

The Senate

Standing Committee on
Community Affairs

Breaking the silence: a national
voice for gynaecological cancers

October 2006

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MEMBERSHIP OF THE COMMITTEE

From 11 September 2006 ¹

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Senator Ruth Webber	ALP, Western Australia

Senate Community Affairs References Committee

Until 10 September 2006

Members

Senator Claire Moore, Chair	ALP, Queensland
Senator Gary Humphries, Deputy Chairman	LP, Australian Capital Territory
Senator Judith Adams	LP, Western Australia
Senator Lyn Allison	AD, Victoria
Senator Carol Brown	ALP, Tasmania
Senator Helen Polley	ALP, Tasmania

Participating Members

Senator Jeannie Ferris	LP, South Australia
Senator Ruth Webber	ALP, Western Australia

¹ The Senate Committee system was restructured on 11 September 2006 to amalgamate the former legislation and references committees. The membership of committees was varied as part of the restructure. Inquiries that were current on 11 September continued with the same terms of reference and reporting dates.

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LIST OF ACRONYMS

AACR	Australasian Association of Cancer Registries
AHMAC	Australian Health Ministers' Advisory Council
AHMC	Australian Health Ministers' Conference
AIHW	Australian Institute of Health and Welfare
AMWAC	Australian Medical Workforce Advisory Committee
ANZGOG	Australia New Zealand Gynaecological Oncology Group
AOCS	Australian Ovarian Cancer Study
APA	Australian Physiotherapy Association
ASAC	Australian Screening Advisory Committee
ASCUS	Atypical Squamous Cells of Uncertain Significance
ASGO	Australian Society of Gynaecological Oncologists
CDMRP	Congressionally Directed Medical Research Program (United States)
CEO	Chief Executive Officer
CNSA	Cancer Nurses Society of Australia
COSA	Clinical Oncological Society of Australia
Department	Commonwealth Department of Health and Ageing
DES	Diethylstilbestrol
DNA	Deoxyribonucleic acid
FECCA	Federation of Ethnic Communities' Councils of Australia
FIGO	International Federation of Gynecology and Obstetrics (United States)
FRANZCOG	Fellowship of the Royal Australian and New Zealand College of Obstetricians and Gynaecologists
GAIN	Gynaecological Awareness Information Network
GMCT	Greater Metropolitan Clinical Taskforce
GOG	Gynecologic Oncology Group (United States)
GP	General Practitioner
HPV	Human papilloma virus
IPTAAS	Isolated Patients Travel and Accommodation Assistance Scheme
LSIL	Low-grade Squamous Intraepithelial Lesions
MCIS	Multicultural Cancer Information Service
MRI	Magnetic Resonance Imaging
MSAC	Medical Services Advisory Committee
MSOAP	Medical Specialist Outreach Assistance Program
NACCHO	National Aboriginal Community Controlled Health Organisation
NBCC	National Breast Cancer Centre

NCCI	National Cancer Control Initiative
NCSP	National Cervical Screening Program
NHMRC	National Health and Medical Research Council
NIH	National Institutes of Health (United States)
NSW	New South Wales
OvCA	National Ovarian Cancer Network
RACGP	Royal Australian College of General Practitioners
RANZCOG	Royal Australian and New Zealand College of Obstetricians and Gynaecologists
RCPA	Royal College of Pathologists of Australasia
RHW	Royal Hospital for Women (NSW)
ROJIG	Radiation Oncology Jurisdictional Implementation Group
RWH	Royal Women's Hospital (VIC)
STI	Sexual Transmitted Infection
TIS	Translating and Interpreter Service
UK	United Kingdom
WA	Western Australia

EXECUTIVE SUMMARY

This inquiry gave the Senate Standing Committee on Community Affairs a unique opportunity to meet with many people in the gynaecological cancer sector, including women with gynaecological cancers, survivors, gynaecological oncologists, medical and allied health professionals, representative bodies and consumer advocacy groups.

Throughout this inquiry, the Committee heard from witnesses who commented that the inquiry's terms of reference had given the gynaecological cancer sector reason to reflect on the current challenges facing them and future directions.

The Committee's focus throughout the inquiry remained primarily with the women with, or at risk of, gynaecological cancers and their needs. Evidence suggested that women in Australia were generally able to access appropriate care and that the gynaecological cancer sector performed well when compared to other countries. Despite this, it was clear that much more still needed to be done to improve health outcomes for women and to lessen the impact of cancer on their lives.

Many of the issues and concerns that arose during this current inquiry were similar to those that the Committee considered during its June 2005 inquiry into cancer services and treatment – *The cancer journey: informing choice* – and its March 2006 Roundtable discussion on gynaecological health issues.

In the area of research, evidence strongly indicated that recurrent funding was needed to drive new developments in gynaecological oncology, particularly a screening test for ovarian cancer to enable earlier identification of the disease. Better funding support was also thought to be essential for maintaining the vitality and the enthusiasm of researchers and for minimising the burden of fundraising on community groups.

The provision of high quality treatment and wider health support programs was also argued to be a critical element in improving health outcomes for women with gynaecological cancers. However, the Committee heard that access was not equal across the community with disproportionate rates of women from rural and remote areas and from culturally diverse populations generally having limited or no access to the services they needed. Evidence suggested that this inequality was particularly evident in the areas of psychosocial and psychosexual support. Allocation of increased funding for treatment and support programs and more targeted national health strategies were considered to be important areas of need.

A pre-requisite for the timely referral of women to specialist care is a strong level of knowledge amongst professionals about gynaecological cancers. It was argued that there were varying levels of awareness amongst the medical community and effort was needed to continually improve the delivery of gynaecological oncology education on a formal and continuing basis. Better support for professionals, particularly general practitioners and nurses, to pursue educational opportunities was also highlighted as a

critical need. A more targeted approach in the delivery of messages and programs were thought to be the key to appropriate referral of women to gynaecological oncologists.

The Committee heard that education for women and the broader community about gynaecological cancers was just as important, if not more so, than education for the medical community. In order for women to be aware of symptoms and to make informed decisions, information needed to be visible and accessible to women and the broader community. Coordination of existing efforts and the development of clear and consistent messages to women – possibly through a national awareness campaign on gynaecological cancers – were argued to be important elements in the way forward.

Evidence to the Committee questioned the extent to which expertise and experience in gynaecological oncology and related issues was being utilised effectively by the national health agencies, particularly Cancer Australia, that advise the Commonwealth Government. The majority of submissions that discussed the issue of representation suggested to the Committee that the gynaecological cancer sector would benefit from having its own structure, its own infrastructure and its own way of doing things. In recognition of the value of bringing people together, many recommended that a national centre be established to strengthen understanding of gynaecological cancer issues at the political and policy level and to provide many of the 'answers' needed to lessen the impact of these cancers on women.

This report has made a number of recommendations. Key amongst these is the call for initial funding from the Commonwealth Government for the establishment of a stand-alone Centre for Gynaecological Cancers within the auspices of Cancer Australia to provide a 'national voice' for gynaecological cancer issues. In making this and other recommendations the Committee saw that real change would only happen if greater emphasis was placed on the needs of women in Australia with, or at risk of, gynaecological cancers.

RECOMMENDATIONS

Chapter 2

Recommendation 1

2.54 The Committee recommends that the Commonwealth Government establish a Centre for Gynaecological Cancers within the auspices of Cancer Australia. The Centre will have responsibility for giving national focus to gynaecological cancer issues and improving coordination of existing health, medical and support services and community projects.

Recommendation 2

2.55 The Committee recommends, as a matter of priority, that the Centre for Gynaecological Cancers develops a website that is a 'one-stop shop' for reliable information on all issues relating to gynaecological cancers, including education, research and availability of services. The website of the National Institutes of Health in the United States is an example of a successful website upon which to base an Australian equivalent.

2.56 In all aspects of its work, the Centre should make optimal use of communications and information technology, including the Internet, to bring people together to discuss issues.

Recommendation 3

2.57 The Committee recommends that a working group be formed, with the support of Cancer Australia, consisting of individuals with experience and expertise in gynaecological cancers to best develop the roles, responsibilities and priorities of the Centre for Gynaecological Cancers.

Recommendation 4

2.58 The Committee recommends that the Commonwealth Government provide the Centre for Gynaecological Cancers with seed-funding of \$1 million for establishment and operational costs.

Recommendation 5

2.59 The Committee recommends that a national secretariat be formed within Cancer Australia to define the Centre for Gynaecological Cancers' ongoing objectives and to evaluate the success of the Centre after two years.

2.60 The Committee further recommends that the Centre and its national secretariat work closely with Cancer Australia and its advisory groups, particularly the Gynaecological Cancer Advisory Group, and the National Breast Cancer Centre to ensure a cohesive approach to improving gynaecological cancer care in Australia.

Chapter 3

Recommendation 6

3.108 The Committee recommends that the Commonwealth Government commit further recurrent funding for:

- basic research and clinical trials on topics relating to gynaecological cancers; and
- academic research positions in areas relating to gynaecological cancers.

Recommendation 7

3.109 The Committee recommends that the Commonwealth Government in collaboration with Cancer Australia:

- review the current level of funding allocated to bodies and individuals undertaking gynaecological cancer research in Australia; and
- provide leadership in relation to the allocation of research funding for gynaecological cancers; and
- improve awareness within the research community about the work being undertaken in order to minimise duplication.

Chapter 4

Recommendation 8

4.183 The Committee recommends that Cancer Australia work with the gynaecological cancer sector on an ongoing basis to develop national strategies improving the visibility of, and access to, screening, treatment and support services for women with gynaecological cancers.

Recommendation 9

4.184 The Committee recommends that the Commonwealth Government's funding and leadership of the National Cervical Screening Program continue and that strategies be implemented to improve screening participation rates for Australian women, particularly for Indigenous women.

4.185 The Committee further recommends that the Commonwealth work collaboratively with State and Territory Governments to promote the National Cervical Screening Program for all Australian women.

4.186 The Committee further recommends that the Commonwealth Government explore the extension of Medicare rebates for Pap tests performed by nurse practitioners, regional nurses and Indigenous health workers who are suitably trained.

Recommendation 10

4.187 The Committee recommends that, as a priority, State and Territory Governments provide further funding so that all women being treated for gynaecological cancers have access, based on need, to clinical psychologists or psychosexual counsellors.

Recommendation 11

4.188 The Committee recommends that Commonwealth, State and Territory Governments work collaboratively to ensure adequate funding for health and support programs in rural and remote areas, such as increased funding for specialist outreach clinics and for the use of modern telecommunications technologies.

Recommendation 12

4.189 The Committee recommends that the Council of Australian Governments, as a matter of urgency, improve the current patient travel assistance arrangements in order to:

- establish equity and standardisation of benefits;
- ensure portability of benefits across jurisdictions; and
- increase the level benefits to better reflect the real costs of travel and accommodation.

Recommendation 13

4.190 The Committee recommends that the Commonwealth Government consider a Medicare Item Number for lymphoedema treatment by accredited physiotherapists and the provision of subsidised lymphoedema compression garments, based on need, for women as a result of cancer treatment.

Recommendation 14

4.191 The Committee recommends that the Commonwealth Government through the Medical Services Advisory Council (MSAC), review the MSAC's decisions on the use of liquid-based cytology (LBC) and high risk human papilloma virus (HPV) DNA testing in cervical screening processes.

Recommendation 15

4.192 The Committee recommends that the Commonwealth Department of Health and Ageing, as a priority, develop national strategies surrounding HPV vaccines and testing. Specifically, targeted and customised strategies to:

- highlight the benefits of HPV vaccines;

- provide easy access to the vaccines and appropriate educational resources, particularly for Indigenous Australians and people from culturally and linguistically diverse backgrounds; and
- develop and encourage the use of self-testing for high risk HPV

Recommendation 16

4.193 The Committee recommends that the Commonwealth Government, in collaboration with Cancer Australia and the Centre for Gynaecological Cancers, develop strategies and targets to improve referral rates from general practitioners to gynaecological oncologists for women with ovarian cancer.

Recommendation 17

4.194 The Committee recommends that the Commonwealth Government, as a priority, assume responsibility for the funding, development and implementation of a national data collection and management system to ensure the appropriate and accurate collection of gynaecological cancer data.

Recommendation 18

4.195 The Committee recommends that the Commonwealth Government in conjunction with the State and Territory Governments to expand the roles and responsibilities of specialist breast cancer nurses to include gynaecological cancers through cooperation with multidisciplinary gynaecological cancer centres.

Recommendation 19

4.196 The Committee recommends that the Commonwealth Government explore the need for Medicare rebates for MRI scans of pelvic, abdominal and breast areas.

Recommendation 20

4.197 The Committee recommends that Commonwealth, State and Territory Governments commit urgently needed funding and increased specialist resources to reduce current waiting times for women seeking the services of gynaecological oncologists and their multidisciplinary teams.

4.198 The Committee further recommends that maximum surgery waiting times are defined by key performance indicators agreed by treating physicians as not putting patients at risk.

Chapter 5

Recommendation 21

5.103 The Committee recommends that an urgent review of the adequacy and provision of information to medical and allied health professionals about gynaecological cancers be undertaken by the Centre for Gynaecological Cancers.

5.104 The Committee further recommends that the gynaecological oncology medical and allied health communities, through the Centre for Gynaecological Cancers, have greater input into decisions about education strategies for professionals, women and adolescents.

Recommendation 22

5.105 The Committee recommends that the Centre for Gynaecological Cancers, with assistance from the gynaecological cancer community, develop culturally appropriate educational material focusing on the risk factors and symptoms of gynaecological cancers. Any such material should specifically meet the needs of general practitioners, nurses (including remote area nurses), Aboriginal health workers, gynaecologists and allied health professionals

5.106 The Committee further recommends that educational materials be provided to general practitioners to inform them about the sub-specialty of gynaecological oncology and the circumstances in which it is appropriate to refer women to gynaecological oncologists.

Recommendation 23

5.107 The Committee recommends that Cancer Australia formally investigate the referral patterns of general practitioners at a national level and devise appropriate strategies to address any concerning trends.

5.108 The Committee further recommends that accurate and accessible service directories should be developed in all jurisdictions to support knowledge-based appropriate referrals.

Recommendation 24

5.109 The Committee recommends the development and distribution of clinical practice guidelines for all gynaecological cancers (or similar consistent and authoritative information) to ensure standard practice across the healthcare system.

5.110 The Committee further recommends that the Australian Divisions of General Practice include gynaecological cancer issues in at least one professional development seminar per year.

Recommendation 25

5.111 The Committee recommends that all gynaecologists involved in treating gynaecological cancers associate themselves with a recognised multidisciplinary specialist gynaecological cancer unit.

Recommendation 26

5.112 The Committee recommends that appropriate educational opportunities be offered to medical and allied health professionals from all settings to increase

skills in gynaecological oncology. Appropriate financial incentives or assistance packages should be offered, and given where required.

Recommendation 27

5.113 The Committee recommends that doctors who are training to be general practitioners be exposed to the concept of multidisciplinary care and the sub-specialty of gynaecological oncology in their training.

5.114 The Committee further recommends that medical professionals receive instruction and experience, where relevant, in diagnosing malignant gynaecological cancers through educational programs.

Chapter 6

Recommendation 28

6.105 The Committee recommends that Cancer Australia, in conjunction with the Centre for Gynaecological Cancers, be given wide-ranging responsibility for the management of coordinated national education strategies targeting women and their families, friends, carers and the broader community about gynaecological cancers.

6.106 The Committee further recommends that a review of all existing gynaecological cancer educational material targeting women and the broader community be undertaken by Cancer Australia, in conjunction with a Centre for Gynaecological Cancers, to review the currency of the content and the appropriateness for the audience.

Recommendation 29

6.107 The Committee recommends that Cancer Australia and the Centre for Gynaecological Cancers work together to develop a resource pack be developed and disseminated to give women and the broader community consolidated and consistent information about gynaecological cancers, treatment options, support groups and other services.

Recommendation 30

6.108 The Committee recommends that Cancer Australia and the Centre for Gynaecological Cancers work together to ensure that medical facilities and support organisations have visible and current information on-site in the form of posters and pamphlets about gynaecological cancers and related services.

Recommendation 31

6.109 The Committee recommends that Cancer Australia analyse and assess the approach taken in the United States in the following areas:

- public education (for example, the strategies of the Centres for Disease Control in relation to ovarian cancer);

- advocacy by gynaecological cancer groups; and
- service provision by support groups.

Chapter 7

Recommendation 32

7.88 The Committee recommends that Cancer Australia collaborate with individuals and groups to identify the best ways to ensure that expertise and experience in gynaecological cancer is represented on national health agencies, particularly Cancer Australia.

7.89 The Committee further recommends that consumer and community representatives have greater involvement in the decision-making of national health agencies.

7.90 The Committee further recommends that when membership of Cancer Australia's Advisory Council is due for review, one or more consumer representatives from the reproductive cancer sector be appointed to maintain the confidence of groups within those areas.

Recommendation 33

7.91 The Committee recommends that the Commonwealth Department of Health and Ageing, Cancer Australia and the Centre for Gynaecological Cancers communicate with each other about the content of future work plans in order to avoid confusion over responsibility for the development of initiatives and program delivery.

Recommendation 34

7.92 The Committee recommends that the Centre for Gynaecological Cancers put arrangements in place to ensure continuity between the work of the now defunct National Cancer Control Initiative and Cancer Australia, particularly in relation to gynaecological cancers.

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.

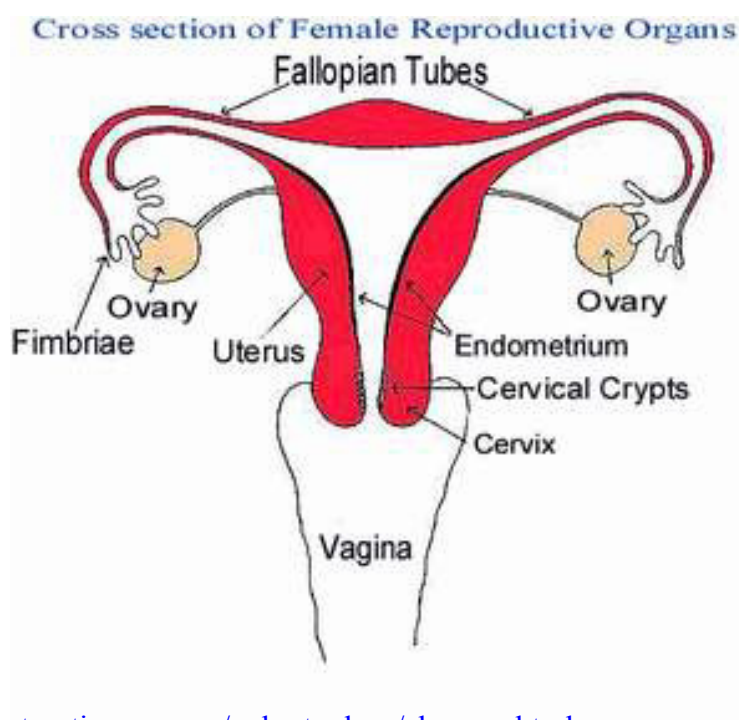
case in relation to any recommendations out of this [Gynaecological Cancer in Australia] inquiry. We welcome this inquiry.²

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.

CHAPTER 2

A STRONGER VOICE FOR GYNAECOLOGICAL CANCERS IN AUSTRALIA

Introduction

2.1 The Commonwealth Government's decision to establish Cancer Australia as part of its Strengthening Cancer Care initiative is a positive and essential step in improving cancer care and lessening the impact of cancer on all Australians. However, the Committee believes that Cancer Australia's formation is simply the first step of many in the ongoing process of improving the approach to cancer prevention and care across the board. In this evolving process more needs to be done immediately for gynaecological cancers.

2.2 During the inquiry, the Committee heard wide-ranging concerns that the combined 'voice' of women and other stakeholders was often overshadowed by other cancers, or worse, not heard at all. Ms Natalie Jenkins, Chairperson of the Gynaecological Awareness Information Network (GAIN), said that something similar to the 'powerful voice' of the National Breast Cancer Centre (NBCC) was needed for gynaecological cancers.

A powerful voice is required to implement national campaigns and programs similar to that of the successful breast cancer movement, which has achieved a great deal for the Australian community.¹

2.3 There is an urgent need to rectify this situation and to ensure that more attention is directed to this important area of women's health.

2.4 It is evident that the gynaecological cancer sector is in need of greater coordination and cohesion which is not met by the existing cancer structures and processes. The current 'state of play' – rising incidence of gynaecological cancers, the lack of equality in service provision and the low levels of funding and awareness – indicates it is of utmost importance to recognise the value of bringing people together with experience and expertise to ensure a better future for women with gynaecological cancers.

2.5 Many witnesses argued that a national approach to gynaecological cancers would provide the answer and that the establishment of a dedicated body would make a significant difference to the lives of women with, or at risk of, gynaecological cancers. This suggestion was supported by many who participated in the inquiry, including cancer survivors, gynaecological oncologists, medical and allied health professionals, professional bodies and consumer advocacy groups.

1 *Committee Hansard* 4.8.06, p.37 (GAIN).

A national approach

2.6 The adoption of a national approach to gynaecological cancer issues was thought to be a positive and necessary step towards strengthening the gynaecological cancer 'voice'. Ms Margaret Heffernan, a gynaecological cancer advocate, stated:

...a unified national approach will create synergy and overcome the imbalance created by the current diversified and inconsistent approach to research, education and resources. These independent and uncoordinated efforts are unwittingly creating barriers to effective collaboration; research of screening tests, especially in ovarian cancer; appropriate consumer resources and education; clinical education and resources; and treatment services, especially in the management of psychosocial and psychosexual needs.²

2.7 It was agreed by many involved in the inquiry that a national approach to gynaecological cancers should be implemented to ensure the timely development and oversight of national strategies aimed at lessening the impact of these cancers on women's lives. Although Cancer Australia is operational, many individuals and groups including the Australian Society of Gynaecologic Oncologists (ASGO), expressed support for the formation of an additional body specifically responsible for coordinating and improving gynaecological cancer services, education, advocacy and research in Australia.³

2.8 The Committee acknowledged that different views were expressed about how a national approach would be implemented and funded.

