

CHAPTER 1

INTRODUCTION

Terms of Reference

1.1 On 11 May 2006, the Senate, on the motion of Senators Moore, Allison and Ferris, referred the following matters to the then Senate Community Affairs References Committee for inquiry and report by 19 October 2006:

Gynaecological cancer in Australia and in particular the:

- (a) level of Commonwealth and other funding for research addressing gynaecological cancers;
- (b) extent, adequacy and funding for screening programs, treatment services, and for wider health support programs for women with gynaecological cancers;
- (c) capability of existing health and medical services to meet the needs of Indigenous populations and other cultural backgrounds, and those living in remote regions;
- (d) extent to which the medical community needs to be educated on the risk factors, symptoms and treatment of gynaecological cancers;
- (e) extent to which women and the broader community require education of the risk factors, symptoms and treatment of gynaecological cancers; and
- (f) extent to which experience and expertise in gynaecological cancers is appropriately represented on national health agencies, especially the recently established Cancer Australia.

Conduct of the Inquiry

1.2 The inquiry was advertised in *The Australian* and through the Internet. The Committee invited submissions from Commonwealth, State and Territory Government departments and other interested organisations and individuals. The Committee continued to accept submissions throughout the inquiry.

1.3 The Committee received 72 public and 7 confidential submissions. A list of individuals and organisations that made public submissions to the inquiry together with other information authorised for publication is at Appendix 1.

1.4 The Committee held public hearings in Canberra, Sydney, Melbourne and Perth. In organising its hearing program, the Committee endeavoured to hear from as many individuals and organisations that represented and supported women with gynaecological cancers. The Committee also heard from three witnesses from the United States via teleconference and videoconference. A list of the witnesses who gave evidence at the public hearings is available at Appendix 2.

1.5 The Committee was pleased to undertake interesting and valuable inspections in Perth and Sydney. In Perth, the Committee had the opportunity to visit the Menopause Symptoms after Cancer Clinic at King Edward Memorial Hospital. In Sydney, the Committee visited the National Breast Cancer Centre and discussed The Ovarian Cancer Program. The Committee also held private discussions with Professor David Currow, CEO of Cancer Australia.

The Committee's report

1.6 Due to the broad range of issues covered within the Inquiry's terms of reference, the Committee has grouped related themes and topics together and allocated chapters accordingly.

1.7 Chapter 1 provides a general overview of the inquiry and provides information to give a basic understanding of gynaecological cancers. Chapter 2 discusses the concerns about the lack of attention given to gynaecological cancers at the national level and contains the major recommendation proposing that separate seed-funding be given to establish a national body focusing exclusively on gynaecological cancers.

1.8 The remaining chapters present and discuss evidence received on the terms of reference. Chapter 3 considers the appropriateness of current levels of funding for research. Chapter 4 discusses the adequacy of current screening, treatment and health support programs for women. Chapters 5 and 6 consider the information needs of the medical community, women and the broader community. Chapter 7 examines the extent to which gynaecological cancer expertise and experience is represented in national agencies, including Cancer Australia.

Background to the Inquiry

1.9 On 23 June 2005, the Senate tabled its report – *The cancer journey: informing choice*.¹ This inquiry considered matters relating to the delivery of services and options for treatment of persons diagnosed with cancer and the role of less conventional and complementary cancer therapies and medicines in treatment. The Commonwealth Government tabled its response to this report on 22 June 2006.

1.10 Evidence received during the current inquiry into gynaecological cancer in Australia raised concerns on the content of the Commonwealth Government's response to the Senate Committee's recommendations. The Cancer Council of Western Australia stated:

We are greatly disappointed about the lack of meaningful response to and action on these recommendations. We are very hopeful that this will not be the

1 Commonwealth of Australia, Senate Community Affairs Reference Committee, *The cancer journey: informing choice*, 23 June 2005.

