer is adenocarcinoma, cancer that begins in glandular cells in the lining of the vagina
Vulval cancer	Vulval cancer is a cancer that arises from the tissues of the vulva. Cancer of the vulva may involve any of the external female sex organs. The most common areas for it to develop are the inner edges of the labia majora and the labia minora. It can also be called cancer of the vulva, vulva cancer or vulvar cancer

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