2.9 The majority of witnesses and submitters supported one of the following two approaches as possible ways of boosting the gynaecological cancer 'voice':

- the establishment of a self-determining national gynaecological cancer body; or
- the expansion of the NBCC's remit to include gynaecological cancers.

2.10 Regardless of the differences in approach, the common theme arising from the evidence highlighted the need for effort to be made to improve coordination and to reduce the duplication of effort and resources.

The need for national coordination

2.11 It was clear from the evidence that a number of obstacles to effective and efficient gynaecological cancer care existed. These included:

2 *Committee Hansard* 3.8.06, p.39 (Ms Margaret Heffernan).

3 *Submission* 24, p.7 (ASGO); *Submission* 40, p.6 (Professor Neville Hacker); *Committee Hansard* 16.8.06, p.7 (United States National Cancer Institute).

- the lack of formal representation of gynaecological cancer expertise and experience at the national level;⁴
- the lack of a separate representative organisation to provide meaningful services for, and representation of, consumers' and professionals' interests;⁵
- the lack of strategic direction, leadership and dedicated resources;⁶ and
- the lack of priority given to funding for gynaecological cancers.

2.12 A number of points were raised throughout the inquiry that indicated the need for improved coordination. Witnesses and submitters argued there was:

- duplication of resources, priorities and programs particularly in the non-government sector in relation to research and education.⁷
- no central reference point for organisations meaning that they often worked in isolation from one another and often competed for limited resources;⁸ and
- ad hoc communication between organisations and professionals that often only occurred on a needs basis.⁹

2.13 What was clear from the evidence presented was not how much was being done in relation to improving quality, but how fragmented the current approach was. Apart from isolated examples of limited coordination (for example, through the Australian Society of Gynaecologic Oncologists (ASGO), the Australia New Zealand Gynaecological Oncology Group (ANZGOG) and the NBCC's Ovarian Cancer Program) there was no national, comprehensive approach to gynaecological cancers.

2.14 It was thought that bringing individuals and organisations together at a national level could lead to greater efficiencies and the better use of funds. It was argued that achieving greater transparency and better coordination become a higher priority.

2.15 Professor Jonathan Carter of Sydney Gynaecological Oncology Group at the Royal Prince Alfred Hospital summed up the views of many of the gynaecological oncologists about the need for a national approach to improve coordination.

4 *Submission 27*, p.20 (Ms Margaret Heffernan).

5 *Submission 27*, p.20 (Ms Margaret Heffernan); *Submission 28*, p.2 (Western Australia Gynaecologic Cancer Service).

6 *Submission 37*, p.4 (The Royal Women's Hospital); *Submission 25*, p.7 (Hunter New England Centre for Gynaecological Cancer); *Committee Hansard 3.8.06*, p.47 (Ms Margaret Heffernan).

7 *Submission 27*, pp.22-23 (Ms Margaret Heffernan); *Submission 24*, p.7 (ASGO); *Committee Hansard 2.8.06*, p.8 (The Cancer Council Australia).

8 *Submission 24*, p.7 (ASGO); *Committee Hansard 3.8.06*, p.47 (Ms Margaret Heffernan); *Committee Hansard 1.8.06*, p.2 (Royal Hospital for Women).

9 *Submission 24*, p.7 (ASGO).

We are all trying to do a good job to a greater or lesser extent but we are doing it in a disjointed fashion. I think what we are lacking in gynaecologic oncology in this country is a national task force or a national gynaecological cancer centre.¹⁰

2.16 The development of a national organisation was suggested as a way of minimising the separate agendas and duplication found in the gynaecological cancer sector (particularly in relation to profile raising and education programs). Many proposed the establishment of a national centre to determine effective mechanisms for the coordination of research, service delivery, community efforts and other issues.¹¹

A self-determining national body for gynaecological cancers

2.17 There was considerable support for the establishment of a self-determining body, frequently referred to in evidence as a National Gynaecological Cancer Centre (or NGCC).¹² The Gynaecological Cancer Society argued:

The establishment of the NGCC can only benefit all gynaecological cancer stakeholders.¹³

Benefits of a NGCC

2.18 Witnesses argued that a well-funded and supported NGCC could bring the following benefits:

- a higher profile for gynaecological cancers at the political level;
- better coordination;¹⁴
- the infrastructure to increase capacity for reducing the burden of gynaecological cancers at a local, national and international level;¹⁵
- creation of a national strategy to coordinate smaller, local initiatives and to ensure targeted initiatives continue in the areas of research, service delivery, resource development and women's needs.¹⁶

10 *Committee Hansard* 2.8.06, pp.82-83 (Royal Prince Alfred Hospital).

11 *Submission* 27, p.20 (Ms Margaret Heffernan).

12 *Submission* 24, p.7 (ASGO); *Submission* 27, p.20 (Ms Margaret Heffernan); *Committee Hansard* 4.8.06, p.44 (GAIN).

13 *Submission* 7, p.3 (Gynaecological Cancer Society).

14 *Submission* 27, p.24 (Ms Margaret Heffernan).

15 *Submission* 27, pp.24-25 (Ms Margaret Heffernan).

16 *Submission* 46, p.10 (Associate Professor Margaret Davy); *Committee Hansard* 4.8.06, p.37 (GAIN); *Committee Hansard* 2.8.06, p.83 (Royal Prince Alfred Hospital); *Committee Hansard* 4.8.06, p.63 (Western Australia Gynaecologic Cancer Service); *Committee Hansard* 16.8.06, p.7 (United States National Cancer Institute).

- a national repository for more accurate data to assist in the development and distribution of educational information and treatment protocols to women, the public, general practitioners and allied health workers;¹⁷
- greater recognition and support for research into gynaecological cancers and standardising treatment and research protocols in line with national and international guidelines;¹⁸
- mechanisms for the involvement of all stakeholders, including broadening the involvement in policy making and planning to include women so that gynaecological cancer programs are more appropriately tailored to the needs of Australian women;¹⁹
- better communication between key stakeholders through a partnerships approach, some of whom are geographically dispersed;²⁰
- improving access to, and creation of, new prevention strategies and multidisciplinary management of individuals at risk or patients with a gynaecological cancer;²¹ and
- creation of a highly visible and accessible resource centre for professionals and for the general public.²²

2.19 Professor Neville Hacker, Director of the Gynaecological Cancer Centre at the Royal Hospital for Women, argued that a NGCC would be a 'linchpin' for research, education and advocacy for gynaecological cancer in Australia.²³

2.20 In addition, Professor J Norelle Lickiss, a palliative medicine specialist, said that the 'symbolic value' of creating a NGCC was important and that its establishment would stimulate greater interest in the situation of women with gynaecological cancers.²⁴

2.21 The Gynaecological Cancer Society argued that all the necessary elements for an effective and efficient NGCC already existed within State-based organisations. Incorporating the best elements of each under the umbrella of the NGCC would

17 *Committee Hansard* 2.8.06, p.83 (Royal Prince Alfred Hospital).

18 *Submission* 10, p.5 (Sydney Gynaecological Oncology Group).

19 *Submission* 27, p.22 (Ms Margaret Heffernan).

20 *Committee Hansard* 2.8.06, p.50 (ASGO); *Committee Hansard* 4.8.06, p.26 (Cancer and Palliative Care Network).

21 *Submission* 10, p.5 (Sydney Gynaecological Oncology Group).

22 *Committee Hansard* 4.8.06, p.43 (GAIN), *Committee Hansard* 2.8.06, p.50 (ASGO).

23 *Committee Hansard* 1.8.06, p.2 (Royal Hospital for Women).

24 *Committee Hansard* 2.8.06, p.73 (Professor J Norelle Lickiss).

quickly, cheaply and efficiently address the problem areas represented by communication, duplication and statistical gathering and analysis.²⁵

Support from the Australian Society of Gynaecologic Oncologists

2.22 The Australian Society of Gynaecologic Oncologists (ASGO) is currently the closest organisation to a national body representing gynaecological oncologists and gynaecological cancer issues. Its work is done in an honorary capacity and ASGO said that it lacked the infrastructure to effectively perform the role needed of it.²⁶ ASGO, and many of the gynaecological oncologists it represents, indicated their strong enthusiasm to work with a national centre should it be established.²⁷

2.23 Associate Professor Tom Jobling, Head of the Gynaecological Oncology Unit at the Monash Medical Centre, was one of many gynaecological oncologists that showed support.

We are very excited about this whole concept of a national gynaecological cancer centre, because we are a very collegiate group.²⁸

2.24 ASGO highlighted that when gynaecological oncology separated itself and became a distinct group from gynaecology within its own college, the change was not without 'certain stresses and territorial conflicts', but that this should not hinder the formation of a national gynaecological cancer centre.²⁹

Support from community organisations

2.25 There was also a lot of support for a NGCC from the community and non-government sector. Many envisaged a NGCC would bring a much broader approach to gynaecological cancer than that which currently exists in Australia.

2.26 There was broad agreement that a NGCC would work collaboratively with, and through existing organisations.³⁰ Given there is a significant amount of expertise and experience within community organisations, it was thought that a NGCC would largely provide strategic direction and coordination rather than usurp the service-provision and support roles that these groups already have.

2.27 Mr Simon Lee, Chair and Founding Director of the National Ovarian Cancer Network, supported a national organisation, but stated that there was still a strong role for community organisations to keep in close contact with patients, families and other

25 *Submission 7*, p.3 (Gynaecological Cancer Society).

26 *Submission 46*, p.10 (Associate Professor Margaret Davy).

27 *Submission 40*, p.6 (Professor Neville Hacker); *Submission 24*, p.8 (ASGO).

28 *Committee Hansard 3.8.06*, p.8 (Monash Medical Centre).

29 *Committee Hansard 2.8.06*, pp.64-65 (ASGO).

30 *Committee Hansard 3.8.06*, p.14 (The Royal Women's Hospital).

community representatives to ensure a 'bottom-up' approach. Mr Lee said this was important to:

...adequately collect that information and to relay information back to them and to make sure that their interests a being represented appropriately for the national organisation's sake.³¹

Relationship with Cancer Australia

2.28 Of those that supported a NGCC, some thought that it may be appropriate for it to be placed as an independent group under the auspices of the recently formed Cancer Australia.³² Professor Michael Quinn, Director of Oncology/Dysplasia at The Royal Women's Hospital supported this idea.

The thing about an NGCC is that it has to be seen as an independent body and that ownership has to be by women, by the community and also by the professional community. It has to be auspiced by a neutral body that everyone has respect for; hopefully, Cancer Australia might become that body.³³

Proposal for a National Women's Cancer Centre

2.29 Of those that supported the formation of a NGCC, many thought for governance purposes that it should sit under a National Women's Cancer Centre.

2.30 Ms Heffernan proposed that a National Women's Cancer Centre should encompass the existing NBCC as well as a NGCC, all of which would sit under the auspices of Cancer Australia.³⁴

2.31 The NBCC also proposed two possible options for broadening the scope of its work program (for further discussion see later in this chapter):

- a single body such as a National Women's Cancer Centre; or
- an overarching banner such as Women's Cancer Australia which would incorporate individual streams such as breast cancer (through the NBCC) and gynaecological cancers (through a possible NGCC).³⁵

A NGCC to be modelled on the NBCC

2.32 A number of witnesses, including Dr Yee Leung, a gynaecological oncologist from the Western Australian Gynaecological Cancer Service, proposed that a NGCC

31 *Committee Hansard* 3.8.06, p.99 (National Ovarian Cancer Network).

32 *Submission* 40, p.6 (Professor Neville Hacker); *Submission* 27, p.22 (Ms Margaret Heffernan); *Committee Hansard* 4.8.06, p.26 (Cancer and Palliative Care Network).

33 *Committee Hansard* 3.8.06, p.19 (The Royal Women's Hospital).

34 *Submission* 27, p.21 (Ms Margaret Heffernan).

35 *Submission* 44a, p.1 (NBCC).

could be modelled on the NBCC in order to successfully address the current gaps and overlaps in the gynaecological cancer sector.³⁶

2.33 Dr Helen Zorbas, Director of the NBCC, thought that much could be learnt from the outputs and success of the NBCC. Ms Heffernan agreed:

The gains that they have made in the treatment, care, resourcing and lobbying are largely due to the initiatives and vigilance of successive individuals and the model.³⁷

2.34 The NBCC said that its work is guided by the following principles:

- *National* – reinforce the NBCC's national focus as an independent and authoritative body;
- *Partnerships* – foster an integrated, collaborative approach through consultation and partnerships with clinical and consumer groups, cancer organisations and governments;
- *Evidence-based* – all aspects of the NBCC's work are informed by, and based on, the best available evidence;
- *Informed by consumers* – the NBCC's work is informed by consumers;
- *Multidisciplinary* – uses a multidisciplinary approach, bringing together individuals with different expertise to achieve a common goal; and
- *Innovative and outcomes oriented* – new approaches to improving outcomes and care for women with breast and ovarian cancer are trialled, evaluated and fostered.³⁸

2.35 The NBCC said its model had been highly successful in relation to improving breast cancer and ovarian cancer control and care. Professor Hacker agreed that the NBCC's approach and guiding principles could be replicated for other types of cancer, including gynaecological cancers.

They have put a lot of mechanisms in place for advocacy and education in breast cancer, and I would like to see the same mechanisms and functions put in place for gynaecological cancer, because they have ovarian cancer under their control. Although it is not acknowledged in the name, it is presently under their jurisdiction. But of course there are other gynaecological cancers apart from ovarian cancers—cervical cancer, uterine cancer, vaginal cancer et cetera—that are also important cancers.³⁹

2.36 The proposal to expand the NBCC's remit to include gynaecological cancers is discussed later in this chapter.

36 *Committee Hansard* 4.8.06, p.63 (Western Australian Gynaecological Cancer Service).

37 *Committee Hansard* 3.8.06, p.40 (Ms Margaret Heffernan).

38 *Submission* 44, p.2 (NBCC).

39 *Committee Hansard* 1.8.06, p.7 (Royal Hospital for Women).

Location of a NGCC

2.37 Many witnesses suggested potential locations for a NGCC and evidence given during the inquiry suggested that this may be a difficult decision.

2.38 Associate Professor Jobling suggested that it would be efficient to utilise existing infrastructure and he recommended Royal Australian and New Zealand College of Obstetricians and Gynaecologists' (RANZCOG) facilities in Melbourne as a viable option.⁴⁰ The Royal Women's Hospital in Melbourne also suggested that their hospital would provide a suitable alternate location because it is a medical model and it has industry partners, the infrastructure, the expertise, the scientists and the laboratories.⁴¹

2.39 In considering location, Ms Heffernan argued that the following factors should be taken into account:

- the location of gynaecological oncologists;
- population centres;
- the location of established organisations whose infrastructure could be utilised; and
- the use of technology and the Internet to overcome geographical distance.⁴²

Cost of NGCC

2.40 It was difficult to estimate the cost of establishing a NGCC with many unknown factors such as size, role and responsibility, location and remit. Associate Professor Jobling discussed the cost of an NGCC:

I am not putting us up as paragons of virtue, but we do all this pro bono. You talk about the infrastructure, and people get a bit frightened of potentially setting up these little things that are all going to gobble up administrative money, but I do not think that needs to be a big issue. ASGO runs as a completely pro bono organisation; it is just a body which gets together. There would be no question that you may need a couple of administrators in such a centre, but most of the work and the organisation of the committee work is going to be done by people like us, who are going to sit together and do this, whether we do it in the national meeting or whatever. There is always going to be a fair bit of goodwill in terms of running these things and deciding where the money should go.⁴³

40 *Committee Hansard* 3.8.06, pp.18-19 (Monash Medical Centre).

41 *Committee Hansard* 3.8.06, p.19 (Royal Women's Hospital).

42 *Committee Hansard* 3.8.06, p.49 (Ms Margaret Heffernan).

43 *Committee Hansard* 3.8.06 p.12 (Monash Medical Centre).

Improve existing arrangements

2.41 Some witnesses, including The Cancer Council of Western Australia, argued that the development of a NGCC 'could represent an inefficient use of resources, likely resulting in duplication of infrastructure'.⁴⁴ Dr Ian Roos, Chair of Cancer Voices Victoria, agreed and expressed concern about the potential for mixed messages stemming from the existence of multiple organisations representing different cancer types at the government level.⁴⁵

2.42 Others questioned whether money and effort would be better used to improve coordination and collaboration within the current system. Mr John Gower, Chief Executive of the Gynaecological Cancer Society argued:

...we favour, if you like, a committee that draws together various elements in each state. Existing units in each state do very well. The problem is that there is nothing to draw them together. The ground rules are different with respect to statistical raising in each state, so it is very difficult to compare what is going on. We are not in favour of setting up a new bureaucracy; we are in favour of coordinating existing units into a cohesive force.⁴⁶

2.43 Although Mr Gower agreed that a single organisation dedicated to gynaecological cancer issues would be beneficial too.⁴⁷

Expansion of the NBCC's remit to include gynaecological cancers

2.44 Given the successes of the NBCC with breast and ovarian cancer, Cancer Voices Australia and the National Ovarian Cancer Network called for the inclusion of all gynaecological cancers within the NBCC's remit.⁴⁸

2.45 The NBCC agreed and suggested that it was 'ideally placed to broaden its remit to all women's cancers, capitalising on its existing expertise, infrastructure and resources'. It argued that it had already established 'an extremely efficient infrastructure' which could be used 'to deliver programs in gynaecological cancer'.⁴⁹

2.46 The NBCC further argued that expanding its 'work program would require additional resources but would not necessitate establishing an entirely new infrastructure'.

44 *Submission 51*, p.30 (The Cancer Council Western Australia).

45 *Committee Hansard 3.8.06*, pp.85-86 (Cancer Voices Victoria).

46 *Committee Hansard 2.8.06*, p.41 (Gynaecological Cancer Society).

47 *Committee Hansard 2.8.06*, p.43 (Gynaecological Cancer Society).

48 *Committee Hansard 2.8.06*, p.24 (Cancer Voices Australia); *Submission 33*, p.12 (National Ovarian Cancer Network).

49 *Submission 44a*, p.1 (NBCC).

2.47 Many argued that the NBCC was an extremely effective model of the outcomes that the gynaecological cancer community is seeking across the board. Dr Zorbas from the NBCC commented that women with ovarian cancer often faced the same issues and had the same needs that women with breast cancer experienced a few years ago and that:

...it would be criminal not to use what we have learnt from breast cancer—it has led the way, there is no question, in all aspects of care—for the benefit of other women with their cancers. I think we would continue to make gains. We would make leaps in other areas because you are coming from a much lower base of information, support and care.⁵⁰

The need for a separate identity for gynaecological cancers

2.48 Expanding the NBCC's remit was not widely supported by a number of gynaecological oncologists, who argued that gynaecological cancers should have a separate identity from breast cancer. A number of reasons for this view were put forward:

- gynaecological cancers have very specific issues, particularly involving psychosocial and psychosexual care, and there is not natural integration of breast cancer and gynaecological cancer issues;⁵¹
- it was inappropriate for gynaecological malignancies to be managed by an organisation whose primary charter is the management of another disease grouping, such as breast cancer;⁵² and
- that gynaecological cancers occurred in sufficient numbers to warrant a stand-alone national body.⁵³

The way forward

2.49 It is clear from the evidence that there is a critical lack of attention given to gynaecological cancers in Australia at the present time. Two options for the way forward were presented to the Committee – the establishment of an independent NGCC and a widening of the remit of the NBCC to include all gynaecological cancers. The Committee recognises the merits and benefits of these two approaches and acknowledges there is strong support from those in the gynaecological cancer sector for both models.

2.50 A strong theme common to both proposals was the necessity to focus on gynaecological cancers to enable the unified voice to be heard. The Committee

50 *Committee Hansard* 1.8.06, pp.67-68 (NBCC).

51 *Committee Hansard* 4.8.06, p.46 (GAIN); *Committee Hansard* 2.8.06, p.64 (ASGO).

52 *Submission* 10, p.5 (Sydney Gynaecological Oncology Group); *Committee Hansard* 3.8.06, p.40 (Ms Margaret Heffernan); *Committee Hansard* 4.8.06, p.46 (GAIN).

53 *Submission* 40, p.6 (Professor Neville Hacker).

strongly believes that, at this time, the much needed impetus to find the solutions to the many problems and questions in the gynaecological cancer sector lies in the establishment of a Centre for Gynaecological Cancers within the auspices of Cancer Australia, the new national body with responsibility for all cancers.

2.51 The Committee considers that a Centre for Gynaecological Cancers, with initial seed-funding, will make considerable steps to build capacity in the gynaecological cancer sector and will provide a mechanism to bring interested and enthusiastic individuals and organisations together to address issues of concern. The Centre will ensure that a stronger voice is given to gynaecological cancer issues at the national level and that the duplication inherent in the current fragmented approach to service delivery is minimised.⁵⁴

2.52 It is envisaged that the establishment of a Centre for Gynaecological Cancers will have:

- a 'top-down' approach to setting priorities and the allocation of funding;
- a 'bottom-up' approach of encouraging the 'voice' of consumers and professionals to be heard in policy and planning decisions;
- a 'relationships' approach to ensure collaboration and communication within the gynaecological cancer sector (particularly between professional and community-based groups) and between the Centre, Cancer Australia, its advisory groups and the NBCC; and
- a 'technological' approach to ensure that it takes advantage of sophisticated communications and information technology that has been developed and which, for example, has been successfully utilised by the National Institutes of Health in the United States.

2.53 The Committee believes that for Australia to be at the cutting edge of gynaecological cancer treatment and control, a Centre for Gynaecological Cancers working in conjunction with Cancer Australia and its advisory groups will enable effective and successful partnerships to be formed to address the needs of this critical area of women's health.

Recommendation 1

2.54 The Committee recommends that the Commonwealth Government establish a Centre for Gynaecological Cancers within the auspices of Cancer Australia. The Centre will have responsibility for giving national focus to gynaecological cancer issues and improving coordination of existing health, medical and support services and community projects.

54 *Submission 24*, p.8 (ASGO); *Submission 27*, p. 22 (Ms Margaret Heffernan).

Recommendation 2

2.55 The Committee recommends, as a matter of priority, that the Centre for Gynaecological Cancers develops a website that is a 'one-stop shop' for reliable information on all issues relating to gynaecological cancers, including education, research and availability of services. The website of the National Institutes of Health in the United States is an example of a successful website upon which to base an Australian equivalent.