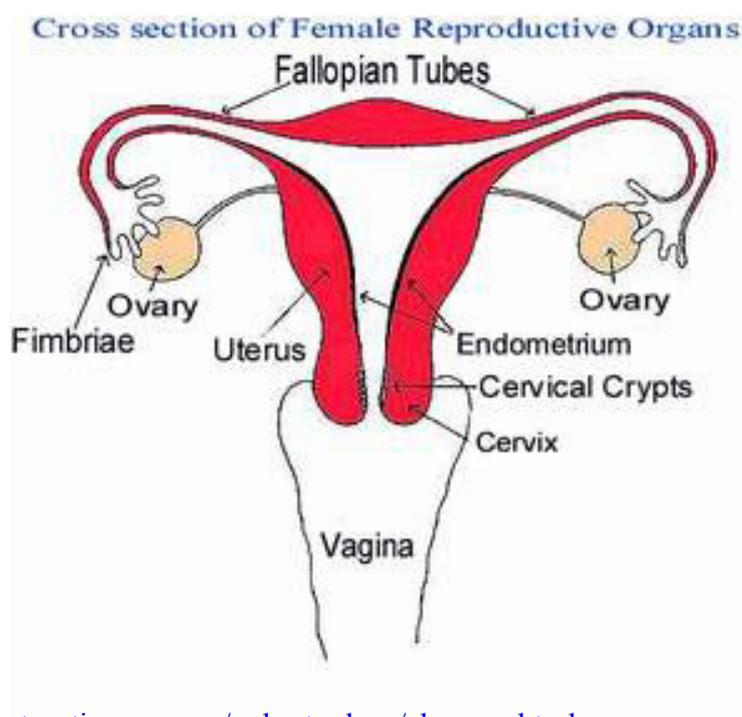
case in relation to any recommendations out of this [Gynaecological Cancer in Australia] inquiry. We welcome this inquiry.²

1.11 The precursor to the current inquiry came on 7 December 2005, when the Senate, on a motion of Senator Allison (on behalf of eight cross-party Senators) referred a petition tabled on 6 December 2005 from 2,887 signatories on the management and prevention of gynaecological cancers and Sexually Transmitted Infections (STIs) to the Committee for response to the Senate by 30 March 2006. The Committee convened a Roundtable discussion on 3 March 2006 in Canberra, from which the Committee recommended that a detailed inquiry into gynaecological cancers issues was warranted.

What are gynaecological cancers?

1.12 The term 'gynaecological cancers' refers to all cancers of the female reproductive tract. The specialist doctors trained to treat these cancers are gynaecological oncologists. A brief overview of gynaecological cancers is provided below including a diagram, symptoms, incidence and survival statistics.

Diagram 1: The Female Reproductive Organs



Source: www.menstruation.com.au/pubertyplace/changes.html

The types of gynaecological cancers

1.13 Gynaecological cancers comprise of cancers of the:

- ovary;
- fallopian tube;
- uterus;
- cervix;
- vagina;
- vulva; and
- placenta and gestational trophoblastic disease (pregnancy related cancers).

Risk factors for gynaecological cancers

1.14 Any woman is potentially at risk of developing a gynaecological cancer. While the exact causes of gynaecological cancers are not known, some factors that may play a role in the development of these cancers have been identified. These include:

- age;
- smoking;
- family history of cancer;
- women whose mothers were given the hormone diethylstilbestrol (DES) during their pregnancy;
- being overweight or obese; and
- personal history of cancer.

1.15 Also, certain subtypes of the human papilloma virus (HPV) have been identified as a major risk factor in the development of cervical cancer.³

1.16 The risk factors vary according to the type of gynaecological cancer and the occurrence of one or more of these risk factors do not necessarily mean a woman will develop a gynaecological cancer.

Prevention of gynaecological cancers

1.17 As the causes of gynaecological cancers are not known, it is important to identify women who may be at a higher risk of developing these cancers and then implement strategies that may assist in prevention and early intervention. The Gynecologic Cancer Foundation in the United States stated:

3 The Cancer Council Western Australia, *Gynaecological Cancer*, http://www.cancerwa.asn.au/resources/documents/patients/0402_gynaecological_dl.pdf; Gynecologic Cancer Foundation, *2005 State of the State of Gynecologic Cancers*, p.1.

Diet, exercise and lifestyle choices play a significant role in the prevention of cancer. Additionally, knowing your family history can increase your chance of early diagnosis and can help you take action toward prevention. Screening and self-examination conducted regularly can result in the detection of certain types of gynaecologic cancers in their earlier stages, when treatment is more likely to be successful and a complete cure is a possibility.⁴

The symptoms of gynaecological cancers

1.18 Most gynaecological cancers do not show early signs or symptoms. Symptoms often appear late in the condition and have been described as vague and ill-defined.⁵ Many of the identified symptoms of gynaecological cancers are common and can be similar to those occurring in women during their monthly menstrual cycle and may also suggest the presence of other medical conditions.