2.56 In all aspects of its work, the Centre should make optimal use of communications and information technology, including the Internet, to bring people together to discuss issues.

Recommendation 3

2.57 The Committee recommends that a working group be formed, with the support of Cancer Australia, consisting of individuals with experience and expertise in gynaecological cancers to best develop the roles, responsibilities and priorities of the Centre for Gynaecological Cancers.

Recommendation 4

2.58 The Committee recommends that the Commonwealth Government provide the Centre for Gynaecological Cancers with seed-funding of \$1 million for establishment and operational costs.

Recommendation 5

2.59 The Committee recommends that a national secretariat be formed within Cancer Australia to define the Centre for Gynaecological Cancers' ongoing objectives and to evaluate the success of the Centre after two years.

2.60 The Committee further recommends that the Centre and its national secretariat work closely with Cancer Australia and its advisory groups, particularly the Gynaecological Cancer Advisory Group, and the National Breast Cancer Centre to ensure a cohesive approach to improving gynaecological cancer care in Australia.

CHAPTER 3

ADEQUACY OF RESEARCH FUNDING FOR GYNAECOLOGICAL CANCERS

There is demonstrably no doubt that Australia possesses the research talent required to make significant, life-saving advances in gynaecological cancer. The will and drive is there; it just takes better funding.¹

Introduction

3.1 Cancer research provides the evidence to drive advances in cancer prevention, cancer treatment and services – these improvements have a positive effect on the survival and quality of life of patients.

3.2 The clear message received from evidence provided throughout the inquiry was that Australian research into gynaecological cancers was extremely under-funded. In particular, witnesses and submitters commented on the low levels of Commonwealth Government funding with the majority of funding being sourced from the general community including non-government organisations, individuals, the corporate sector, pharmaceutical companies and charitable foundations and in some cases international sources.

Gynaecological cancer research

3.3 Professor Neville Hacker, Director of the Gynaecological Cancer Centre at the Royal Hospital for Women described medical research as having two elements:

- clinical research, which investigates the optimal approach to the diagnosis and treatment of cancer. This research is performed on patients, by clinicians, with help from statisticians; and
- basic or laboratory research, which aims to develop new diagnostic tests and therapeutic agents. This research is performed by research scientists, who have no direct contact with patients.²

Clinical trials

3.4 Clinical trials test promising new treatments on people to see if they are more successful than existing treatments. Clinical trials undertaken in Australia and internationally have found safer and more effective treatments for many cancers.

1 *Submission 7*, p.1 (Gynaecological Cancer Society).

2 *Submission 40*, p.1 (Professor Neville Hacker).

The role of Australia New Zealand Gynaecological Oncology Group

3.5 The Australia New Zealand Gynaecological Oncology Group (ANZGOG) was formed in July 2000 and is committed to achieving the best of health outcomes for women with gynaecological malignancy through clinical trials research.³

Where is the research money coming from?

3.6 Major funding sources for gynaecological cancer research included the National Health and Medical Research Council (NHMRC), State and Territory governments, Cancer Councils, charities and other non-government organisations. The disparity of funding sources makes it difficult to determine the amount of money dedicated to gynaecological cancer research.

Commonwealth funding for gynaecological cancer research

3.7 The NHMRC is the primary Commonwealth agency that administers funding for health and medical research. Its total expenditure for the 2005-2006 financial year was approximately \$460 million of which approximately 22 per cent (\$100 million) was allocated to cancer research.⁴

3.8 The NHMRC's Research Committee covers the full range of health and medical research, including public health. It awards grants judged by peer-review on the basis of scientific quality across the entire spectrum of health, medical and public health research.

3.9 From 2000 to 2006, the NHMRC provided approximately \$44.25 million in research grants into the causes, screening and treatment of gynaecological (cervical, endothelial and uterine) cancers and related malignant neoplasms. This research was dispersed in 84 different grants which is illustrated in the Table 4.

3.10 A full list of successful grant recipients including the administering institution, project title, the duration of funding and the total amount of funding, is available at Appendix 3.

3.11 To boost Australia's capacity to undertake world-class clinical trials, the Commonwealth provided \$5 million in 2005-2006 to cancer cooperative groups providing much needed infrastructure support to ten cancer clinical trial groups. One of these groups was ANZGOG who received \$440,105 for infrastructure support for gynaecological cancer clinical trials.⁵

3 The Cancer Council New South Wales, *Cancer Trials NSW – Gynaecological*, <http://www.cancercouncil.com.au/editorial.asp?pageid=551>.

4 *Committee Hansard* 23.6.06, p.28 (NHMRC).

5 *Committee Hansard* 23.6.08, p.53 (Commonwealth Department of Health and Ageing); *Submission* 52, p.13 (Commonwealth Department of Health and Ageing).

Table 4: Grants awarded by NHMRC during the period 2000-2006

Funding Type	No of Grants	Total amount of the funded grant
Program Grants	3	\$14,018,503
Project Grants	51	\$20,695,736
Scholarships	16	\$976,585
Strategic awards	2	\$3,811,598
Career Awards	7	\$2,932,999
Training Awards	4	\$1,304,082
Fellowships	1	\$516,262
TOTAL	84	\$44,255,765.00

Source: Submission 42, p.2 (NHMRC).

3.12 In the 2005-2006, the NHMRC allocated approximately \$8.1 million of the total \$460 million to gynaecological cancer research.⁶ This allocation of \$8.1 million represented approximately eight per cent of the overall allocation to cancer research which was \$100 million. In addition to the \$8.1 million for gynaecological cancer research, there was also a large proportion of basic cancer research, population health research, clinical research and health services research that was not allocated to particular cancer sites but which may have relevance to and benefits for the understanding and advancement of gynaecological cancers.

3.13 The NHMRC funds on the basis of excellence, significance and relevance via peer review. In 2006, the NHMRC received 43 applications for research on gynaecological cancers and 19 of these applications were funded, giving a success rate of approximately 44 per cent, which is double the general research approval rate of 20 per cent.⁷

Other Commonwealth research funding

3.14 As part of the Strengthening Cancer Care initiative, the Commonwealth committed additional funding of \$39.2 million in the 2005-2006 Federal Budget over

6 *Committee Hansard* 23.6.06, p.28 (NHMRC).

7 *Committee Hansard* 23.6.06, p.35, p.33 (NHMRC); Commonwealth Department of Health and Ageing, Answers to Estimates Questions on Notice, Budget Estimates 2006-2007, 31 May – 1 June 2006, Question: E06-194.

the four years to 2008-09 for a dedicated cancer research budget and infrastructure grants to build Australia's capacity for clinical trials.⁸

3.15 The Commonwealth Department of Health and Ageing (the Department) provided information on dedicated Commonwealth funding for cancer research.

For the four years to 2008-2009 \$17.6 million has been appropriated for dedicated cancer research. Cancer Australia will oversee the dedicated cancer research budget. One of the initial priorities for this cancer research measure will be the early detection of breast and ovarian cancer.⁹

The priority of research funding

3.16 The NHMRC's Research Committee consults with the NHMRC about the allocation of research funding between areas of strategic importance, identified priority areas (NHMRC Priorities, National Research Priorities, and National Health Priority Areas), and funding schemes (including capacity building). Evidence received called for there to be priority for ovarian cancer research and is discussed in more detail later in this chapter.

3.17 The strategic research priorities are established for each three-year period. These priorities are determined in consultation with the Minister for Health and Ageing and the Commonwealth Department of Health and Ageing and on consideration of individual submissions received from interested parties.

Research and the National Breast Cancer Centre's Ovarian Cancer Program

3.18 Dr Helen Zorbas, Director of the National Breast Cancer Centre (NBCC) commented that the Centre receives approximately 93 per cent of its funding from the Commonwealth Government.

On the basis of the Centre's successes in breast cancer and providing extraordinary value for money, the Government extended the work of the Centre to include an ovarian cancer program in 2001. It provided an additional \$500,000 funding at that time over two years. In 2003 an additional \$150,000 was provided for work in ovarian cancer. Since 2004, following discussions with the then ovarian cancer expert advisory group, ovarian cancer has been incorporated as an integral part of our work.¹⁰

3.19 The NBCC's Ovarian Cancer Program, although not undertaking gynaecological cancer research, states that it supports research that helps doctors to differentiate symptoms which may be ovarian cancer, from those which may indicate

8 Commonwealth Department of Health and Ageing, *Health Fact Sheet 1 - Investing in Australia's health: Strengthening Cancer Care*, <http://www.health.gov.au/internet/budget/publishing.nsf/Content/health-budget2005-hbudget-hfact1.htm>.

9 *Submission 52*, p.13 (Commonwealth Department of Health and Ageing).

10 *Committee Hansard* 1.8.06, p.56, p.69 (NBCC).

the existence of benign conditions. The Ovarian Cancer Program commissioned the AIHW to develop the first national report about ovarian cancer which includes data on incidence, mortality and survival. This report is due for release later in 2006.¹¹

3.20 The Committee heard many positive comments about the NBCC's Ovarian Cancer Program and its initiatives. However, when considering the adequacy of funding for gynaecological cancer research, some witnesses expressed concern about the allocation of funding for ovarian cancer research. Associate Professor Tom Jobling, Head of the Gynaecological Oncology Unit at Monash Medical Centre commented:

We have been a bit lost in the National Breast Cancer Centre. I may well be wrong, but, looking at the funding, I gather there was \$20 million allocated in 2002 and I think about \$4½ million or \$5 million of that went to ovarian cancer research, and the broad perception within our area of endeavour—gynaecological cancer—was, ‘What happened to the other money? Why has that not been distributed to ovarian cancer research?...those of us that are a bit passionate about ovarian cancer research would argue that we need to be stand-alone so that we can maximise our efforts in terms of public awareness, education and directed research.’¹²

3.21 Furthermore, Dr Robert Rome a gynaecological oncologist, stated that ‘minimal funding has flowed from the NBCC for research into gynaecological cancer’.¹³

3.22 Professor Michael Quinn, Director of Oncology/Dysplasia at The Royal Women's Hospital commented that not enough funding flowed to the NBCC and this impacted its ability to allocate sufficient funding to ovarian cancer research:

I endorse wholeheartedly the fact that the National Breast Cancer Centre has been a very effective advocate for women with breast malignancy. It has done a wonderful job in terms of community education and also in coordinating professional education. I do not think they have done as well with ovarian cancer, but I believe that that is because of two things: I think they have been grossly under funded and there has not been the leadership within the NBCC to drive the ovarian cancer priority.¹⁴

Community funding for gynaecological cancer research

3.23 There are a multitude of organisations contributing to gynaecological cancer research throughout Australia and the resources required to attract this money and undertake fund-raising activities are significant. Whilst an exact figure is unknown,

11 NBCC, *About the Program* (www.ovariancancerprogram.org.au/about/).

12 *Committee Hansard* 3.8.06, p.13 (Monash Medical Centre).

13 *Submission 32*, p.2 (Dr Robert Rome).

14 *Committee Hansard* 3.8.06, p.14 (The Royal Women's Hospital).

witnesses advised that a large proportion of funding for gynaecological cancer research is sourced from members and groups in the general community.

3.24 The Royal Women's Hospital, the largest gynaecology service in Australia, commented:

As the National Health and Medical Research Council does not prioritise gynaecology and gynaecological cancers, research centres are dependent on philanthropic funding and limited in their capacity to experiment and innovate. Over the past 8 years, the Gynaecology Cancer Research Centre has received only 30% of its funding, or \$200 000, from government grants and relies on the corporate sector to sustain its research.¹⁵

3.25 The Monash Medical Centre stated that their research program was funded by public donations and corporate sponsorship.

We have received no government funding in any way, shape or form...there is an urgent need for far greater access to public funds.¹⁶

3.26 The commitment to gynaecological cancer research from community organisations is considerable. Professor Quinn provided the Committee with two examples of community funding for gynaecological cancer research at The Royal Women's Hospital.

We have such support as BOOTS—'breasts, ovaries and other things sacred'—which is a group of women in Geelong who raise money, and have done for the last five years. They provide a research scientist for our laboratory. We have ROCAN, which is a Rotary group, who also provide us with a scientist, a postdoctoral fellow, in the laboratory. So we have these community partnerships that we go to, and they go out there, and they are fantastic. These are women who are out raffling, and making cakes, and organising balls and functions, and they are fantastic. But we have to depend on them. We have an annual budget of \$800,000 and about \$600,000 of that comes from the community. It is amazing.¹⁷

3.27 The Committee heard from many witnesses about the positive impact and influence that sizeable contributions from community organisations make to centres undertaking research. However, Professor Quinn commented on the time and resources required to raise public funds for basic research.

It gets back to the issue that this is us [gynaecologic oncologists] out there in the community raising money for research which is not available from other sources. About 70 per cent of the money that comes in to us is raised by the community. For Professor Jobling's laboratories, it is exactly the same, if not more. We are dependent on the community to help the basic science research. We need help in this area, because Tom [Associate

15 *Submission 37*, p.3 (The Royal Women's Hospital).

16 *Submission 13*, p.7 (Monash Medical Centre).

17 *Committee Hansard 3.8.06*, p.16 (The Royal Women's Hospital).

Professor Jobling] and I spend a lot of money trying to raise funds for our laboratories when we should be looking after patients.¹⁸

Cancer Councils' funding of gynaecological cancer research

3.28 The Cancer Councils fund external researchers to conduct evidence-based studies through a grant allocation process managed by the NHMRC. Several State and Territory Cancer Councils also fund their own research units. Collectively, the Cancer Councils have allocated \$5.5 million to tumour type-specific research projects, of which \$1.34 million, or 24.3 per cent, will contribute directly to gynaecological cancer research.¹⁹

3.29 The Cancer Councils have also contributed more than \$520,000 to the Australian Ovarian Cancer Study (AOCS), a study funded by an overseas research grant from the United States Department of Defense.²⁰

3.30 The Cancer Council New South Wales has contributed to gynaecological research, commenting:

This year we are supporting more research than ever before with 23 new external grants as well as major new projects in our own behavioural and epidemiological research programs...In 2006, through the generosity of the people of NSW, we have boosted our research spend to \$10 million. Total \$10 million, of which 4% is dedicated to Gynaecological Cancers.²¹

3.31 The Cancer Council Western Australia provided the following information on their funding contribution to clinical trials in Western Australia:

In Western Australia, I think there has been an overdependence upon the charity—the Cancer Council—to fund clinical trial participation. It is definitely a barrier.

While clinical trials were not a big part of our submission, we very much support the position put by Cancer Council Australia in relation to support of clinical trials as being a very important way forward. We do fund a chair in clinical cancer research at the University of Western Australia...We also fund Cancer Council Clinical Trials WA and have established collaboration with the Western Australian Institute for Medical Research, which is about boosting the entire capacity for clinical trials conduct in Western Australia.²²

18 *Committee Hansard* 3.8.06, p.15 (The Royal Women's Hospital).

19 *Submission* 56, p.11 (The Cancer Council Australia, COSA, NACCHO).

20 *Submission* 56, p.11 (The Cancer Council Australia, COSA, NACCHO).

21 The Cancer Council NSW, *2006 Research Profile*,
<http://www.cancercouncil.com.au/editorial.asp?pageid=725>.

22 *Committee Hansard* 4.8.06, p.8 (The Cancer Council Western Australia).

Pharmaceutical company funding for gynaecological cancer research

3.32 Pharmaceutical companies contribute significant funding to medical research to advance treatment, vaccines and other drugs to improve cancer care, prevention, detection, treatment regimes and the overall quality of care.

3.33 CSL Limited is a substantial contributor to medical research in Australia providing approximately \$200 million every year to research programs which link to their core business. Dr Rachel David, Director of Public Affairs at CSL Limited stated:

We do look very carefully at what the risks and benefits are. Particularly in the biopharmaceutical industry where CSL comes from we are looking at very high risk and the prospect of 10 to 15 years before any return is realised. So that is quite a complex process. Certainly, when we embark on a project we are not necessarily expecting that there will be a return—most of the time there is not. However, there must be some synergy with our core business, which is biopharmaceuticals, plasma products and vaccines.²³

3.34 Dr Jane Leong, Medical Director at CSL Limited provided the Committee with an example of funding directed to Australian gynaecological cancer research:

We currently have a collaboration with Professor Suzanne Garland looking at the prevalence of HPV in women in Australia—remote, rural and urban. It includes a significant number of Aboriginal candidates as well in this particular research. That is certainly ongoing.²⁴

3.35 The Australian Society of Gynaecologic Oncologists (ASGO) commented on the multiple sources of funding for gynaecological cancers and pharmaceutical companies funding research:

Each of the country's gynaecological cancer centres is involved in a number of crucial research projects, both at a national and an international level. But there is little co-ordination and precious little funding. In many cases, the funding comes from the private sector, usually drug companies. It can be argued that funding from such sources is not always appropriate and that the integrity of any research findings is at its highest when the funding source is an independent party.²⁵

International funding for gynaecological cancer research

3.36 The amount of international funding for Australian gynaecological cancer research generated much discussion during the inquiry. Many witnesses commented on the contribution made by international funding bodies to gynaecological cancer research in Australia. Researchers who had received overseas funding explained to the

23 *Committee Hansard* 3.8.06, p.70 (CSL Limited).

24 *Committee Hansard* 3.8.06, p.71 (CSL Limited).

25 *Submission* 24, p.8 (ASGO).

Committee that this funding was normally sought because investigators had struggled for some time and without success to obtain funding for research projects through Australian channels.

3.37 Professor Michael Friedlander, Chairman of the Australia New Zealand Gynaecological Oncology Group (ANZGOG) provided the example of the establishment of ANZGOG.

Initially, there were no funds available to establish ANZGOG. We were very fortunate in being accepted for provisional membership by the United States GOG [Gynecologic Oncology Group]. The US GOG are the foremost clinical trials group in the world...In fact, they provided funding for us to set up ANZGOG in Australia and New Zealand. So we got money from the United States—we could not get it in Australia—to set up ANZGOG. We also were fortunate enough to get money from a number of very generous benefactors, including Lady Fairfax, and number of patients and also some unrestricted funds from the pharmaceutical industry that allowed us to establish the group.²⁶

Australian Ovarian Cancer Study

3.38 The United States Department of Defense, through the Congressionally Directed Medical Research Program (CDMRP) awarded the Australian Ovarian Cancer Study \$US2 million over four years. CDMRP grants are fiercely contested and this is the first time that an ovarian cancer program has been supported outside the United States.²⁷

3.39 The National Ovarian Cancer Network (or OvCa) commented:

The largest research project for ovarian cancer in Australia is principally funded through the US Department of Defense. The fact that the Australian Ovarian Cancer Study was able to win a large overseas grant is testimony to the quality and capability of this Australian research team. However again this reflects poorly on Commonwealth priorities for funding of research into ovarian cancers.²⁸

3.40 A number of witnesses expressed frustration at the lack of Commonwealth funding available within Australia for gynaecological cancers. Dr Peter Grant representing the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) and the Mercy Hospital for Women, commented on Australia's potential to be a world leader in research:

Australia is regarded with absolute envy overseas because of our bio laboratory, particularly for ovarian cancer specimens, which is an enormous resource for research...That is the biggest bio-specimen resource in the

26 *Committee Hansard* 1.8.06, p.43 (ANZGOG).

27 AOCs, *Funding*, http://www.aocstudy.org/org_funding.asp.

28 *Submission* 33, p.8 (National Ovarian Cancer Network).

world. And it should be things that we can make use of here in Australia, but there are significant problems with funding to be able to look at this resource.²⁹

3.41 Associate Professor Kailash Narayan from the Peter MacCallum Cancer Centre also expressed his frustration at Australia's reliance on international funding for medical research:

I get a visceral reaction every time people talk about 'overseas' and 'international'. I think it is all right to get some support internationally for monetary purposes. I think we are a wealthy country, and taking a begging bowl for international money I regard personally, as an Australian, shameful. The second thing which gets my blood boiling is that research which I have done is not done anywhere else in the world, and people here wonder, if it is accepted, have I got international collaboration to make it a little bit better. When will Australia have pride and think that we are second to none?³⁰

Incentives for research contributions

3.42 Evidence received discussed the possibility of offering tax incentives to encourage further research contributions. Mr Aleco Vrisakis, Chairman of GO Fund, an organisation which raises funds to support research into the prevention, early detection and treatment of gynaecological cancers, stated:

Australian Government funding initiatives, which we ask be undertaken, should include a greater incentive for the making of donations from the private sector through a greater than 100 per cent tax deduction being offered for donations to fund cancer research...The use of such a fiscal measure to promote desirable areas of activity properly within the competence of the Australian Government has many precedents.³¹

3.43 GO Fund provided examples of existing tax incentives provided to the Australian film industry and the Australian thoroughbred industry to illustrate the feasibility of establishing such a scheme.

Adequacy of research funding for gynaecological cancers

3.44 Many issues were raised regarding the level of Commonwealth and other funding for research into gynaecological cancer, including:

- the lack of academic research positions;
- the lack of database management facilities and resources;
- inadequate clinical trial funding; and

29 *Committee Hansard* 3.8.06, p.17 (RANZCOG and Mercy Hospital for Women).

30 *Committee Hansard* 3.8.06, p.17 (Peter MacCallum Cancer Centre).

31 *Committee Hansard* 1.8.06, p.3 (GO Fund).

-
- an overall inadequacy in the level of Commonwealth funding available for research.

3.45 The National Ovarian Cancer Network commented that when compared to some other cancers, especially breast and cervix, the remaining gynaecological cancers receive substantially less funds for research (both clinical and basic scientific research) and for health promotion activities.

For example, in the Commonwealth 2005-06 budget initiative 'Strengthening Cancer Care' \$189.4 million was allocated over five years to enable 'the Australian Government deliver its election commitment to help reduce the burden of cancer'. Of this funding, \$5 million was specifically allocated to breast cancer initiatives while other types of cancer did not receive any block grants. Organisations for other forms of cancer were only able to apply for seeding grants of up to \$90,000.³²

3.46 Professor Quinn from The Royal Women's Hospital provided additional comments:

We believe that most of the funding is in fact not being directed towards gynaecological cancer but to breast cancer, because they are often lumped together. It is hard for us to say how much is being spent but I think the estimate was about \$6 million maximum per year. It was around that figure.³³

3.47 The Queensland Centre for Gynaecological Cancer, the largest tertiary referral centre for gynaecological cancers in Australia, commented on the inadequacy of research funding.

In the last 12 months, our centre was offered to participate in two large, multi-institutional and international important research projects on the prevention of ovarian and uterine cancer. Unfortunately, we were not able to participate because of lack of funding. We could have contributed significantly to those two studies but we did not have the funds available to participate in this important research.³⁴

3.48 Professor John Shine, Executive Director of the Garvan Institute of Medical Research, commented on the need for specific funding for research initiatives which provide the greatest value for the money allocated. Professor Shine pointed out the unique position that Australia is in with regards to ovarian cancer research and stated:

When it is timely, when our scientific knowledge is at a certain point, you can get great value by saying, 'Let's have an extra initiative in this particular area,' wherever it may be, because the scientific base is right, the need is

32 *Submission 33*, p.7 (National Ovarian Cancer Network).

33 *Committee Hansard 3.8.06*, p.10 (The Royal Women's Hospital).

34 *Submission 11*, p.4 (Queensland Centre for Gynaecological Cancer).

there, and a little extra support targeted to that will produce a lot of outcomes.³⁵

3.49 Professor Robert Sutherland, Director of the Cancer Research Program at the Garvan Institute of Medical Research, stated that 'the reality is that, despite the fact that we have quite a lot of money in the NHMRC budget, we could do with more'.³⁶

Barriers to adequate gynaecological cancer research funding

3.50 Other than the lack of Commonwealth and other funding for gynaecological cancer research, many specific barriers were identified that impeded the level, quality and efficiency of gynaecological cancer research. Concerns regarding the duplication of research effort and the lack of coordination were frequently raised in evidence.

Duplication and an uncoordinated approach

3.51 Gynaecological cancer research is being undertaken by many different research centres around Australia and witnesses expressed concern at the duplication of effort. It was argued that when investigators are working to similar goals this potentially wasted scarce resources such as funding allocations.

3.52 On the issue of duplication in research, Professor Ian Olver, Chief Executive Officer of The Cancer Council Australia argued:

What is being done now needs to be identified because the worst duplication is where you do not actually know that another group in another state is doing the work.³⁷

3.53 Mr John Gower, Chief Executive of the Gynaecological Cancer Centre commented:

There are some excellent centres, as you well know, in Australia, and almost all those centres are looking at ovarian cancer. That is fine, except that one of those centres will one day come up with a eureka moment, and all the money being spent by the other centres will in fact be lost. If there is any duplication it really should not be tolerated, because there are just not the funds.³⁸

3.54 Professor Jonathan Carter of the Sydney Gynaecological Oncology Group at Royal Prince Alfred Hospital commented on the disjointed approach to clinical trial access and the impact on patient care.

At the moment everybody is doing a little bit of everything and it is just not coordinated; it is quite disjointed. That is the issue that I see that we all

35 *Committee Hansard* 1.8.06, pp.13-14 (Garvan Institute of Medical Research).

36 *Committee Hansard* 1.8.06, p.14 (Garvan Institute of Medical Research).

37 *Committee Hansard* 2.8.06, p.16 (The Cancer Council Australia).

38 *Committee Hansard* 2.8.06, p.39 (Gynaecological Cancer Centre).

face. Some of the more prolific units or the units with more go-get-em leaders are doing well, but there are pockets elsewhere where the care is suffering because of that. When patients are put on clinical research protocols, it usually implies the next step in cancer care. If you are not attached to a major teaching hospital with access to those trials, those patients will miss out. That is where we need a coordinated approach, where indeed everybody can have access to a clinical trial, whether you come from Sydney or Bourke.³⁹

Lack of academic research positions

3.55 The Committee heard that the lack of funding for academic research positions in the field of gynaecological oncology impacted on the potential to undertake research. Many practitioners are committed to the delivery of health care to patients and without any extra funding for research positions, are unable to contribute any time away from their clinical commitments to gynaecological cancer research.

3.56 Professor Quinn from The Royal Women's Hospital commented on the impact of reduced research training positions.

Secondly, in terms of basic science research, the major problem we have is a shortage of academic positions in gynaecological oncology. The reasons for this are disparate, but the wide gulf in income for academics compared to non-academics has to play a part. I think all academics in medicine in Australia face recruitment problems; not only in gynaecological oncology, but one area that we have not done well in is in research training, in that it is not part of our subspecialty training program.⁴⁰

3.57 Dr Rebecca Strutt, Director of Community Palliative Care Services at the Prince of Wales Hospital, commented on the benefits of clinical fellowships.

Having a clinical fellowship in continuing care, which I see could be very useful for someone like me, whereby GPs and clinical specialists could maybe get three months experience and take that back with them. I always feared discharging a patient to a rural area. I know, in my heart of hearts, that it is a lottery as to whether they get the right treatment, even in Sydney. The reason is that a GP may see only one palliative care patient per year, so they do not have the experience. I do want to stress the morbidity rate, that many women will still fall into the category of late diagnosis and that is a real concern for me looking after women in the community.⁴¹

39 *Committee Hansard* 2.8.06, pp.89-90 (Royal Prince Alfred Hospital).

40 *Committee Hansard* 3.8.06, p.3 (The Royal Women's Hospital).

41 *Committee Hansard* 2.8.06, p.73 (Dr Rebecca Strutt).

Lack of clinical trial funding

The importance of clinical trials

3.58 The Committee received strong support in favour of Australia establishing and participating in more clinical trials. The importance of clinical trials and advancements in cancer treatment as a result of successful clinical trials was reiterated time and time again by medical and specialist practitioners, academics and cancer survivors.

3.59 Professor Friedlander from ANZGOG commented on the importance of clinical trials for better health outcomes:

Women on clinical trials get far more information about the treatment. There is far more oversight, audit and meticulous attention to detail. I think there is clear evidence from around the world that people who participate in clinical trials tend to do better than those who do not. That may be because of selection bias as well. But there are many examples in breast cancer, soft tissue sarcoma and paediatric tumours—right across the board—where outcomes are improved... They are essential in order to improve outcomes, to improve the quality of care and, very importantly, to develop a strong evidence base for treatment decision making.⁴²

Australia's experience with gynaecological cancer clinical trials

3.60 Professor Carter expressed concern about Australia's clinical trial participation and recognition of the benefits of clinical trials when compared to the United States:

I must say, when I was in America, every person was put on a clinical trial. In this country, a lot of our patients still consider it an experiment. Awareness and education need to be increased to emphasise to patients that, in fact, it is not an experiment but an advance. It is usually gold standard treatment against what we think is the next available and best line treatment. So participation in clinical trials is very important, and that was one of the highlights in our submission. There needs to be support of a national clinical trials group. The Australia New Zealand Gynaecological Oncology Group is really the one involved and with which we are involved as well regarding clinical based, advanced cancer trials which are often of international significance.⁴³

3.61 Dr Julie Martyn, an Associate Program Manager from ANZGOG, discussed how Australia's clinical trial participation compared internationally.

Currently, we estimate that about three per cent of gynaecological cancer patients are enrolled in clinical trials in this region. Internationally those numbers are much higher—that is, six to 14 per cent in the US, the UK and

42 *Committee Hansard* 1.8.06, p.42, p.49 (ANZGOG).

43 *Committee Hansard* 2.8.06, p.90 (Royal Prince Alfred Hospital).

Europe, and we would very much like to have our region at around that level.⁴⁴

Participation in clinical trials by Indigenous Australians and people living in rural, remote and regional communities

3.62 Participation in clinical trials is recognised as a positive experience for women with gynaecological cancers often providing better standards of care and treatments. The infrastructure required to establish and run clinical trials can make it difficult for patients living in rural and remote areas of Australia to participate in such programs. Added to these difficulties are the cultural and linguistic barriers for Indigenous women and women of other cultures.

3.63 Dr Sophie Couzos, a Public Health Officer with the National Aboriginal Community Controlled Health Organisation (NACCHO), described some of the barriers to participation in clinical trials described by Indigenous people:

We found that, in our grants submission, the NHMRC would not accept the salaries that Aboriginal health workers were paid as part of their pay rate because they are ranked so lowly as research assistants that the pay scale does not match, even though an Aboriginal health worker's salary is so low anyway. So we had to seek supplementary funding from alternative sources...Human research ethics committee approval needs to be appropriately given. University human research ethics committees may not have appropriate Aboriginal representation to be able to make appropriate judgements. If the research is investigator driven and could potentially be seen as a threat by the Aboriginal community then it will not be supported. There are many barriers that prevent good quality randomised controls from taking place.⁴⁵

3.64 The barriers to participation in clinical trials by women living in regional, rural and remote areas are caused primarily by geographical distance from major centres and the infrastructure costs of setting up and running these trials. Professor Friedlander commented on some additional barriers:

There are a number of issues. The first one relates to the sort of study that is being done. If it is being done with a new investigational agent, there has to be the facilities available in the centre to use that drug and they have to have the pharmacy services and all the other support services. Then there are costs involved because each site is audited regularly. You have to go out to all the centres that are involved and there are significant costs associated with oversight and audit. That has been one of the barriers, certainly with new agents and new drugs. The other problem is related to whether ethics committees in regional and rural areas are prepared to open studies. One of

44 *Committee Hansard* 1.8.06, p.48 (ANZGOG).

45 *Committee Hansard* 2.8.06, p.19 (NACCHO).

the major barriers we are facing at the moment relates to trial insurance and who is going to insure the patient and the study.⁴⁶

3.65 Dr Mary Ryan from the Cancer Nurses Society of Australia (CNSA) commented on the obstacles for women from other cultural backgrounds in relation to clinical trials.

Most clinical trials exclude women who cannot read English or speak English. So the research that is going on does not include those women. It may well be that those women have different issues from women who do speak English and who are literate. If you are not literate or not literate in English you are also unable to participate in clinical trials because you cannot actually read the consent form, which usually runs for about three or four pages, to be able to enrol.⁴⁷

3.66 Although the majority of the evidence indicated unequal access to clinical trials, the Committee did receive some positive evidence of rural and remote participation in clinical trials. Examples were provided by Professor Friedlander from ANZGOG and The Cancer Council Western Australia.

A number of regional and rural centres are now members of ANZGOG and are beginning to participate in trials. So it is happening. One of the big problems, of course, relates to funding the studies and setting them up, but we have started that now. We are about to commence a study shortly that will be open to people in regional and rural Australia.⁴⁸

Here in Western Australia we have had some experiences where we tried to set up clinical trial activities in Bunbury. When we have an enthusiastic clinical community located in rural and regional locations, the biggest frustration we come across is the coordinating centres, which usually are international or eastern states based. They quite often restrict participation to a centre according to volume, so it has been a long, hard and tortuous path for us to get clinical trials running in Bunbury.⁴⁹

Adequacy of funding for clinical trials

3.67 Although there was resounding evidence that highlighted the value of clinical trials, the reason given by witnesses for the lack of Australian clinical trial research undertaken was inadequate Commonwealth funding. Professor Friedlander stated:

There are a number of barriers to running a successful trials group, but without a doubt the most critical issue has been and continues to be a lack

46 *Committee Hansard* 1.8.06, p.47 (ANZGOG).

47 *Committee Hansard* 1.8.06, pp.71-72 (CNSA).

48 *Committee Hansard* 1.8.06, p.46 (ANZGOG).

49 *Committee Hansard* 4.8.06, p.9 (The Cancer Council Western Australia).

of recurrent funding to support infrastructure as well as funds for specific trials.⁵⁰

3.68 The Cancer Council Western Australia stated that their successful regional clinical trials in Bunbury had been funded through non-government means. Mr Paul Katris, an Executive Officer of The Cancer Council's Western Australian Clinical Oncology Group, stated:

Again I remind the inquiry that this has occurred in the absence of any state injection. The charity have really pushed this to ensure that we get at least a little more clinical trial participation in rural and regional Australia.⁵¹

3.69 Professor Quinn from The Royal Women's Hospital commented on the absence of Commonwealth funding for surgical trials and the reliance on the pharmaceutical companies and the private sector.

I think surgical trials are very difficult to undertake in Australia. We are dependent so much on pharmacy and industry to fund our trials that key issues around surgery are often not dealt with. I think centralisation and an overview of effort is urgently needed.⁵²

3.70 Professor Olver from The Cancer Council Australia recognised recent Commonwealth initiatives to assist clinical trial research but indicated that an increased and consistent funding commitment is still required.

We believe in—and we strongly support—the Strengthening Cancer Care initiative that has attempted to get some system into the clinical trials environment by encouraging groups to form national groups and by then providing the infrastructure for those groups so that there can be some system for investigators to do clinical trials under national umbrellas and those groups...There needs to be more of that infrastructure funding. Strengthening Cancer Care has been a good start...So that initiative simply needs to be taken further and the funding needs to be secured over longer periods of time so these groups can be confident that they can develop a program of research rather than doing a bit here and a bit there.⁵³

Adequacy of NHMRC funding for clinical trials

3.71 Clinical trial funding is very expensive and the infrastructure and other resources required are significant. When competing for NHMRC research grants, investigators compete not only against other clinical trial research groups but also basic laboratory research groups which is often not as expensive and resource intensive.

50 *Committee Hansard* 1.8.06, p.43 (ANZGOG).

51 *Committee Hansard* 4.8.06, p9 (The Cancer Council Western Australia).

52 *Committee Hansard* 3.8.06, p.2 (The Royal Women's Hospital).

53 *Committee Hansard* 2.8.06, p.17 (The Cancer Council Australia).

3.72 Professor Friedlander from ANZGOG commented on some issues with NHMRC funding for clinical trial research.

Clinical trials are very expensive and the outcome is unknown. When you are setting out to answer a question, you are not too sure whether in fact that question will be answered. Sometimes the questions we are answering may not necessarily be viewed as very important from a scientific point of view, but they may have great implications in how we manage patients. It is about trying to compete with someone about to develop a new vaccine versus trying to improve survival in women with cervical cancer, for example. I think that is one of the problems.⁵⁴

3.73 Associate Professor Jobling at Monash Medical Centre provided further comment.

Classically, the NHRMC has not looked kindly upon surgical trials because historically perhaps they have not been very well run, they have not been able to attract good support from the industry and also surgery is a peculiar science, if you loosely call it a science. It is hard to compare one operator to another, so broadly speaking it is not as easy as giving a drug A or a drug B. With regard to the funding of surgical trials, of course there are a lot of consumables. It is expensive, you have to have people doing the operations and there is quite a difficult process involved in accruing patients for surgical trials.⁵⁵

Link between research funding and intellectual interest

3.74 Many witnesses highlighted the importance of adequate funding and the availability of opportunities to gain funding for research. In addition, it was argued that adequate funding created interest from investigators and academics into particular areas of research.

3.75 The Cancer Council Australia commented that poor levels of research funding will not attract research investigators.

The NHMRC mechanism has been very successful, but you cannot help noticing that psychosocial research under that banner is poorly funded. When it is poorly funded it discourages young investigators to go into that field in the first place and it becomes a vicious circle. So expanding the idea of what the most useful research is that you can do for the patient is part of what you are suggesting. We need to identify those big research questions and then, hopefully, through Cancer Australia try and encourage all the funds to be strategically directed towards those big questions.⁵⁶

54 *Committee Hansard* 1.8.06, p.48 (ANZGOG).

55 *Committee Hansard* 3.8.06, pp.7-8 (Monash Medical Centre).

56 *Committee Hansard* 2.8.06, p.16 (The Cancer Council Australia).

3.76 Professor J Norelle Lickiss, a specialist in palliative medicine, described the importance of attracting the interest of young researchers and academics:

If there is a resource injection you get injection of intellectual energy, you get interest of young people in the field and you do start to see a take-off. I think the example of breast cancer has been magnificent, and I think the time has come when the gynaecological cancers should be given that kind of boost.⁵⁷

3.77 Professor Sutherland from the Garvan Institute of Medical Research, provided the example of breast cancer research to demonstrate how an initial funding allocation can grow over time and thereby attract an increase in the level of resources.

I think the other point you make is that when the additional resources go in, it attracts people. Researchers are attracted to the dollar because they need the dollar to support their laboratories. I will give you an example. When I started in breast cancer research in this country—I won't tell you how long ago—there were only about three or four groups working in breast cancer. Today there must be 50, and this is all as a direct result of additional monies going towards that particular specialty. Also, I think that basic researchers who were looking at more basic research problems could see the application of their research to a particular disease entity, and then drag their research more to addressing directly the initiatives. So I think the evidence is that, if you put some extra money into something that is a priority, then you will drag people into it. Not only will that money get used, but some of the other money that is in the bigger pool will be pulled towards that particular activity.⁵⁸

Recommended funding levels for gynaecological cancer research

3.78 The Committee was interested in quantifying the amount of research money required to adequately address gynaecological cancer research needs. This proved difficult for witnesses, mainly due to the number of research projects being undertaken and the inability to determine the existing commitment to gynaecological cancer research. However, Professor Quinn provided a conservative estimate for basic research:

For laboratory based research, it is a little harder to estimate because there is not a huge number of laboratories in Australia doing gynaecology cancer research, but I believe that if you provide the money then the researchers follow the money. We saw that in breast cancer and, if we do it in gynaecological cancer, then I would see the basic science research increasing also. I think \$10 million is a conservative and realistic figure in terms of our basic science, as it stands at the moment.⁵⁹

57 *Committee Hansard* 2.8.06, p.72 (Professor J Norelle Lickiss).

58 *Committee Hansard* 1.8.06, pp.19-20 (Garvan Institute of Medical Research).

59 *Committee Hansard* 3.8.06, p.9 (The Royal Women's Hospital).

3.79 For clinical trial research, witnesses were able to provide indicative figures of the cost of clinical trial research and the amount required for adequate clinical trial research. Dr Julie Martyn from ANZGOG stated:

We have worked out an annual budget for clinical trials in Australia through ANZGOG: if they received between \$2 million and \$3 million a year in funding, then we would be able to do the trials that we would want to do in Australia.⁶⁰

3.80 Dr Trimble from the National Cancer Institute in the United States commented on the cost of clinical trials in the United States.

We know that many of the institutions that participate in our clinical trials have to contribute their own money to supplement the money we give them so that they can conduct that research. We pay on average a per capita payment of \$US2,000 for each patient approved for clinical trials. At the current time the pharmaceutical industry pays closer to \$US5,000 to \$US6,000, which we think is closer to the true cost at the institutional level.⁶¹

3.81 Dr Martyn commented that from ANZGOG's last four trials, Australia is operating at a cost of approximately \$5,000 to \$6,000 per patient, which is about half the operating cost of clinical trial expenditure of \$US7,500 per patient in the United States. ANZGOG estimated the funding required to raise clinical trial participation to 10 per cent noting that this amount would still be 4 per cent below international participation rates:

We estimate that we would need to have sufficient trials to recruit another 240 patients per year to reach our target of 10 per cent. The maths is fairly simple: \$5,000 per patient at 240 patients per year is \$1.2 million per year to get us to where we would like to be.⁶²

3.82 Professor Friedlander from ANZGOG stated that funding required would be 'at least \$2 million plus a year to run a viable clinical trials program' and for future funding:

We should be setting money aside specifically for clinical trials and obviously having peer review. We are not saying just to give money without having some sort of oversight and review process. I think it would be good to have a separate set of money set aside for clinical trials in Australia—not specifically for gynaecological cancer trials; it could be for all clinical trials—and for clinical research.⁶³

60 *Committee Hansard* 3.8.06, p.9 (The Royal Women's Hospital).

61 *Committee Hansard* 16.8.06, p.6 (Dr Edward Trimble).

62 *Committee Hansard* 1.8.06, pp.47-48 (ANZGOG).

63 *Committee Hansard* 1.8.06, p.48, p.55 (ANZGOG).

Future gynaecological cancer research needs

3.83 Many witnesses commented that gynaecological cancers do not attract much government attention or media coverage and subsequently not as much research funding. This is due in part to the 'silence' and 'stigma' around gynaecological issues as well as the fact that these conditions do not have a high profile in the Australian community when compared to some other conditions.

It is appreciated and accepted that [research] funding must be competitive and based on merit through a peer review process, but there are some studies which are of great importance, but not seen as 'sexy' which are not going to be picked up by alternative funding from industry or other sources.⁶⁴

The priority of research

3.84 Many witnesses discussed the application of 'value for money' principles around gynaecological cancer research and how priorities should be determined and communicated for future research needs.

3.85 The Cancer Council Australia described the necessity of assessing the current research strengths when looking at future priorities:

I think the most important part of the question is establishing what the research priorities are. It does not matter whether you have small organisations or large ones, we need to know which questions Australia can most effectively answer using the strengths of its current research team and the capabilities that we have. We know that Australia has been capable in the past, and continues to be, in leading the world in certain areas in the right type of research. I think the HPV vaccine is a great example of that. We need to identify those priorities.⁶⁵

3.86 The Cancer Council Australia also discussed how prioritising the key issues could assist in identifying areas requiring targeted research funding.

I think the key issues in research in Australia is to determine what are the big questions that we need to answer in a range of tumours and what are the big questions that we in Australia have the capability of answering. It is no good competing against, say, a multi-billion dollar group in the United States that are going along a research line. In my opening remarks I made a comment about targeted research. If in ovarian cancer, for example, you thought the biggest question was that we needed to find a good screening test for ovarian cancer, then you would organise the funding so that you were saying: 'This is targeted funding. Applications from people who are working in this area will be invited to try and solve that question'.⁶⁶

64 *Submission 46*, p.6 (Associate Professor Margaret Davy).

65 *Committee Hansard 2.8.06*, p.15 (The Cancer Council Australia).

66 *Committee Hansard 2.8.06*, p.4 (The Cancer Council Australia).

3.87 Professor Philip Di Saia, a gynaecological oncologist from the United States, provided his opinion on the current research priorities for gynaecological cancers. Professor Di Saia identified three priority areas where if research funds were allocated would result in beneficial outcomes for the health and wellbeing of women with gynaecological cancers.

Cervix cancer requires only a pap smear, which is inexpensive, easy to do and not something which most women dread. The most difficult problem we have in gynaecological cancer, however, is ovarian cancer. This is a very deadly disease which is difficult to diagnose, and we do not have a good screening tool...Until we have such a test, I do not know that government can input a lot of money into that area, except for research, and get good bang for their buck.