1.19 Commonly identified symptoms for gynaecological cancers are:

- abdominal bloating and/or feeling full;
- appetite loss;
- excessive tiredness and fatigue;
- unexplained weight gain;
- heartburn;
- increased swelling of the lower abdomen without weight gain elsewhere;
- increased swelling of the lower abdomen which does not improve with diet or exercise;
- a lump or mass in the abdomen, especially the lower abdomen;
- lower abdominal or pelvic pain that does not settle quickly and simply;
- feelings of pressure on the bowel or bladder and a feeling that the bowel or bladder cannot be completely emptied (constipation/urinary frequency);
- abnormal bleeding from the vagina, especially bleeding after the menopause;
- bleeding after intercourse;
- pain during intercourse;
- unusual vaginal discharge;
- leg pain or swelling; and/or
- low back pain.⁶

4 Gynecologic Cancer Foundation, *2005 State of the State of Gynecologic Cancers*, p.1.

5 *Submission 5*, p.6 (Mrs Lisle Fortescue); *Submission 14*, p.3 (GAIN).

6 The Cancer Council New South Wales, *Signs and Symptoms*, <http://www.cancercouncil.com.au/editorial.asp?pageid=475>; Gynaecological Cancer Society, *Tubal Cancer – Fact Sheet*, http://www.gcsau.org/qcgc/tubal/fact_sheet.asp#What.

1.20 The need for education to inform women, the broader community and the medical community of the symptoms of gynaecological cancers is discussed in Chapters 5 and 6.

Statistics on gynaecological cancers in Australia

1.21 The Australian Institute of Health and Welfare's (AIHW) most recently published report *Health System expenditures on cancers and other neoplasms in Australia* (May 2005) records data for the year 2000-2001.⁷ The fact that the most recent figures are five years old at publication creates difficulties when using these statistics as the basis for public policy decisions.

1.22 Evidence presented during the inquiry identified a number of difficulties relating to adequate data collection, including inconsistent cancer registry data and the ad hoc collection of gynaecological cancer data. Particular inadequacies were identified for Indigenous women and women from culturally and linguistically diverse populations. Data collection is discussed in Chapter 4.

Incidence of gynaecological cancers

1.23 In Australia in 2001, 3,886 women developed gynaecological cancers making this as a group of cancers the third most common for women, behind breast (11,791), colorectal cancer (5,883) and ahead of melanoma (3,861) and lung (2,891).⁸

1.24 The AIHW commented that for the period 1991 to 2001, there was:

- an 8 per cent increase overall in new cases of gynaecological cancers;
- a 31 per cent increase of the number of new cases of cancer of the uterus;
- a 23 per cent increase of the number of new cases of ovarian cancer and other cancers of the female genital organs;
- a 18 per cent increase of the number of new cases of cancer of the vulva, vagina and placenta; and
- a 33 per cent decrease of the number of new cases of cervical cancer.⁹

7 Australian Institute of Health and Welfare (AIHW 2005). *Health system expenditures on cancer and other neoplasms in Australia, 2000-01*. AIHW cat. no. HWE 29. Canberra: AIHW (Health and Welfare Expenditure Series no.22).

8 Australian Institute of Health and Welfare (AIHW) & Australasian Association of Cancer Registries (AACR) 2004. *Cancer in Australia 2001*. AIHW cat. no. CAN 23. Canberra: AIHW (Cancer Series no.28).

9 *Submission 3*, p.1 (AIHW).

Table 1: Number New Cases of each Gynaecological Cancer, 1998 - 2001

	1998	1999	2000	2001
Vulval	211	200	203	252
Vaginal	56	73	71	62
Cervical	855	794	754	735
Uterine	1397	1434	1580	1537
Ovarian	1232	1218	1263	1248
Other Gynaecological	50	67	58	52

Source: Submission 24, p.5 (ASGO).