...The most common gynaecological cancer is so-called endometrial cancer—cancer from the lining of the uterus. There you have a highly curable disease, and education is the main assist in early diagnosis. The postmenopausal woman who has any bleeding at all from the vagina must be alerted to visit her physician and have a sample taken from inside the uterus...So I would say that the Pap smear is the best bang for your buck, the next best bang for your buck is good education about postmenopausal bleeding and the next is research into finding a blood test for early diagnosis of ovarian cancer.⁶⁷

A commitment to ongoing funding

3.88 Aside from the overall need for more funding for both basic and clinical research, an important issue for gynaecological cancer research is the ongoing commitment to research funding from the Commonwealth Government. Guaranteed funding should be for a period that is sufficient to allow investigators the time to conduct research and to be assured that they need not spend half of the time allocated for their research grant endeavouring to secure further funding.

3.89 Professor Quinn from The Royal Women's Hospital commented on the need for long term funding and stated:

It is hard for us to say how much is being spent but I think the estimate was about \$6 million maximum per year. It was around that figure. So this [conservative estimate of \$10 million for future basic research funding] would double that, which would be a great start. But it is the consistency of the funding: you cannot just fund for one year; it has to be ongoing commitment by governments to say, 'This is something that we need to support for 10 years'.⁶⁸

67 *Committee Hansard* 10.8.06, pp.2-3 (Dr Philip Di Saia).

68 *Committee Hansard* 3.8.06, pp.9-10 (The Royal Women's Hospital).

The continued need for collaboration

3.90 The Committee heard during this inquiry that Australia's gynaecological oncology specialists and centres operated in a collegiate manner. Professor John Shine from the Garvan Institute of Medical Research commented on need for collaboration to be balanced with competition in research endeavours to remain internationally competitive:

There is always a fine balance between competition and collaboration. Having said that, in today's modern medical research, to be internationally competitive you really need a critical mass of different expertise to bring to these complex research problems. So the whole drive in modern medical research is for more collaboration between disciplines which are complementary and groups which are complementary to each other... You talk about collaboration between like-minded groups—for instance, the Garvan or the Peter MacCallum Cancer Centre, who may have similar sorts of molecular and cellular biology approaches. We collaborate in many ways. Also, of course, people go in slightly different directions, because if we knew the answer we would not be sitting here today. You need a multifaceted approach to these disorders. Often the reality of it is that you need competition and people pursuing different aims and exercises.⁶⁹

3.91 Professor Shine also commented on the need for critical mass in modern medical research:

There is very good research around Australia in several centres. I think it is incredibly important that, as we move forward to use the potential of things like the human genome database, we try as much as possible to foster collaboration between these centres. Critical mass in modern medical research really is the important thing, and if we can bring together some of the outstanding resources we have around Australia, integrated with the outstanding health system we have, we can gain enormously both socially and economically from such an investment. So, from the point of view of research, I would like to stress how important it is that we have well-funded research that is as collaborative as possible around the country.⁷⁰

The need for a national approach

3.92 Many organisations recommended the establishment of a national body and many witnesses named this body the National Gynaecological Cancer Centre (NGCC). The benefits of establishing a national body to gynaecological cancer research include leadership and strategic vision and improved coordination of research. Further discussion on a national approach for gynaecological cancers is detailed in Chapter 2.

69 *Committee Hansard* 1.8.06, p.5 (Garvan Institute of Medical Research).

70 *Committee Hansard* 1.8.06, p.2 (Garvan Institute of Medical Research).

3.93 Throughout Australia there are a number of gynaecological cancer centres and each of these centres endeavours to undertake research work collaboratively. The benefits of having a national body overseeing gynaecological research includes the reduction in duplication of research and inefficiency of resources.

3.94 Associate Professor Jobling from the Monash Medical Centre commented on the advantage of having a national coordination body for clinical surgical trials, similar to the ANZGOG, for non-surgical clinical trials:

I think that the best place [for surgical clinical trial research] would be a national gynaecological cancer centre...if you have a central body to coordinate and distribute funding for these things, it is going to be easier to run than having it run out of one centre or being initiated in one centre.⁷¹

3.95 Professor Quinn gave his thoughts on a national centre's potential contribution to gynaecological cancer research:

I think the National Gynaecological Cancer Centre would be responsible for a much broader approach to gynaecological cancer, and that would include the basic research groups—the Ovarian Cancer Institute, the OCRF [Ovarian Cancer Research Foundation] and all the players in the basic science—and ANZGOG, the Australian and New Zealand gynaecological oncology trials group, under one umbrella. It would have education for the community through OvCa Australia, or the Ovarian Cancer Network Australia, and then we would have the very important areas of the social sciences and the epidemiological aspects, together with data collection.⁷²

A screening test for ovarian cancer

3.96 Early diagnosis is an important goal for ovarian cancer because chances for long-term survival are intimately tied to the extent of the disease at diagnosis. In fact, 'seventy per cent of ovarian cancers are advanced at the time of diagnosis and only about 42 per cent of women with ovarian cancer will survive five years or more from diagnosis'.⁷³

3.97 The Committee heard resounding evidence that a screening test for ovarian cancer should be the highest priority for funding in the area of gynaecological cancer research. This in part was due to the continued high mortality rate combined with the opportunity that exists for Australian researchers to make advancements in the development of a screening test.

3.98 The National Ovarian Cancer Network commented that a significant investment in screening for ovarian cancer is required.

71 *Committee Hansard* 3.8.06, p.8 (Monash Medical Centre).

72 *Committee Hansard* 3.8.06, p.14 (The Royal Women's Hospital).

73 AIHW and Australasian Association of Cancer Registries. *Cancer survival in Australia. Part 1: National summary statistics*. Canberra: AIHW, 2001.

OvCa Australia would like to see a consolidated, collaborative effort to develop and implement an early diagnostic test and subsequent potential screening program... We need to work for a common goal. The initiatives we have raised impact on the health and wellbeing of all Australian women and their families—the blokes too. They transcend state borders; therefore we need a significant contribution from the federal government to fix this problem.⁷⁴

3.99 Mrs Lisle Fortescue, an ovarian cancer survivor, provided the Committee with a summary of her personal journey and the marked difference an ovarian cancer screening test would have made to her treatment.

Had this physician been able to take a diagnostic blood test which identified ovarian cancer, my life would have been different. I speak for all females—not for any specific group but for all of us. Without a diagnostic ovarian cancer blood test for population screening we are all at risk. Had I been diagnosed in October 1997 with stage I ovarian cancer I would have been treated with surgery alone—no chemotherapy, no second-look operation—and I would have had a five-year survival rate of about 85 per cent. Instead, because there was no blood test in October 1997, I was diagnosed in March 1998 with stage II clear cell ovarian cancer. I had to undergo not only a hysterectomy to confirm ovarian cancer but then six chemotherapy treatments and a serious second-look operation.⁷⁵

3.100 Professor Lickiss described the known causes of gynaecological cancer and the need for more research into the causes of cancer, in particular ovarian cancer.

In my younger life I was a little interested in the causes of cancer. There is some evidence, for example, that obesity is tied up with uterine cancer—corpus uteri. We know that there are some viral associations with cancer of the vulva, not in all of them. We know that HPV is accompanied by smoking as a risk factor for cancer of the cervix. Cancer of the ovary is a mystery. We know there are genetic factors, but we also know that anything that you can show genetically in the way of genetic markers is responsible for a very small amount of the incidence of ovarian cancer, and that is the big mystery. Anyone who is working in this field knows that ovarian cancer is the great challenge.⁷⁶

3.101 Professor Hacker from The Royal Hospital for Women discussed the high costs of treating cancer, and the advantages of contributing money to research early detection technologies and screening tests.

Could I also make the point that some of these new therapies are so-called gene therapies—for example, Herceptin for breast cancer. Herceptin and other gene therapies are enormously expensive. The government has just approved Herceptin for the national medical benefits scheme at a cost of

74 *Committee Hansard* 3.8.06, p.93 (National Ovarian Cancer Network).

75 *Committee Hansard* 1.8.06, pp.26-27 (Mrs Lisle Fortescue).

76 *Committee Hansard* 2.8.06, p.74 (Professor J Norelle Lickiss).

something like \$100 million. That is an enormous cost for people with advanced and recurrent breast cancer. These types of therapies are also now coming on line for ovarian cancer, but they are extraordinarily expensive. We really would be better to put a lot of that money into research to develop a screening test to allow the disease to be diagnosed in its early stages.⁷⁷

3.102 Information published by the United States Gynecologic Cancer Foundation in *2005 State of the State of Gynecologic Cancers* reported that:

Over the past year, several research groups have reported potential new and hopeful markers. The individual markers are categorised with unusual names, such as sEGFR, IGF II and CKB, and typically can be measured from a blood test. Proteomics holds promise for a future test that may look at hundreds of blood proteins at one time to determine a characteristic 'signature' that may signal ovarian cancer at the earliest stages.⁷⁸

3.103 Combined with overseas advancements into ovarian cancer screening and detection, evidence demonstrated that Australia has much potential, with further research funds, to make discoveries into ovarian cancer screening and detection. Mr Vrisakis of Go Fund argued:

There is a sound scientific basis, I believe, to conclude that it should be possible to develop a screening test through research that is currently being undertaken. The GO Fund's principal, present function is to raise money to fund such research. I need say no more now about the importance of extending and accelerating that research through Australian government funding initiatives.⁷⁹

Understanding the symptoms and causes of gynaecological cancers

3.104 Understanding the causes and subsequent symptoms of gynaecological cancers provides valuable information that can be used in the research and development of screening technologies. Professor Lickiss stated that this area of research is inconsistent and variable:

We do not have enough descriptive research and descriptive studies of the lifetime experience of people with this disease. We just do not have it. We have patchiness. There is one doctorate, as I am sure you know, done by one of the nurses who presented some material to you yesterday, but there is not much. So there is an area of research that is needed, particularly in the area of symptoms—understanding symptoms, clarifying symptoms, treating symptoms. That area of research is missing.⁸⁰

77 *Committee Hansard* 1.8.06, p.15 (The Royal Hospital for Women).

78 Gynecologic Cancer Foundation, *2005 State of the State of Gynecologic Cancers* p.9; *Committee Hansard* 16.8.06, p.3 (Dr Edward Trimble).

79 *Committee Hansard* 1.8.06, p.3 (GO Fund).

80 *Committee Hansard* 2.8.06, p.72 (Professor J Norelle Lickiss).

Conclusion

3.105 The time committed by, and financial contribution of, the individuals and community organisations towards gynaecological cancer research is substantial and the benefit to gynaecological health can not be underestimated. However, extensive resources from the community and corporate sectors are required and these funds can not be guaranteed over time.

3.106 Although the Commonwealth, primarily through the NHMRC, has allocated funds to gynaecological cancer research, overwhelming evidence indicated that this allocation will be inadequate to sustain improvements in gynaecological cancer care.

3.107 The high quality of Australia's gynaecological oncologists and investigators in this area is evident and potential exists for Australia to make international advancements to improve the delivery and provision of services and programs for gynaecological cancers. One particular opportunity identified was the development of an ovarian cancer screening test, which witnesses say Australia can make possible with adequate, long term recurrent Commonwealth funding for gynaecological cancer research.

Recommendation 6

3.108 The Committee recommends that the Commonwealth Government commit further recurrent funding for:

- **basic research and clinical trials on topics relating to gynaecological cancers; and**
- **academic research positions in areas relating to gynaecological cancers.**

Recommendation 7

3.109 The Committee recommends that the Commonwealth Government in collaboration with Cancer Australia:

- **review the current level of funding allocated to bodies and individuals undertaking gynaecological cancer research in Australia; and**
- **provide leadership in relation to the allocation of research funding for gynaecological cancers; and**
- **improve awareness within the research community about the work being undertaken in order to minimise duplication.**

CHAPTER 4

THE ADEQUACY OF GYNAECOLOGICAL CANCER CARE

Introduction

4.1 A woman's experience of gynaecological cancer and its treatment has many dimensions and comprehensive care involves the provision and coordination of a large range of services. This includes information, counselling, psychosocial and psychosexual support, specialist diagnostic and pathology services, surgical, medical and radiation oncology services as well as other services such as the management of lymphoedema and menopause.

4.2 The Committee received a large volume of evidence on the extent, adequacy and funding of screening programs, treatment services and wider health support programs for women with gynaecological cancers. The main areas of concern related to low levels of funding for staffing positions, overall care and service provision, access to psychosocial and psychosexual support, the inequity of access experienced by women living in rural and remote areas of Australia, Indigenous women and women from culturally and linguistically diverse backgrounds.

Gynaecological cancer services

4.3 Evidence received during the inquiry indicated that the nature and quality of gynaecological cancer services throughout Australia varied. As such, the ability of women to access appropriate care and services in a timely way differed according to a range of factors, including their geographical location. Inadequacies in the level of services provided to women with gynaecological cancers were identified throughout evidence.

4.4 Dr Peter Grant, representing the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) and the Department of Gynaecologic Oncology at the Mercy Hospital for Women, commented:

There are many challenges currently facing the provision of treatment services to women with gynaecological cancer. These include the inadequate numbers of gynaecological oncologists and trainees – and there are many reasons for this; the inadequate funding for the employment of gynaecological oncologists, particularly within public health settings; inappropriate referral of 40 to 50 per cent of women with ovarian cancer, which brings us back to information; inadequate funding of multidisciplinary care services – that includes not only medical but nursing paramedical; inequality of access to multidisciplinary care for rural and remote women; difficulty in accessing or inability to access psychosocial

support and rehabilitation services through any structured framework – at the moment it is an ad hoc access.¹

4.5 Determining the adequacy of gynaecological cancer care and the provision of services necessitates consideration of the coordination and delivery of gynaecological cancer services. Services include screening and early diagnosis, treatment, and wider supportive health programs. Further challenges arise in this complex service delivery because of issues such as geography and inadequate Government funding for services and the mix of public and private health service delivery.

4.6 Associate Professor Kailash Narayan from the Peter MacCallum Cancer Centre commented on the need to have adequate resources to provide quality gynaecological cancer services:

We need to be able to do things, because this is why we are where we are. If facilities are not provided, you cannot stop us. It is just that we cannot do a good job.²

Screening programs

4.7 The aim of screening is to identify as yet undetected diseases while cures are still possible. A screening program refers to the testing of a sector of the population which has no overt signs or symptoms of the disease in question. Screening tests do not diagnose illness, but in the case of gynaecological cancers, can be used to identify women who require further investigation to determine the presence or absence of disease.

4.8 The medical community in Australia does not have the ability to screen for all gynaecological cancers. The exception is the ability to screen for cervical cancer using the Pap test (or Pap smear) as part of the National Cervical Screening Program.

4.9 Witnesses and submitters called for urgent attention to be given to this situation. The need for additional Commonwealth funding was thought to be important to improve the ability to screen and detect gynaecological cancers which, although not as prevalent as some other cancers, have higher mortality rates.

4.10 Other issues relating to screening included the need to advance technology and processes for an ovarian cancer screening test and the need to progress with human papilloma virus (HPV) DNA testing and liquid-based cytology for Pap tests. Many comments focused on the recent release of the HPV vaccine for cervical cancer as a preventive measure.

1 *Committee Hansard* 3.8.06, p.4 (RANZCOG and Mercy Hospital for Women).

2 *Committee Hansard* 3.8.06, p.6 (Peter MacCallum Cancer Centre).

Cervical cancer

4.11 Cervical cancer is one of the few cancers where screening can detect precancerous cell growth. Changes to the cervical cells precede the development of cervical cancer by years and with appropriate screening programs, combined with early diagnosis and treatment, cancer of the cervix is often preventable.

What is a Pap test?

4.12 The Pap test is a screening test that provides a quick and simple check for changes to the cells of the cervix. The test looks at a sample of cells from the cervix to determine if any cells are abnormal. This test can find cervical cancer cells, but also cells that might become cancerous in the future.

4.13 Different technologies for collecting and screening cervical cells are available. There are new instruments for collecting the Pap test as well as technological advancements, such as liquid-based cytology, which have enabled new laboratory tests to be performed on samples. HPV DNA testing is now available to test for the presence of high risk strains of the virus linked to the development of cervical cancer.

Liquid-based cytology

4.14 Liquid-based cytology (LBC) is a method used to collect cells of the cervix in a liquid-based solution. Once the sample arrives in the laboratory, a machine filters the cells from the liquid removing any unnecessary material and then the cells are deposited as a single layer onto a slide, stained and examined under a microscope. The major strength of LBC is claimed to be its increased sensitivity to detect abnormalities.³

4.15 A 2003 Commonwealth Government review by the Medical Services Advisory Committee (MSAC) that assessed the safety, effectiveness and cost-effectiveness of LBC for improved cervical screening concluded that there was insufficient evidence to suggest that LBC was superior to the conventional Pap test, and recommended that public funding not be supported for this screening test in Australia at this time.⁴

4.16 Liquid-based cytology is now used as the technique of choice in many countries. In Australia, it is usually performed as an additional test and at present LBC accompanies about 30 per cent of screening Pap tests. The cost of the test using LBC (about \$40) must be met by the patient.⁵

3 Foran, T, Perfect Pap Smears, *Australian Doctor*, 3 March 2006, p.35 & p.37.

4 MSAC Reference 12a, *Assessment report*, <http://www.msac.gov.au>.

5 Foran, T, Perfect Pap Smears, *Australian Doctor*, 3 March 2006, p.35 & p.37.

4.17 Dr Alan Carless commented that Medicare funding of LBC, as an improved method of examining the cervical cells, was long overdue and that previous funding was refused because of perceived inadequacy of locally collected data. Dr Carless stated:

There is justification for better Medicare funding for this approach than for the existing one, at laboratory level, because of improved efficiency of sampling and detection. Saving some women from the consequences of errors would be significant and in the long term would benefit all, but the overall short term dollar cost to the community from such a change would probably increase, to a degree depending on the ability of the government to negotiate sensible volume discounts for the more expensive consumables.⁶

Adequacy of the existing Pap test for cervical cancer screening

4.18 The National Cervical Screening Program was introduced in 1991 and deaths from cervical cancer have steadily decreased in Australia since its introduction. It is estimated that population screening using the Pap test has the potential to reduce cervical cancer by up to 90 per cent. This is because the Pap test is able to identify early changes or pre-cancerous lesions, as well as low and high-grade abnormalities of the cervix.⁷

4.19 Data from the International Agency for Research on Cancer demonstrated that Australia now has the lowest rate of cervical cancer mortality in the world. Both incidence and mortality rates have decreased. The South Australian Government stated:

- the incidence rate of cervical cancer amongst women 20-69 years has fallen from 17.1 per 100,000 women in 1991 to 9.5 in 2001; and
- mortality from cervical cancer has declined from 3.8 per 100,000 in 1993 to 2.2 in 2003.⁸

4.20 Dr Marion Saville, Director of the Victorian Cytology Service and Professor Ian Hammond, Gynaecological Oncologist and Director of Gynaecology at King Edward Memorial Hospital, discussed the National Health and Medical Research Council's (NHMRC) new guidelines for cervical cancer screening on *The Health Report* on ABC Radio National. Dr Saville and Professor Hammond made the following comments on the efficacy of the Pap screening program:

We're revising the guidelines to integrate new evidence to ensure that we're balancing really the benefits and harms of screening. We think we've been

6 *Submission 61*, p.4 (Dr Alan Carless).

7 Australian Institute of Health and Welfare 1998, *Breast and cervical cancer screening in Australia 1996-1997*, AIHW Cat. No. CAN 3, Cancer Series number 8, AIHW, Canberra.

8 *Submission 54*, p.2 (South Australian Government).

over investigating and over managing a number of women and we can pull back from that without impacting our success on cancer.⁹

Every year about 2 million women will have a Pap smear and of those about 100,000 women will have a report of a low grade abnormality and about 20,000 would have a high grade abnormality. But the trouble is that with the low grade abnormality, women are almost never destined to get cervical cancer. Yet they've been investigated in the same way as the high grade abnormality women and that's one of our problems.¹⁰

4.21 Australia's cervical screening program is provided in primary care facilities and mainly by general practitioners. In rural areas, where there are fewer general practitioners and at times great distances to travel, the ability of women to access cervical screening is sometimes impaired. In addition, for some women, the ability to access a female general practitioner or other Pap test provider will be an important determinant of participation.

4.22 The Gynaecological Cancer Society argued that two factors impeded the continued success of the National Cervical Screening Program:

- the dropping participation rate, which has for some years reduced from a high of 67 per cent to the current rate of 57 per cent; and
- cultural factors which impede access to any form of sexual examination remain a barrier to effective participation in groups that are often the most isolated, both culturally and geographically.¹¹

4.23 Research cited in evidence provided further statistics on the participation rate in cervical screening. In 1999-2000, 62.6 per cent of eligible women participated in screening.¹² In 2002-2003, the participation rate was 60.7 per cent. However, participation rates for Queensland women living in the Fraser Coast region, Barcaldine and Burke were 49.3 per cent, 45.7 per cent and 32.8 per cent respectively. Similarly, the participation rate for Australian women in their sixties is only 48.8 per cent.¹³

4.24 Certain female populations in Australia have lower cervical screening rates when compared to the community as a whole. Lower screening participation for these communities contributes to the higher incidence of cervical conditions. For example, 'A woman is of increased risk of developing cervical dysplasia and cervical cancer if

9 Dr Marion Saville, *The Health Report – Cervical Cancer Screening*, ABC Radio National, 20 March 2006.

10 Professor Ian Hammond, *The Health Report – Cervical Cancer Screening*, ABC Radio National, 20 March 2006.

11 *Submission 7*, pp.4-5 (Gynaecological Cancer Society).

12 National Health Priority Action Council (NHPAC) (2006), *National Service Improvement Framework for Cancer*, Commonwealth Department of Health and Ageing, Canberra.

13 *Submission 15*, p.2 (Women's Health Queensland Wide Inc.).

she identifies as an Indigenous Australian or is from a non-English speaking country'.¹⁴

4.25 The Royal College of Pathologists of Australasia commented:

While the cervical screening program has been very successful there is still a considerable number of women who do not have regular Pap smears. This needs to be addressed. Indigenous and women of some ethnic groups are under screened. Initiatives to improve participation in these women are required.¹⁵

Indigenous Australians and the Pap test

4.26 The cervical screening program has not been as effective in Indigenous communities, with screening rates very low. The incidence of cervical cancer and all other gynaecological cancers is higher in Indigenous communities.

In Queensland, there were seven times as many deaths from cervical cancer among Indigenous females as among non-Indigenous females.¹⁶

Compared to the total Australian rate, the incidence rate for NT Indigenous women in 1991-2001 was higher for cancer of the cervix (35 compared with 9 per 100,000) and vulva cancer (13 compared with 2 per 100,000), but similar for cancer of the uterus (14 compared with 15 per 100,000) and lower for cancer of the ovary (6 compared with 13 per 100,000).¹⁷

4.27 Dr Sophie Couzos, a public health officer with the National Aboriginal Community Controlled Health Organisation (NACCHO) commented:

The other major point is the inequity, particularly at the federal level, of the national cervical screening program in reaching the Aboriginal population. We have very limited data at the federal level on the accessibility of the programs that have been developed to reach under screened women and how effectively those programs target Aboriginal women.¹⁸

4.28 Professor Neville Hacker, Director of the Gynaecological Cancer Centre at the Royal Hospital for Women, described his experience when visiting Bamaga, a Torres Strait Island settlement, and commented:

It was typical to see a young woman coming in with her third pregnancy never having had a pap smear. That amazed me, because we would see that when you turn up pregnant it is an ideal time to take a pap smear. But apparently there is reluctance among Aboriginal women to have a pap

14 Dietsch.E, Gibb.H, Francis. K, 'Abnormal Pap test results and the rurality factor', *Australian Journal of Rural Health* (2003) 11, 50–56.

15 *Submission 57*, p.3 (RCPA).

16 AIHW, *Jurisdiction Reports, ATSI Health Performance Indictor*. 2003-04, p.248.

17 *Submission 58*, p.2 (Menzies School of Health Research).

18 *Committee Hansard 2.8.06*, p.2 (NACCHO).

smear when they are pregnant, so that is the first thing. It is clearly an educational issue. But also the sexual health worker told me that women, just because of embarrassment, are very reluctant to have pap smears, even by an Aboriginal or Torres Strait Islander health worker.¹⁹

4.29 The Menzies School of Health Research commented on initiatives, such as the Pap test register, which have resulted in increased participation in screening and successful follow-up for Indigenous women in the Northern Territory:

Following the introduction of the NT Pap Test Register in 1994, the Women's Cancer Prevention Program in 1996 and the Gynaecology Outreach Service in 1997, there was a large improvement in participation in cervical screening rates for Indigenous women in remote areas of the NT that commenced in the late 1990s and has been sustained since then. The Gynaecology Outreach Service has also achieved and maintained a very high level of follow-up of Indigenous women with high-grade abnormal Pap smears since its inception; over 80% of Indigenous women from remote communities have been treated within six months. Unfortunately, these improvements have been largely confined to the Top End of the NT; similar improvements have not yet occurred in Central Australia.²⁰

4.30 The Commonwealth announced in its 2006-2007 Federal Budget that continued funding of \$97.2 million over four years would be provided to encourage general practitioners to screen women between the ages of 20 and 69 years and, in particular, unscreened and under-screened women such as those in rural and remote areas, Indigenous women and women from linguistically diverse backgrounds.²¹

4.31 The Medicare rebate for Pap tests undertaken by practice nurses was raised as a model that could be replicated for Indigenous communities. In particular, the possibility of Aboriginal health workers qualifying for this rebate was raised as an initiative to address poor screening rates. Dr Couzos commented:

It [the Medicare rebate] is currently restricted only to practice nurses. Aboriginal health workers who take pap smears will not be able to claim under that rebate, which is an unfortunate arrangement because it sets up a system where Aboriginal health workers are considered less capable and where general practitioners are more likely to employ practice nurses rather than Aboriginal health workers, if there is currently an incentive for the employment of a practice nurse or an Aboriginal health worker. If the Aboriginal health worker cannot generate Medicare claims, obviously a GP will go towards the employment of a practice nurse.²²

19 *Committee Hansard* 1.8.06, p.24 (Royal Women's Hospital).

20 *Submission* 58, p.2 (Menzies School of Health Research).

21 Commonwealth Department of Health and Ageing, *Cervical Cancer Screening Initiatives for General Practitioners – Continue funding*, <http://www.health.gov.au/internet/budget/publishing.nsf/Content/budget2006-hfact47.htm>.

22 *Committee Hansard* 2.8.06, pp.6-7 (NACCHO).

Utilising regional and rural nurses to conduct Pap tests

4.32 To counter the difficulties faced by women living in rural, regional and remote areas in accessing general practice and also to address barriers relating to cultural diversity and stigma, witnesses discussed the appropriateness and potential benefits of rural, regional and remote nurses performing Pap tests.

4.33 Dr Mary Ryan from the Cancer Nurses Society of Australia (CNSA), commented on some of the benefits of nurses conducting Pap tests but emphasised the importance of training to undertake this function:

Many nurses, particularly women's health nurses and rural health nurses, provide Pap smear services for women. In big city centres, women's health nurses often provide them for women of socioeconomic disadvantage and for women from non-English-speaking backgrounds. Women's health nurses often have programs where they go out into the workplace to do pap smears because women who work in lower paid jobs are often not able to take time off work to get to a GP in working hours to have a pap smear or any other sort of health check. So women's health nurses will go out into the workplace and conduct not just pap smears but also breast examinations and other health promotion activities.²³

4.34 Dr Carless commented:

There is a bit of a downside to that in that the nurses need to be specially trained if they are going to be able to do efficient internal examinations...I trained practice nurses to take pap smears and I am a strong believer in things being done highly efficiently. I strongly recognise that in rural and remote communities the best people to take pap smears are often dedicated practice nurses.²⁴

Human papilloma virus (HPV)

4.35 HPV is a sexually transmitted infection that is very common among young men and women in many parts of the world. It is estimated that four out of five people will have it at some stage of their lives.

HPV and cervical cancer

4.36 Over 100 different types of HPV have been identified. Of these, approximately 30 infect the anogenital region, of which about 13 are considered 'high risk' as these have the potential to cause high-grade abnormalities of the cervix. The

23 *Committee Hansard* 1.8.06, p.73 (CNSA).

24 *Committee Hansard* 1.8.06, p.91 (Dr Alan Carless).

association between these 'high risk' types (especially types 16 and 18) of HPV and the development of cervical cancer is now certain.²⁵

4.37 CSL Limited argued that HPV is associated with:

- 99.7 per cent of cervical cancers;
- 50 per cent of vulval, vaginal and penile cancers;
- 85 per cent of anal cancers;
- 10 per cent of cancers of larynx and aero-digestive tract, recurrent respiratory papillomatosis; and
- more than 90 per cent of all genital warts.²⁶

4.38 Most women who have HPV clear the virus naturally and do not go on to develop cervical cancer. In a small number of women, the HPV stays in the cells of the cervix. When the infection is not cleared, there is an increased risk of developing abnormalities. In very rare cases, these abnormalities of the cervix can progress to cancer. Research worldwide has clearly shown that virtually all cervical cancer is caused by persistent HPV infection.

4.39 Due to the growing evidence that HPV is a necessary factor in the development of cervical cancer, high risk HPV DNA testing and HPV vaccines for primary prevention will be possible future developments for the cervical screening program.

The difference between HPV DNA testing and the Pap test

4.40 The Pap test looks at morphology (of the cervical cells) which is the structure, make-up and form of the cells. Dr Gabriele Medley from the Cytopathology Advisory Committee of the Royal College of Pathologists of Australasia (RCPA) provided an explanation of HPV testing:

The HPV test is a molecular test—it is a sort of sophisticated chemical test in a way—that looks not at what the cells look like but at whether there is evidence that there is a virus in that patient's cervix. The virus may be there and it may be in a latent form. It may just be sitting there and not doing anything and there is no morphological sign in the cells. On the other hand, it may have actually influenced the cells that are perhaps higher up the cervical canal where you cannot sample. In that case you would always put that information of a positive test in the context of that patient: could that

25 National Cervical Screening Program, *Cervical Screening Essentials –Implementation of the revised NHMRC Screening to prevent cervical cancer for the management of asymptomatic women with screen detected abnormalities*,
[http://www.breastscreen.info.au/internet/screening/publishing.nsf/Content/cv-info-kit/\\$File/essentials.pdf#search=%22HPV%20DNA%20testing%22](http://www.breastscreen.info.au/internet/screening/publishing.nsf/Content/cv-info-kit/$File/essentials.pdf#search=%22HPV%20DNA%20testing%22).

26 *Submission 21*, p.4 (CSL Limited).

patient have a lesion that you might have missed on the pap smear? The thing is that it is very sensitive but not so specific.²⁷

4.41 Mr Mark Van Asten, Managing Director of Diagnostic Technology Pty Ltd, a manufacturer of HPV DNA tests, stated that the HPV DNA test has a higher sensitivity than the Pap test.

The single test performance of pap smear is between 50 and 80 per cent. Recent studies have shown that HPV DNA testing has a performance level of well over 96 per cent and, when used in combination with cytology, could be close to 100 per cent.²⁸

4.42 Dr Medley explained how HPV testing has been used:

There are actually two ways that HPV testing has been utilised. One is as an original screening test, where women are tested for HPV, and those who are positive subsequently go on to have a pap smear to determine whether they have active disease present that needs to be treated. That improves the specificity of the test. The other is as a triage, where, if the Pap test indicates that there is probably or possibly a lesion, HPV testing will perhaps resolve that issue, because if the HPV test is negative then that woman can be reassured that she probably does not have significant disease. If the test is positive then it is appropriate to go and investigate that woman further.²⁹

The benefits of HPV DNA testing to cervical cancer screening

4.43 The direct detection of HPV in cervical specimens may offer an alternative to or complement population-based cytological screening. Recent studies have demonstrated that HPV test results are more sensitive (although they are less specific) than Pap tests in detecting high-grade dysplasia in older women. In most scenarios women with positive HPV tests still have Pap tests or a diagnostic procedure to provide cytological or histological confirmation of their disease.³⁰

4.44 Commercially available HPV DNA testing kits can detect thirteen high risk and five low risk types of HPV. Identification of women with persistent HPV infection may reduce unnecessary colposcopy and biopsy in some women. Furthermore, cervical screening intervals may also be altered depending on the presence or absence of HPV DNA.

27 *Committee Hansard* 1.8.06, p.98 (RCPA).

28 *Committee Hansard* 1.8.06, p.87 (Diagnostic Technology Pty Ltd).

29 *Committee Hansard* 1.8.06, p.93 (RCPA).

30 Malloy, C, Sherris, J, Herdman, C, December 2000, *Technical and Programmatic Issues for Cervical Cancer Prevention in Low-Resource Settings*, Alliance for Cervical Cancer Prevention.

4.45 The HPV DNA test alone is not a definitive indicator of disease. However, by combining the information provided by the Pap test and a HPV DNA test, the physician can better determine the relative risk and therefore the appropriate course of treatment.³¹

International advancements and HPV DNA testing

4.46 The United States Food and Drug Administration approved the HPV DNA test in 2004 as a primary screen for cervical cancer for women aged over 30. The test, performed in this setting alongside the Pap test, showed significant improvements in the detection of cervical disease. The American College of Obstetricians and Gynecologists endorsed the use of the HPV DNA test and has recommended an extension of the screening interval from one year to every three years if a woman is negative for HPV. In many countries—the United Kingdom, the Netherlands and Finland—the interval between screening events is being considered to be extended to five to 10 years with the adoption of HPV DNA testing.³²

Australia's experience with HPV DNA testing

4.47 Evidence indicated that Australia had not progressed with HPV DNA testing as far as other countries. Dr Phillip Baird commented:

We now have a vaccine for papilloma virus, but we do not have any tests for it. This seems to me to be a complete non sequitur. If we believe that the vaccine is important, how come we are not screening women for the virus? I can not understand this. I have been involved with papilloma virus research since 1976, so it is not a new idea. Many other countries have taken it on board more than Australia has. That strikes me as being odd.³³

4.48 In August 2002, the Medical Services Advisory Committee (MSAC) assessed the safety, effectiveness and cost-effectiveness of HPV testing in women with a prediction of low-grade abnormality from Pap test cervical screening. MSAC recommended that there was insufficient evidence to support public funding for the use of the HPV test for triaging of women with equivocal (uncertain) cervical screening results.³⁴

4.49 Dr Huw Llewellyn, Senior Staff Specialist Anatomic Pathology at The Canberra Hospital, stated:

The 2002 Medical Services Advisory Committee decision only allows HPV DNA testing for 'test of cure'. The MSAC decision has been rendered obsolete by multiple additions to scientific literature and is anomalous as

31 *Submission 50*, p.4 (Diagnostic Technology Pty Ltd).

32 *Committee Hansard 1.8.06*, p.87 (Diagnostic Technology Pty Ltd).

33 *Committee Hansard 1.8.06*, p.83 (Dr Phillip Baird).

34 MSAC reference 12b, *Assessment report*, <http://www.msac.gov.au/>.

the evidence for triage is at least as good as that for test of cure. The MSAC decision needs to be revisited urgently.³⁵

4.50 The RCPA provided further comment on the MSAC determination:

There now exists good scientific evidence that supports the use of HPV testing for triage smears reported as ASCUS [Atypical Squamous Cells of Uncertain Significance] or possible LSIL [Low-grade Squamous Intraepithelial Lesions]. There is also new evidence that supports this approach as cost effective. This evidence was not in existence when the Medical Services Advisory Committee (MSAC) last considered this issue in 2002. It would be prudent and timely for MSAC to perform a further assessment for HPV testing for this purpose.³⁶

4.51 Professor Hacker from the Royal Hospital for Women commented on Australia's use of the HPV DNA test in triage and primary screening.

I think that [HPV testing] is a whole area that we in Australia are not really investigating. We now know that HPV is a causative agent of cervical cancer, but we are not doing any research really. We have developed a vaccine, and clearly that will be an important issue, but the role of HPV in terms of triaging low-grade abnormalities and primary screening has been completely neglected. We have basically rejected overseas evidence but have not done any investigation of this in the Australian context, which I think we should be doing.³⁷

Potential benefits of HPV DNA testing for Australian women

4.52 Dr Baird stated that the HPV DNA test provides a win-win situation for patients, the Government and the community. Dr Baird commented:

I believe DNA technology offers us as a country and as a population a win-win-win situation. The patient wins because they can have less testing, they can have better testing, and the cultural and remote issues are resolved because samples can be sent to a central laboratory... We are facing a crisis in terms of our skilled people, but we can introduce automation and so the costs will come down. Government wins because you get cost-effective services. The community wins because the service is now accessible to everyone, it is appropriate and it resolves many of the cultural sensitivities that we have in our community.³⁸

4.53 A potential benefit of HPV DNA testing for certain groups of women lies in the fact that the test can be completed by self-sampling. For example, this means that women can use a tampon to test themselves and this is then sent to the laboratory for

35 *Submission 22*, p.2 (Dr Huw Llewellyn).

36 *Submission 57*, p.2 (RCPA).

37 *Committee Hansard* 1.8.06, p.24 (Royal Hospital for Women).

38 *Committee Hansard* 1.8.06, p.84 (Dr Phillip Baird).

testing. Self-sampling has a number of flow-on benefits. It could address issues of staffing in rural and remote areas of Australia and may also alleviate some of the barriers to women undertaking cervical smear procedures. Mr Van Asten from Diagnostic Technology Pty Ltd commented:

There is also the opportunity of doing self-sampling in rural and remote conditions where, culturally, it is difficult for a woman to present to a health care worker. Those self-sampling or self-testing programs have actually been validated in places like Canada, China, Taiwan, Korea and India and continue to be developed around the world, with very substantial publications showing outcomes that are on a par with, if not better than, normal cytology based programs.³⁹

4.54 Professor Hacker commented on the benefit of self-sampling. During his visit to Bamaga, a Torres Strait Islander settlement, the sexual health worker advised him that women were happy to seek medical assistance with sexually transmitted infections, because the testing for Chlamydia, gonorrhoea is self-testing and they do not have to be examined. Professor Hacker concluded that 'it is possible to self-test for human papilloma virus'.⁴⁰

HPV vaccines

4.55 HPV vaccines 'protect against HPV infection primarily by inducing the production of neutralising antibodies, thereby preventing the development of cervical intraepithelial neoplasia – the precursor to invasive cervical carcinoma'.⁴¹

4.56 Professor Ian Frazer pioneered the first HPV vaccine Gardasil, which is manufactured by CSL Limited. This vaccine is a quadrivalent vaccine for use in men and women. Gardasil is designed to protect against HPV types 16 and 18, which are responsible for an estimated 70 percent of cases of cervical, anal, and genital cancers, and HPV types 6 and 11, which cause an estimated 90 percent of cases of genital warts. GlaxoSmithKline is testing for use in women, Cervarix, a bivalent vaccine against HPV types 16 and 18.⁴²

4.57 Gardasil is now commercially available and pending a decision on Commonwealth Government subsidies, patients will pay for the full cost of Gardasil which includes three separate doses that retail for approximately \$450.00 to \$460.00 for the full course.⁴³ Evidence shows that the maximum benefits of vaccination occurs when used in young girls and women. At the time of writing the report, the vaccine's

39 *Committee Hansard* 1.8.06, p.93 (Diagnostic Technology Pty Ltd).

40 *Committee Hansard* 1.8.06, p.24 (Royal Hospital for Women).

41 Steinbrook, R, 'The Potential of Human Papillomavirus Vaccines', *The New England Journal of Medicine*, March 16, 2006. p.1109.

42 'US approval of cancer drug to save thousands', 20 May 2006, *Canberra Times*, p.3.

43 *Committee Hansard* 3.8.06, p.69 (CSL Limited).

inclusion in the National Immunisation Program was under review by the Commonwealth Government.

4.58 Dr Edward Trimble, Head of the Gynecologic Cancer Therapeutics at the National Cancer Institute in the United States, commented that the Centers for Disease Control and Prevention in the United States have recommended the inclusion of the Gardasil vaccine in the standard vaccination program. Dr Trimble stated:

This means that automatic financial coverage for the vaccine is available for 40 per cent of the population—essentially the poorest members of our population. It is anticipated that our third-party payers, the insurance companies, will also pay for the vaccine.⁴⁴

Benefit of vaccines in Indigenous communities

4.59 The benefits of the HPV vaccines include addressing low cervical screening participation rates and the lack of adequate follow-up in Indigenous communities and the subsequent high levels of mortality from cervical cancer.

4.60 The Menzies School of Health Research commented on the benefits of a HPV vaccine in primary prevention strategies for Indigenous people:

There is a high incidence of several ano-genital cancers in NT Indigenous people, including cancer of the cervix, vulva, penis and anus...Indeed; over sixty percent of the NT Indigenous women diagnosed with vulvar cancer or high-grade VIN between 1996 and 2005 were also diagnosed with invasive disease or intraepithelial neoplasia of the cervix, vagina or anus. The high burden of HPV-related ano-genital cancer seen in these communities highlights the need for adequate primary prevention, including an investigation of the potential effectiveness of an HPV vaccine in these communities.⁴⁵

The ability to screen for ovarian cancer

4.61 There is no widely accepted and effective screening test for ovarian cancer. Recently there has been intense interest in utilising a method called 'proteomics' to screen for ovarian cancer. Proteomics involves the analysis of proteins in the blood.⁴⁶

4.62 The detection of ovarian cancer can occur by utilising two tests – measuring levels of a protein marker in blood plasma (CA125), which is thought to be increased in ovarian cancer and transvaginal ultrasonography, an ultrasound of the ovaries. However, both of these tests have not been very successful as a screening tool for

44 *Committee Hansard* 16.8.06, p.3 (Dr Edward Trimble).

45 *Submission 58*, p.3 (Menzies School of Health Research).

46 Gynaecological Cancer Foundation, *2005 State of the State of Gynaecological Cancers*, p.8; *Committee Hansard* 16.8.06, p.3 (Dr Edward Trimble).

ovarian cancer. In fact, the National Breast Cancer Centre (NBCC) in its guide to general practitioners on symptoms that may be ovarian cancer stated:

CA125 alone should not be used to either rule in or rule out ovarian cancer. While a very high value may assist in confirming the diagnosis, a low value is not helpful because of the non-specific nature of the test.⁴⁷

4.63 Mr Terry Slevin, Director of Education and Research at The Cancer Council Western Australia, commented on early detection of ovarian cancer:

We do not have good means by which we can detect it early in a successful way which will result in better prognosis for those women diagnosed with the disease. Therefore the outcomes are poor for that disease. The frustrating thing is that there is not anything that is immediately on the horizon that might better guide us as far as early detection of ovarian cancer is concerned. There are trials under way, but we really do need to await the outcome of those trials before we can confidently go forward when it comes to finding a solution for ovarian cancer.⁴⁸

4.64 The majority of witnesses appearing before the Committee called for more Commonwealth funds to be invested into research and development of an ovarian cancer screening blood test. The GO Fund, summed up their main goal:

Despite some improvements in 5-year survival rates over the past 20 years, the outlook is still poor, the overall survival being only 40 per cent about half that of breast cancer. Hence the main goal for GO Fund is to find a simple blood test that could identify the disease in the early stages, when the chances of cure are 80-90 per cent. In addition to the blood test, results from research can help to devise new, targeted treatments.⁴⁹

4.65 Further discussion on the need for future research commitment into ovarian cancer screening and early detection is included in Chapter 3.

Treatment services

4.66 Gynaecological cancers are treated by using one or more of the following options: surgery, radiation therapy, chemotherapy, and experimental treatments. Other treatment services include psychological counselling, physiotherapy, dietetics and nutrition and the management of lymphoedema and menopause. The choice of therapy and breadth of treatment services depends on the type and stage of the cancer as well as the ability of the patient to access services.

4.67 The provision of high quality clinical services requires adequate funding and resources. On a national level there is considerable variation in the level of resources

47 NBCC, *Assessment of symptoms that may be Ovarian cancer: a guide for general practitioners*, 2005.

48 *Committee Hansard* 4.8.06 p.2 (The Cancer Council Western Australia).