Projections for new cases of gynaecological cancers

1.25 With an increase in the age of the population, the overall number of new cases of gynaecological cancers is projected to increase by almost 15 per cent from 3,886 in 2001 to 4,487 in 2011.¹⁰

1.26 The AIHW project that the incidence of gynaecological cancer as a group will slowly decline over time as a result of the decrease in the incidence of cancer of the cervix. The improvement in the cervical cancer incidence rate has been attributed in part to the National Cervical Screening Program and the early detection of cervical cancer.

1.27 In fact, cancer of the cervix is the only gynaecological cancer for which the expected number of new cases is projected to decrease even with the expected ageing of the population. The number of new cases reported in 2001 was 735, which is projected to decrease by 37 per cent to 461 by 2011.¹¹

1.28 The AIHW has projected the incidence of new cases of gynaecological cancers in 2006 and 2001 and these figures are detailed in Table 2.

¹⁰ *Submission 3*, p.1 (AIHW).

¹¹ AIHW, *Cancer incidence projections Australia 2002 to 2011*, p.11.

Table 2: AIHW projection of incidences of gynaecological cancers

	2006	2011
<i>Gynaecological cancer</i>		
	Number	
Cervical cancer	582	461
Cancer of uterus	1 738	1 967
Ovarian cancer and other unspecified cancers of the female genital organs	1 465	1 645
Cancer of vulva, vagina and placenta	367	414
Total cancers of female genital organs	4 152	4 487
	Per cent	
Cervical cancer	14.0	10.3
Cancer of uterus	41.9	43.8
Ovarian cancer and other unspecified cancers of the female genital organs	35.3	36.7
Cancer of vulva, vagina and placenta	8.8	9.2
Total cancers of female genital organs	100.0	100.0

Source: Submission 3, p.1 (AIHW).

Deaths from gynaecological cancers

1.29 When considering mortality from gynaecological cancers, the AIHW stated:

The risk of developing a malignant gynaecological cancer is 1 in 34 by 75 years of age and increases to 1 in 23 by 85 years of age. The risk of dying from a malignant gynaecological cancer is 1 in 103 at 75 years of age and rises to 1 in 55 by 85 years of age.¹²

1.30 The Sydney Gynaecological Oncology Group commented on the high mortality rate for gynaecological cancers compared with breast cancer.

The number of women dying from gynaecological cancers is disproportionately high compared to breast cancer which only had a comparative 22% mortality rate in 2001. Much of this effect is from ovarian cancer with a 66% death rate in the same period.¹³

¹² Submission 3, p.2 (AIHW).

¹³ Submission 10, p.3 (Sydney Gynaecological Oncology Group).

Table 3: Deaths from gynaecological cancers

	1991	2001	2004
<i>Gynaecological cancer</i>			
	Number		
Cervical cancer	336	262	212
Cancer of uterus	257	293	327
Ovarian cancer and other unspecified cancers of the female genital organs	728	846	851
Cancer of vulva, vagina and placenta	72	117	89
Total cancers of female genital organs	1 393	1 518	1 530
	Per cent		
Cervical cancer	24.1	17.3	14.3
Cancer of uterus	18.4	19.3	22.1
Ovarian cancer and other unspecified cancers of the female genital organs	52.3	55.7	57.5
Cancer of vulva, vagina and placenta	5.2	7.7	6.0
Total cancers of female genital organs	100.0	100.0	100.0

Source: Submission 3, p.2 (AIHW).

Survival rates for women with gynaecological cancers

1.31 The AIHW provided the life expectancy for women (relative survival) five years after diagnosis for the following gynaecological cancers:

- endometrial – 81.4 per cent;
- cervical cancer – 74.6 per cent; and
- ovarian cancer – 42 per cent.¹⁴

1.32 The Garvan Institute of Medical Research provided a comparative relative survival rate for breast cancer of 84 per cent and commented that ovarian cancer was less than half this figure.¹⁵

¹⁴ *Submission 3, p.5 (AIHW).*

¹⁵ *Submission 29, p.1 (Garvan Institute of Medical Research).*

Conclusion

1.33 Some gynaecological cancers remain a mystery with an absence of knowledge and definitive understanding of the causes, signs and symptoms. The incidence of these types of cancer (with the exception of cervical cancer) is projected to increase in years to come. Although the Committee heard that Australia is performing well when compared internationally, the fact remains that in 2004, 1,530 Australian women died as a result of gynaecological cancers and this figure will most likely increase if further advancements in screening, treatment and wider health support programs are not found.