49 GO Fund, *Chipping Away at Ovarian Cancer*, <http://www.gofund.org.au/html>.

available to gynaecological oncology centres. The Australian Society of Gynaecological Oncologists (ASGO) stated:

Centres in capital cities are generally better staffed than those in regional areas and waiting times for consultations and treatment tend to be shorter. However, all centres have deficiencies in their clinical service levels which need addressing.⁵⁰

4.68 The provision of services close to where a person with cancer lives is inevitably limited by the local population density and the distance from major centres of population. Some services, such as radiotherapy, are not available outside capital cities or a few major towns.

Multidisciplinary treatment

4.69 Following on from the introduction of gynaecological oncology as a subspeciality in the United States, the concept of multidisciplinary care was also adopted in the Australian gynaecological cancer community. The first Australian multidisciplinary gynaecological cancer centre, the Department of Gynaecological Oncology was established at Royal Prince Alfred Hospital in Sydney and this model has been used throughout Australia and internationally.⁵¹

4.70 Since the 1980s, multidisciplinary specialist gynaecological cancer units have been established in all Australian capital cities except Darwin. Multidisciplinary teams include (but are not limited to) gynaecological oncologists, medical oncologists, radiation oncologists, palliative care specialists, specialist gynaecological cancer nurses, dedicated physiotherapists, clinical psychologists, dieticians, social workers, supportive care and pastoral care workers.

4.71 The CNSA commented on the imperative to deliver cancer care in a multidisciplinary treatment model incorporating both medical and other health services.

We also recognise that multidisciplinary care is the model of care that is proposed as best practice and that when we refer to multidisciplinary care we are referring to not just the medical disciplines of surgery, radiotherapy and medical oncology but also the other health disciplines, including nursing, social work, psychology, occupational therapy, physiotherapy and those sorts of things. When we speak about multidisciplinary care we are referring to those disciplines as well as the medical disciplines.⁵²

4.72 Principles that provide a framework for the delivery of multidisciplinary care have been identified as:

50 *Submission 24*, p.10 (ASGO).

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

52 *Committee Hansard 1.8.06*, pp.70-71 (CNSA).

- a team approach, involving core disciplines integral to the provision of good care, with input from other specialities as required;
- communication among team members regarding treatment planning;
- access to the full therapeutic range for all patients, regardless of geographical remoteness or size of institution;
- provision of care in accord with nationally agreed standards; and
- involvement of patients in decisions about their care.⁵³

4.73 In Australia, specialists treating women with gynaecological cancers may work in geographically separate places and a person with cancer may be treated in the private and/or public sectors making the delivery of a multidisciplinary model of care more difficult to achieve.

Adequacy of care and provision of treatment services

4.74 ASGO commented on best practice in gynaecological cancer care:

Current best practice worldwide is for patients with gynaecological cancers to be treated in dedicated gynaecological cancer centres by specialist teams of gynaecological, radiation and medical oncologists, specialist pathologists, specialised nursing staff, psychologists, social workers and palliative care services. Treatment is usually complex and prolonged and very taxing on both the patient and her family / friends.⁵⁴

4.75 Many witnesses commented on the importance of a woman being referred to a specialist gynaecological cancer unit and in particular, to a gynaecological oncologist and the impact that this referral has on the outcome of treatment.

To improve patient outcomes, the treatment for ovarian cancer requires extensive, specialised surgery that should be performed by specialist Gynaecologic Oncology Surgeons. However, currently only about 50% of women diagnosed with ovarian cancer are treated by specialist Gynaecologic Oncologists and the outcomes for women with an inappropriate referral will more than likely be poorer than those referred to the right specialist.⁵⁵

Outcomes including survival rates are improved for women who are informed about their treatment options and subsequently receive treatment at a specialist gynaecological oncology unit.⁵⁶

53 H. Zorbas, B. Barraclough, K. Rainbird, K. Luxford, S. Redman. 'Multidisciplinary care for women with early breast cancer in the Australian context: what does it mean?', *Medical Journal of Australia* 2003; 179:528–531.

54 *Submission 24*, p.6 (ASGO).

55 *Submission 33*, p.6 (National Ovarian Cancer Network).

56 *Submission 6*, p.2 (Psychosocial Support Project).

4.76 Professor Michael Quinn, Director of Oncology/Dysplasia at The Royal Women's Hospital in Melbourne, commented:

In relation to service delivery, I think we are doing a reasonable job in the care of women with gynaecological cancers. This has largely been due to the energy and the vision of the members of the Australian Society of Gynaecologists, who have been preoccupied with ensuring appropriate standards of training and care, together with a long history of commitment to the concept of multidisciplinary team management, which was started in the world of gynaecological oncology.⁵⁷

4.77 Although witnesses agreed that many women with gynaecological cancers receive treatment and access to services, these services were often deficient, uncoordinated, not funded or were unavailable to certain women.

4.78 Ms Tanya Smith, an ovarian cancer survivor, commented on the difference between the services she received in Sydney as compared to those in Perth. Ms Smith stated:

Just over a year ago my partner and I moved to Perth, Western Australia, where I continue to have treatment every month. The move has highlighted to me the differences in gynaecological cancer patient services and facilities. There are excellent support services such as the Brownes Cancer Support Centre at Sir Charles Gairdner Hospital, which provides free complementary therapies and information for cancer patients and their carers. This facility should be duplicated in all the cancer centres around Australia. Disappointingly, there is no gynaecological cancer centre in Perth. I am unable to access all my medical requirements in one specialist location such as a gynaecological cancer centre, as I did in Sydney. This makes it more difficult for my partner and I, as I often go to one hospital for tests, and to another hospital for treatment, while scans and other testing, counselling or other services are done at other hospitals.⁵⁸

4.79 The level of care and treatment women receive for gynaecological cancers was reported as variable. Factors influencing the level of care and treatment provided included:

- inadequate levels of Commonwealth, State and Territory funding;
- the differences in services in through public and private treatment centres and funding channels;
- cultural differences and language barriers to seeking treatment; and
- geographical location.

4.80 The Gynaecological Cancer Society commented:

57 *Committee Hansard* 3.8.06, p.3 (The Royal Women's Hospital).

58 *Submission* 34, p.3 (Ms Tanya Smith).

Although gynaecological cancer treatment services nationally are adequate there are some geographical anomalies in service delivery that cause significant and unacceptable delays in treatment.⁵⁹

Issues that impact on the adequacy of treatment services

State and Commonwealth funding for treatment

4.81 The Commonwealth performs a leadership role in policy making, particularly in national issues like public health, research and national information management. The Commonwealth funds most out of hospital medical services and most health research.

4.82 The States and Territories are primarily responsible for the delivery and management of public health services and for maintaining direct relationships with most health care providers.

4.83 Ms Elizabeth Chatham, Director of Women's Services at The Royal Women's Hospital in Melbourne, said that 'state and federal funding processes are very different, and they do impact on how we deliver services every day'. Ms Chatham expanded on her statement:

About the federal/state boundaries and how they get on, I think there is a significant issue in the way that health care is provided in the states. Federally they seem to have a disease focus. They have identified obesity, breast cancer, mental health, a whole range of important diseases that need work, but if you do not fit into those strategies it is difficult to get funding...The state often has a different approach from the way health care is delivered in the federal framework. We have a different state framework and there are clashes in relation to how to go forward, how that then rolls out in research and services.⁶⁰

Service provision in the private and public health systems

4.84 In Australia, a mix of public and private sector providers deliver health care. The Committee heard that the mix of providers and the variability in service quality caused much frustration in survivors of gynaecological cancers. Notably, the differences in the level and coordination of services received particular criticism from witnesses. It was clear from the evidence that the public health system provided a more comprehensive service and better overall gynaecological cancer care.

4.85 Ms Karen Livingstone, Founding Director and Chief Operating Officer of the National Ovarian Cancer Network conveyed some of the feedback from participants at the ovarian cancer patient forum held in Melbourne in February 2006:

59 *Submission 7*, p.5 (Gynaecological Cancer Society).

60 *Committee Hansard 3.8.06*, p.11 (The Royal Women's Hospital).

One of the things that was quite disturbing, particularly for private patients, was the perception that, as a private patient, if you are paying for a service, you would be getting quality service, or the top service. Certainly a lot of the private patients who were present at that patient forum were very disappointed to hear that they were not getting as much as public patients through the public system. We believe there was a considerable gap between the private patients, who were actually out of pocket, and the services the public patients were getting.⁶¹

4.86 Mrs Sushama Sharma, an ovarian cancer survivor and advocate, representing The Cancer Council Western Australia, provided further comment:

What I and a lot of patients find very puzzling is that, if this system can work in public hospitals, why doesn't it work in private hospitals? Often the doctors are the same in both setups. Are they not exerting enough pressure on private hospitals to take it up more seriously? It does not just help the patient; it helps the doctors as well because there is not just one person responsible for the welfare of the patient. There is a lot more security knowing that you are getting this care within the hospital system when you first come in. All in all, I think it does affect the outcome, how well the patient lives for whatever time they live for.⁶²

Lack of funding for database management infrastructure and resources

4.87 The lack of funding and resources available for database management resources and infrastructure is a major impediment to adequate gynaecological cancer research and the measurement of adequate treatment levels and outcomes. Many witnesses indicated that this issue sometimes resides with the States and often funding is not available.

4.88 Professor Ian Olver, Chief Executive Officer of The Cancer Council Australia, stated that the lack of data collection or cancer registries may be a casualty of the state-federal divide, commenting:

On the question of data collection or cancer registries...it is absolutely essential that we record precisely what our cancer and our mortality rates are...We need to be able to identify those trends and be able to do something about them or at least affirm that a program has hit its target. And there is no substitute for meticulous data collection. There are areas in Australia that have done it very well. But they are subject to the vagaries of state government funding and some states that in the past have led the nation are now not quite so prominent in that because the funding for the registry is not there.

The Australian Institute of Health and Welfare trying to bring it all together is obviously very important, but I gather there are some issues of states with

61 *Committee Hansard* 3.8.06, pp.97-98 (National Ovarian Cancer Network).

62 *Committee Hansard* 4.8.06, p.3 (Ms Sushama Sharma).

particular legislative structures not being able to make that data available in the same format as others.⁶³

4.89 Dr Grant representing RANZGOG and the Mercy Hospital for Women added that the lack of database management systems impacts on the ability to evaluate and assess treatment outcomes.

The other critical thing, I think, is an inadequacy in the data that we have that not only pertains to patients on trials and accrual of patients on trials but just to look at the assessment of outcome of our interventions, how we treat people, and what happens to these people. We have no mechanism to assess what our treatment is doing or what changes to our treatment paradigm might lead to over time. I believe that all of these issues are worthy of discussion and certainly will enable us to improve the care for women with gynaecological cancer.⁶⁴

4.90 Associate Professor Tom Jobling, Head of the Gynaecological Oncology Unit at the Monash Medical Centre, identified data management as the second biggest problem for the Centre:

We are, supposedly, the biggest health care network in this state and yet we have no data management whatsoever, so we are unable to tell our patients how we compare to our opposite numbers north of the Yarra and I think that is really an appalling situation. I believe that if all the units in the country had a common database and a well-coordinated data management system, we would be able to say, both to the community at large and to each other, 'Yes, we are reasonably good at what we are doing and we're all pretty well up to the mark.' But at the moment I do not think that any of us can say that. That is my biggest issue at the moment.⁶⁵

4.91 Associate Professor Narayan from the Peter MacCallum Cancer Centre told the Committee of the processes he undertook over a period of six months to implement a database management process.

Having got it all together, I do not know, myself, any programming or anything, but I learnt Access and I designed the form and I started a database...I could not find any data manager myself, but after hours I stuck with it and I collected data, and I have evidence to show that, with diligent data collection in a collaborative fashion, you can demonstrate improved outcomes and you can reduce toxicities; but since I could not find any data manager, I had to do it myself after hours.⁶⁶

4.92 Professor Hacker from the Royal Hospital for Women provided information on the existing FIGO system for data collection. FIGO is an International Federation

63 *Committee Hansard* 2.8.06, pp.17-18 (The Cancer Council Australia).

64 *Committee Hansard* 3.8.06, p.4 (RANZCOG and Mercy Hospital for Women).

65 *Committee Hansard* 3.8.06, p.5 (Monash Medical Centre).

66 *Committee Hansard* 3.8.06, p.6 (Peter MacCallum Cancer Centre).

of Societies of Obstetrics and Gynaecology, and every three years they publish an 'Annual Report'. Professor Hacker suggested that 'if all units in Australia collected data according to the FIGO format, we could all contribute to this triennial report, and also better communicate with each other'⁶⁷

4.93 Professor Hacker commented on the current usage of FIGO:

We have got some coordination through the New South Wales Cancer Institute, which has put some money into data collection for all of the cancers. In the GYN area—in the South Eastern Sydney Area Health Service—we are going to trial this FIGO data system. The advantage of that system is that it is already developed; we do not have to reinvent the wheel. Secondly, it is adopted internationally and those data can then be reported...The Royal Women's Hospital in Melbourne, the centre in Adelaide and a number of centres around Australia contribute to the annual report, so I think it would be a unifying thing.⁶⁸

4.94 Professor Quinn from The Royal Women's Hospital, summed up the overall evidence regarding the impact that the lack of data collection and data management processes has in the provision of gynaecological cancer care:

In conclusion, I think it is probably a national disgrace that we are unable to give women in Australia advice as to what the likely outcome for any given cancer, stage for stage, is likely to be. This is across all tumours; not only related to gynaecological malignancy. We urgently need the infrastructure support to ensure that core clinical data are collected so that we can identify geographical areas for women who are being disadvantaged in their care, even only using CRIB mortality rates as a benchmark.⁶⁹

Staff shortages and lack of funding

4.95 Evidence provided to the Committee indicated that with the ageing Australian population and resultant increases in gynaecological cancers, the complexity of care and the need to accommodate women who live outside of major treatment centres, achieving and maintaining adequate staff numbers in the gynaecological oncology field will be of great concern.

4.96 Associate Professor Narayan commented:

I want to say briefly that the radiation Oncological aspect of gynaecological cancer is completely ignored in this country. I do not know of many radiation oncologists, except us two, who solely practise in gynaecological radiation oncology. Elsewhere, it is done in a sporadic fashion. We have

67 *Submission 40*, Additional Information, 24.8.06 (Professor Neville Hacker).

68 *Committee Hansard* 1.8.06, p.20 (Royal Hospital for Women).

69 *Committee Hansard* 3.8.06, p.4 (The Royal Women's Hospital).

demonstrated that, with specialised care and expertise, it is possible to improve the treatment results.⁷⁰

4.97 In relation to gynaecological oncology, the estimated workforce requirements are one sub-specialist for 400,000–500,000 population which means that for adequate care of Australian women approximately 48 specialists in clinical practice are required. There are currently 34 in Australia and five trainees but 25 per cent of the workforce is 55 years or older.⁷¹

4.98 The Australian Society of Gynaecologic Oncologists stated:

Even on the current numbers of gynaecological cancers (setting aside the predicted increase in incidence), Australia is 14 Gynaecological Oncologists short. It is well documented in the literature that patients treated by specialist doctors have a better outcome. The shortfall in the number of specialist doctors will have enormous implications for the community.⁷²

4.99 The Royal College of Pathologists of Australasia (RCPA) expressed concern about the adequacy of specialist staff in Australia:

Currently in Australia there are about 1,300 active pathology specialists, and about half of them are tissue and cell pathologists. Unfortunately, the demographics of this in our country have become slightly adverse. Over 20 per cent of our practising tissue and cell pathologists are over 60 years of age and 10 per cent are over 65 years of age.⁷³

4.100 The Australian Medical Workforce Advisory Committee (AMWAC) conducted a review of the specialist pathology workforce in Australia and recommended:

To achieve an appropriate supply of pathologists from 2008 onwards there should be 132 pathology entrants entering the workforce. Based on the average number of new pathology trainees between 1998 and 2002 (52) and an average attrition rate of 20%, this would require an additional 100 trainees per annum from 2004. In the interim there should be every effort to increase the workforce as much as possible.⁷⁴

70 *Committee Hansard* 3.8.06, p.6 (Peter MacCallum Cancer Centre).

71 *Submissions* 39, p.2 (RANZCOG & Mercy Hospital for Women); 24, p.10 (ASGO); 27, p.9 (Ms Margaret Heffernan).

72 *Submission* 24, p.10 (ASGO).

73 *Committee Hansard* 1.8.06, p.90 (RCPA).

74 AMWAC, *The Specialist Pathology Workforce In Australia*, AMWAC Report 2003.5, Sydney.

4.101 Evidence indicated that despite the recommendation of the AMWAC that 100 new pathology training positions be created each year for five years, so far there have been only 39 new trainee or registrar positions.⁷⁵

4.102 Comments provided during the inquiry indicated that a lack of funding for training positions is a major contributor to the shortage of staff in both specialist pathology and gynaecologic oncology.

[Gynaecologic Oncology] training positions can be made available within the currently recognised training centres in Australia but there is inadequate funding for these positions in most states and more importantly no funding for employing these new sub-specialists within the Gynaecological Oncology Units.⁷⁶

For pathologists the issue relates to insufficient funding for training positions. There are many laboratories ready and willing to train pathologists, there are more medical students wishing to train in pathology than there are training places, the issue is purely the availability of funding for training.⁷⁷

Extended surgical waiting times

4.103 Many witnesses commented on the lack of funding for theatre availability and the resultant delays in surgical treatment.

Patients currently wait up to ten weeks for a gynaecological cancer operation in the Hunter New England Area Health Service. The long waiting times are a combination of a shortage of gynaecologists in the Region and a lack of operating theatre time. This is substantially more than the waiting time in the cancer centres in the Sydney Metropolitan.⁷⁸

The greatest delays occur in the public sector due to the disproportionate spread of specialist gynaecological oncologists between the states and territories. Against a national waiting list average of two weeks for surgical treatment Queensland performs the worst with usual waiting lists of up to six weeks.⁷⁹

Inability to access Magnetic Resonance Imaging (MRI)

4.104 The Royal Women's Hospital commented that access to MRI scans is restricted due to the absence of a Medicare rebate for gynaecological treatment such as scans of the pelvis, abdomen and breasts. The Hospital stated:

75 *Committee Hansard* 1.8.06, p.90 (RCPA).

76 *Submission* 39, p.2 (RANZCOG Mercy Hospital for Women).

77 *Submission* 57, p.2 (RCPA).

78 *Submission* 25, p.6, p.8 (Hunter New England Centre for Gynaecological Cancer).

79 *Submission* 7, p.5 (Gynaecological Cancer Society).

Currently, Magnetic Resonance Imaging (MRI) scans for spine, head, neck, musculoskeletal and cardiovascular system are listed on the Medicare Benefits Schedule, while scans that would benefit diagnosis and treatment of women, such as scans of the pelvic, abdominal and breast areas, are not. From the perspective of providers, there is no financial incentive to provide scans that do not attract a Medicare rebate. This has a considerable impact on the supply of women's MRI imaging. While ultrasound is still the mostly useful diagnostic tool in gynaecology, access to MRI on site would significantly enhance this hospital's diagnostic and research capacity.⁸⁰

4.105 The Commonwealth Department of Health and Ageing provided evidence that the Medical Services Advisory Committee (MSAC) is reviewing the use of annual MRI screening for women at high risk of breast cancer, under the age of 50 years. This assessment is expected to be finalised by the end of 2006.⁸¹ However, the absence of considering MRI for gynaecological cancer areas of body remains an issue.

Adequacy of psychosocial treatment and services

4.106 Psychosocial issues facing women with gynaecological cancers include emotional issues, social issues, psychological issues, physical issues, survival issues, practical needs and financial issues and towards-end-of-life issues. These issues can be complicated by special considerations of culture, geography, sexual orientation and age.

4.107 Following the diagnosis of a gynaecological cancer many women and their families experience major degrees of psychological distress. Ms Jane Mills from the NSW Psychosocial Support Project at the Westmead Hospital, stated:

The term 'psychosocial support' encompasses access to accurate information about the impact of a cancer diagnosis and access to ongoing emotional, psychological, psychosexual, practical and pastoral support from the point of diagnosis, throughout treatment, after care, during the survivorship stage and throughout palliative care, if needed.⁸²

4.108 A resounding amount of evidence indicated that psychosocial and psychosexual treatment and services are a major element of a woman's recovery and these needs are often ignored and neglected. Ms Kim Hobbs, a social worker from the Westmead Centre for Gynaecological Cancer and member of the NSW Psychosocial Support Project provided the following statement:

The provision of expert psychosocial support throughout the cancer journey is an ethical imperative not an added extra.⁸³

80 *Submission 37*, p.3 (The Royal Women's Hospital).

81 *Submission 52*, p.9 (Commonwealth Department of Health and Ageing).

82 *Committee Hansard* 1.8.06, p.30 (NSW Psychosocial Support Project).

83 *Committee Hansard* 1.8.06, p.31 (NSW Psychosocial Support Project).

4.109 Ms Rosalind Robertson, Senior Psychologist at the Royal Hospital for Women, described a screening tool being used in her department to identify psychosocial needs:

We have just started using a small screening tool in our department. It is a 'distress thermometer' and the doctors use it at the first visit of a patient. The patient just fills it out. It is very quick. It is a visual analogue scale. It alerts us to how much stress they are feeling and they can nominate certain areas they are feeling very distressed about.⁸⁴

4.110 At the Ovarian Cancer Consumers' Forum held in Melbourne in February 2006, a common theme arose that inappropriate referrals to support services frequently occurred because the support service was:

- not available;
- overbooked;
- geographically inaccessible; or
- not affordable.⁸⁵

4.111 The Gynaecological Oncology Unit at Monash Medical Centre identified the lack of funding preventing the Unit from providing psychological, psychosexual and social support services as part of their service provision to women with gynaecological cancers.

Despite the NH&MRC publication, in 2003, of Clinical Practice Guidelines for the psychosocial care of adults with cancer we currently have no psychological service provision for our cancer patients and only limited access to liaison psychiatry services...This situation is not unique to our Unit and is standard in most Units around the country. Given the psychological impact of Gynaecological cancer on women and the report produced two years ago it is a glaring omission that we have no funding for a psychologist and appropriate psychological support for our women.⁸⁶

4.112 The Gynaecological Cancer Society commented on the inadequacy of psychosocial services.

Emotional support for gynaecological cancer patients is the most neglected area in the treatment regimen. The nation's major public treatment centres usually employ social workers; however they are usually understaffed and consequently overworked. Public patients can expect only one visit from a social worker during their management and often only upon specific request. In the private sector the situation is even worse. Many private treatment centres do not employ social workers and these patients, who

84 *Committee Hansard* 1.8.06, p.35 (Royal Hospital for Women).

85 *Submission* 39, p.3 (RANZCOG and Mercy Hospital for Women).

86 *Submission* 13, p.5 (Monash Medical Centre).

account for approximately 50% of all gynaecological cancer patients, are left to fend for themselves.⁸⁷

4.113 Professor Quinn provided further comment:

I am aware that service delivery is a matter for the states, not for the Commonwealth, but it is clear from the numerous submissions to this inquiry and to many other cancer inquiries in Australia that the appropriate provision of adequate psychosocial care is extensively lacking. This needs to be addressed, I believe, as a priority area at all levels. I believe that a holistic approach to care is mandatory, and the use of complementary practices such as massage and meditation, which we currently provide at our own hospital in Melbourne, need to be incorporated into mainstream practice.⁸⁸

4.114 Discussion during public hearings raised the need for sexuality and psychosexual support for women with gynaecological cancers. Sexual dysfunction as a result of treatment for gynaecological cancers is often underestimated, forgotten, not spoken of or ignored.

4.115 Research referred to in evidence estimated that 20-90 per cent of gynaecological cancer patients experience significant sexual difficulties, 30 per cent of women with gynaecological cancers will experience sexual dysfunction, with 50 per cent experiencing dyspareunia (painful sex), and only 50 per cent of women remain sexually active after treatment.⁸⁹

4.116 Ms Robertson commented on the range of sexuality issues experienced by women with gynaecological cancers:

Women with gynaecological cancer have unique problems in the oncology setting. The patient is placed at high risk of developing sexual and body image problems, infertility – sometimes at a very young age – and the associated grief of never being able to bear a child, hormonal dysfunction and premature menopause...Patients indicate that sexuality is an important concern that needs to be addressed but is often neglected in the cancer care setting. We presume that is because the focus is on getting the patient through difficult treatments and the life and death issues. So sexuality gets left behind.⁹⁰

4.117 A table detailing the possible sexuality issues involved with gynaecological cancer surgery is available at Appendix 4.

87 *Submission 7*, pp.5-6 (Gynaecological Cancer Society).

88 *Committee Hansard 3.8.06*, p.3 (The Royal Women's Hospital).

89 *Submissions 9*, p.2 (Ms Alexa Rosengarten); 10, p.6 (Sydney Gynaecological Oncology Group).

90 *Committee Hansard 1.8.06*, p.29 (Royal Hospital for Women).

Inadequacy of treatment provision to rural and remote areas

4.118 Treatment for gynaecological cancers in rural and remote areas is difficult due to geographical locations, lack of service providers and the need to travel distances at inconvenient times, at a financial and emotional cost often without the support of loved ones.

4.119 The Country Women's Association of New South Wales commented:

Treatment may prolong life but in some cases because of the trauma and problems of travel, being away from home and loved ones, support networks etc., that quality of life is questioned. That is why so many country women (and men) consider it is simply not worth the effort.⁹¹

4.120 Access to gynaecology oncology services and appropriate treatment facilities are often unavailable to rural and remote women. For example, North Queensland has a population of 500,000 and does not have a full time gynaecology oncology service. A visiting service is available three days a month in Townsville from Brisbane which is not convenient as more than half of the women live in the Cairns drainage population and have trouble accessing this service. Dr Paul Howat, Director of Obstetrics and Gynaecology and Director of Outreach Services, Cairns Base Hospital, commented:

Access to radiotherapy services at Townsville Hospital is poor and often delayed. The visiting gynaecological oncologists are all in private practice and some display little interest in public patients or their treatments. Gynaecological oncology is very much a private practice sub-speciality. This means that rich white women, not surprisingly, have the best outcomes in the world for treatment of their malignancies.⁹²

4.121 Professor Quinn commented on the inadequate funding available for specialist doctors to provide services to remote and rural communities.

There is no funding available for specialists to go to rural communities. We have all gone, off our own bat, to do clinics in the country for which we cannot be paid because the local hospital does not have the money, and our mother hospital does not want to pay for us doing clinics out there, so who actually pays for the personnel?⁹³

4.122 Outreach is one way for specialist medical services to get to patients living in rural and remote areas of Australia. The Department of Obstetrics and Gynaecology at Cairns Base Hospital has provided outreach services for Far North Queensland women for over 15 years which is funded entirely through State Government Queensland Health funding. Dr Howat commented on the absence of Commonwealth

91 *Submission 16*, p.4 (Country Women's Association NSW).

92 *Submission 1*, p2 (Dr Paul Howat).

93 *Committee Hansard 3.8.06*, p.22 (The Royal Women's Hospital).

funding and the inability to bulk bill patients and the restrictions this causes to an effective outreach service:

We are not allowed to bulk bill patients, and we have been refused MSOAP (Medical Specialist Outreach Assistance Program) funding for enhancing outreach services because we had an existing service. Hence, some of the poorest and most remote, and underprivileged women in Australia, have virtually no federal input into the treatment and care of premalignant conditions – it is all state based. This is inequitable, and I assume, not what these funding models intended to happen.⁹⁴

Tele-medicine and satellite clinics

4.123 Many witnesses provided information on using communication technology to provide assorted medical services to rural and remote areas. Examples given include diagnostic services, case conferences with specialists and satellite follow-up clinics.

We started a tele-colposcopy pilot project that was funded by the state health department to provide diagnostic services for women in rural areas with precancerous lesions. That has been very successful, and a publication is going to come out of it soon. We have just received funding for a tele-health project within our unit, which will enable us to conference with specialists in Wollongong and Wagga Wagga and Canberra so that our tumour boards, where we discuss all new cases and get a consensus on management, can involve the people in the rural areas—Canberra is probably not that rural—away from the tertiary referral centres. There is a great deal of value in it.⁹⁵

The model of a central referral with satellite follow-up clinics in the local area seems to be working reasonably well, but we have never had evaluation of this model.⁹⁶

Psychosocial service provision to rural and remote areas

4.124 Evidence received during the inquiry indicated that adequate psychosocial support for all patients can not be achieved even in large metropolitan centres, so the provision of these services in rural and remote areas of Australia is extremely limited.

4.125 Ms Robertson from the Royal Hospital for Women stated that studies suggest that people with cancer living in rural areas are more likely to report problems and greater concerns associated with travel for treatment, follow-up care and psychosocial services. Ms Robertson also commented:

Within the psycho-oncology literature there is little practical advice about the best way to deliver this care. Triage to a tele based counselling service staffed by social workers, psychologists, nurses and nurse counsellors is a

94 *Submission 1*, p.2 (Dr Paul Howat).

95 *Committee Hansard 1.8.06*, p.50 (GMCT).

96 *Committee Hansard 3.8.06*, p.4 (The Royal Women's Hospital).

concept worthy of consideration for gynaecological cancer patients requiring specialist care. It is a concept that the Queensland Cancer Fund has adopted, and it may be a useful concept for us to consider in order to help overcome some of the current problems created by the tyranny of distance.⁹⁷

4.126 Associate Professor Jobling, Monash Medical Centre, provided an example to illustrate the immense need for supporting patients in rural and remote areas:

I have a patient at the moment who is terrified of going home, because she has what turned out to be a pancreatic cancer and she is going to be dying in the next two to three months. She is terrified of pain and she lives 40 kilometres from Ballarat. She is asking, ‘What’s going to happen when I get my pain? Who’s going to look after me? Who’s going to help me?’ and it is very difficult to answer those questions for that particular woman.⁹⁸

4.127 Ms Robertson commented on the psychosocial support she provides to patients who live in rural and remote areas and are experiencing distress:

However, in my experience in dealing with patients who go home to remote areas from our centre, I think many of them would probably just like to hear somebody’s voice—a human being rather than a computer.

I do take a lot of telephone calls from rural people who are upset; they are often crying. I know the nursing staff in my department also get a lot of calls from people. So we do a lot of that. I cannot spend all day on the phone, so it is limited really. It is difficult.⁹⁹

The role of regional nurses and specialist nurses

4.128 The possibility of using existing regional nurses to assist women living in the community with gynaecological cancers and establishing outreach programs with specialist oncology nurses was raised in evidence.

If doctors are expensive, then...this is where gynaecological cancer nurses may have a role, and we should actually be looking at expanding, training and looking at community outreach from our nurses, because I think that they have a huge amount of value-add to the care of women with these cancers.¹⁰⁰

I think women need to be under the care of specialists that are generally centrally located in metropolitan centres, but you could develop a state-wide regional nurse practitioner or just gynae nurse or oncology nurse in a case management model, because the hospital episodes are just hospital episodes. The disease process for the woman is an everyday event, where

97 *Committee Hansard* 1.8.06, p.29 (Royal Hospital for Women).

98 *Committee Hansard* 3.8.06, p.24 (Monash Medical Centre).

99 *Committee Hansard* 1.8.06, p.32, p.34 (Royal Hospital for Women).

100 *Committee Hansard* 3.8.06, p.22 (The Royal Women's Hospital).

she is managing her symptoms and her family. The fact is that they are women, they are often young and they often have other roles of caring for young children or elderly parents. You could place regional nurses to do that case management. It is not just the hospital episode that is important.¹⁰¹

4.129 The Cancer Council Western Australia provided an example of a rural specialist breast nurse program which has been in operation but expressed concern as State Government funding will soon cease.

The Cancer Council has run a rural specialist breast nurse program—putting part-time nurses in Albany, Bunbury and Geraldton over the last four or five years—which was funded by the Commonwealth department of health through the state department of health. It has proved a very successful model, specifically in the area of breast cancer, and to an extent it has shown the way in which those services can be provided. That program is due to wind up at the end of this current financial year, but, with our support, on the basis that an ongoing service provision should be provided by the state, they are putting in place state funded cancer support nurses.¹⁰²

4.130 Professor Hacker from the Royal Hospital for Women commented on regional nurses providing psychosocial and palliative support in rural areas. Professor Hacker stated:

In terms of psychosocial and palliative support, which of course is also lacking in rural areas, my own belief is that we probably need to train nurses to do a lot of this type of thing. It is probably unrealistic to expect that palliative care physicians will be working in rural areas. It is more realistic to think that nurses who come from that area could be specifically trained and then go back and stay there.

They would need to spend three or four months in major centres in the cities before going back. I do not think you can just take any nurse and give her a week in a city centre and expect that she will go back and be able to do the work. I think she has to spend time with the psychologist, the physiotherapist, the palliative care people and the gynaecological oncologist or the medical oncologist so that she gets to know those people and gets to meet and work with the women who have these cancers and becomes familiar with all the issues.¹⁰³

Adequacy of treatment provision to Indigenous Australians

4.131 Dr Howat from Cairns Base Hospital has a practice population that is thirty per cent Indigenous and commented on the overall situation with Indigenous women with gynaecological cancers:

101 *Committee Hansard* 3.8.06, p.22 (the Royal Women's Hospital).

102 *Committee Hansard* 4.8.06, p.12 (The Cancer Council Western Australia).

103 *Committee Hansard* 1.8.06, p.17 (Royal Hospital for Women).

Indigenous women in particular have some of the worst gynaecological cancer incidence rates and survival rates in the world, whereas Australia has amongst the best treatment successes and survival rates overall. There is a huge discrepancy of access and outcome of these women, and it is a great shame which must be corrected.¹⁰⁴

4.132 Dr Gerard Wain, former Co-Chair of the Greater Metropolitan Clinical Taskforce's (GMCT) Gynaecological Oncology Service, provided an example which highlighted the difference in approach and the requirement for specialised resources to ensure adequate care is provided to women living in Indigenous and isolated communities.

We had a patient last week who was not appearing for surgery. We had to contact the Aboriginal medical service in the local area. They did not have a telephone contact so they got in a car and went to the community, drove around and knocked on the door, found out where she was, made sure that the kids were okay and then drove the patient to hospital... That is what you sometimes have to do with the patients who are really disenfranchised from the health system. They are not high users of the health system... So the provision of not just psychological support but even just practical support measures across that pathway becomes a challenge often to be coordinated at the local point where the patient lives.¹⁰⁵

4.133 The provision of treatment for Indigenous women living in more remote areas requires the transfer of patients to major centres. The Queensland Centre for Gynaecological Cancer has initiatives to assist Indigenous women with the transfer to a major treatment centre and provide cultural specific and sensitive medical and health services within the tertiary centre.

At both the Royal Women's and Brisbane Hospital and The Townsville Hospital a full time Indigenous Women's Liaison Officer has been appointed funded by Women's Cancer Screening Services, Queensland Health under the title of Program Coordinator, Indigenous Women's Cancer Prevention and Support. These officers have access to an office and a vehicle and perform a number of valuable roles including concentrating on the provision of cultural specific and sensitive support services within the tertiary centre.¹⁰⁶

4.134 The provision of treatment to Indigenous Australians often requires long periods at or frequent visits to places that are unfamiliar and lacking in cultural awareness. People living in rural and remote areas, or even in Darwin, are reported as being particularly disadvantaged in accessing cancer services, especially radiotherapy.

104 *Submission 1*, p.1 (Dr Paul Howat).

105 *Committee Hansard 1.8.06*, pp.38-39 (GMCT).

106 *Submission 11*, p.6 (Queensland Centre for Gynaecological Cancer).

4.135 As part of the 2006-2007 Federal Budget, the Commonwealth committed new funding of \$80.3 million over four years to improving access to radiation oncology facilities in the Northern Territory. A radiation therapy facility in Northern Australia has been identified as a priority and this facility can be accommodated within the programme funds, with private sector and Northern Territory Government contributions.¹⁰⁷

Adequacy of treatment for women from multicultural and linguistically diverse populations

4.136 Australia has one of the most multicultural populations in the world and language and cultural barriers limit the effective access of women from culturally diverse backgrounds to adequate health information, treatment options and support.

The adequacy of interpreting services

4.137 Ms Robertson from the Royal Hospital for Women indicated that interpreting services provide one strategy to promote understanding and open communication between cultural and linguistically diverse patients and health professionals. Ms Robertson commented on the very high demand for interpreters which impacts on this being a viable solution and said 'I sometimes find it very hard to get an interpreter on the day on which I really need one'.¹⁰⁸

4.138 The Westmead Centre for Gynaecological Cancer commented on problems they have accessing interpreters. Ms Hobbs stated:

Our Health Care Interpreter Service in New South Wales is excellent but it is inadequately funded. So to get an interpreter in the room at a timely moment to discuss major surgery, pathological findings and adjuvant treatment is a challenge, particularly for some of the less common community languages. The response always is, 'Well, you could use the Telephone Interpreter Service.' But the logistics of passing the phone back and forth to a lady who is post-operative in a bed mean that it is difficult.¹⁰⁹

4.139 Ms Margaret Heffernan commented on the need for Government support and funding for increased access to interpreters for women with gynaecological cancers. Ms Heffernan commented that interpreters are most needed:

...where discussion of sensitive and intimate issues is often difficult in patriarchal and 'loss of face' cultures. Current interpreter services are not available on all working days. Although TIS [the Translating and Interpreter Service] is available 24 hours, 7 days a week it has to be booked

107 Commonwealth Department of Health and Ageing, *Better Access to Radiation Oncology – Continue Funding*, <http://www.health.gov.au/internet/budget/publishing.nsf/Content/budget2006-hfact49.htm>.

108 *Committee Hansard* 1.8.06, p.29-30 (Royal Hospital for Women).

109 *Committee Hansard* 1.8.06, p.37 (NSW Psychosocial Support Project).

in advance. It is not appropriate or realistic to expect the carer of family to fill the role of psychosocial support when often they are loss for appropriate action. The MCIS [Multicultural Cancer Information Service] is a telephone service available to ALL Australians for the cost of a local call it is only promoted within NSW and therefore remains unknown to most or all other cancer patients and their families.¹¹⁰

Cultural differences impacting on treatment services

4.140 The Federation of Ethnic Communities' Councils of Australia (FECCA) defined cultural competence.

Cultural competence is not knowing everything about every culture, but recognising and respecting difference and having attitudes, skills and knowledge that support individuals and organisations to work effectively in cross cultural situations. The ability to work effectively with interpreters is one indicator of cultural competency.¹¹¹

4.141 Ms Hobbs commented on the need to be aware of the impact of cultural differences and illustrated some problems she has experienced, stating:

One needs to be aware of cultural sensitivities. There may be a request from many cultures, from the male members of the family and the children of many women, 'Please don't tell mum she has cancer; in our culture that's not done.' So we are always skirting around that issue of how one should deal with that, while at the same time obtaining informed consent for treatment and giving the woman an opportunity to do with the rest of her life as she would want to do. So that is a challenge. With respect to gender issues, in our department we are lucky in that we have one full-time female gynaecological oncologist. They are a rare breed in Australia. But we do not always have female junior staff—registrars and residents—and we do not always have access to female interpreters. So the problems are huge.¹¹²

4.142 The CNSA provided examples of cultures where it is not appropriate for women to seek health care themselves and the dominant male in the family decides whether or not they seek health care. Dr Ryan from the CNSA commented:

For some of those women, their culture does not allow somebody other than their husbands to deal with that part of the body. An example is the Pacific Island cultures. I have been told by a woman: 'That is our husband's business down there. It's nobody else's business.' The idea of even a female health worker doing a pap smear on those women is culturally not acceptable to them...If a woman has a gynaecological problem they may in

110 *Submission 27*, p.16 (Ms Margaret Heffernan).

111 *Submission 43*, p.4 (Federation of Ethnic Communities' Councils of Australia).

112 *Committee Hansard 1.8.06*, p.37 (NSW Psychosocial Support Project).

fact find it difficult to discuss it with the dominant male in their family. That delays them seeking health care.¹¹³

The adequacy of treatment to disadvantaged groups in Australia

4.143 The inquiry also examined the problems experienced by other women in Australia who often found it difficult to access appropriate care, treatment and support for gynaecological cancers due to mental health issues, poverty or socioeconomic disadvantage.

Most deaths [from cervical cancer] are in poor women who have seldom or never been screened. In the developing world, where screening is less available, cervical cancer kills about 250 000 women a year and is the second most common cause of death from cancer.¹¹⁴

4.144 Dr Ryan commented that:

Mental health problems are a significant issue for a number of women...

I work in a disadvantaged area, where we see that on a daily basis. That includes not only women from a non-English-speaking background but also women who are immigrants or refugees, women of socioeconomic disadvantage, women of low education and literacy levels, women with substantial mental health problems and women who are victims of domestic abuse. Providing a whole lot of the stuff that we have talked about today for those women is particularly challenging.¹¹⁵

4.145 Dr Wain from the GMCT commented on the specialised needs of some of his patients.

They come from quite deprived situations. Sometimes it is the first time they get to make contact with social workers and social support systems. Sometimes it is the cancer that brings them into the network of health services and often it is the first time people have had these facilities available for adequate health care. Despite their health and psychiatric status—many of those conditions—sometimes it is the cancer diagnosis that precipitated the contact with the health system.¹¹⁶

Patient assisted travel schemes

4.146 The Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS) was established by the Commonwealth Government on 1 October 1978. The scheme aimed to provide financial assistance to persons (and their escorts) residing in isolated areas who were referred to specialist medical treatment and oral

113 *Committee Hansard* 1.8.06, p.72 (CNSA).

114 Tanne. J.H, Vaccines against cervical cancer provoke US controversy, *British Medical Journal* 8 April 2006, 332, p.814.

115 *Committee Hansard* 1.8.06, pp.71-72 (CNSA).

116 *Committee Hansard* 1.8.06, p.38 (GMCT).

surgery not available locally (that is in excess of 200 kilometres). In 1983 the scheme was extended and flexibility for approval for further specialist treatment was introduced.¹¹⁷

4.147 Following wide-ranging criticism of IPTAAS, the Commonwealth abolished the scheme in the 1986-87 Federal Budget and responsibility for management of patient assistance travel schemes was transferred to the States and Territories from 1987. The then Minister stated that:

The Federal Government recognises that having the Commonwealth manage that scheme is inefficient and administratively cumbersome, particularly because the isolated patients by and large are living not in Canberra but in outlying areas of the States and they are seeking assistance and care in the States. It is quite appropriate and proper, and far more administratively streamlined, for the States to manage that scheme.¹¹⁸

4.148 The Commonwealth provided increased funding at that time to the States and Territories for the provision of patient transport assistance arrangements.

Current arrangements

4.149 The States and Territories now maintain schemes to assist eligible patients to travel to receive health care. The schemes vary across jurisdictions as does the level of funding. A 2002 report from Western Australia provided some comparative data on expenditure. In 1999-2000, Queensland spent \$15.7 million, the Northern Territory spent slightly less (\$14 million) while WA spent \$8 million, NSW spent \$7.5 million, South Australia \$2.6 million, Victorian 2.5 million, Tasmania \$2 million and the ACT \$0.2 million.¹¹⁹

4.150 The following table provides a summary of current eligibility requirements, travel and accommodation assistance and the patient contribution required as part of the patient travel assistance schemes of each State and Territory.

117 Senator the Hon R Crowley, *Senate Hansard*, 13.12.83, p.3685.

118 Senator the Hon R Crowley, *Senate Hansard*, 25.9.86, p.825.

119 Department of Health, *PATS review*, WA Department of Health, 2002, Appendix 5.

Table 5: Summary of patient assisted travel schemes in Australia

State/ territory	Eligibility requirements	Travel assistance	Accommodation assistance	Patient contributions	Escorts
NSW	Patient must usually live more than 100 km from the nearest treating specialist Referred by a medical practitioner	Assistance provided at economy surface rail or bus rates Fuel subsidy of 15c/km for private car	Commercial: \$33/night (single) or \$46/night (double) Private: \$30/week after 1st week for pensioner patients with a Health Care Card	\$40 (\$20 for pensioner or Health Care Card holders) personal contribution deducted from the total benefits paid per claim	Medical practitioner or treating specialist certifies that escort medically necessary or person less than 17 years
Vic	Patient must live more than 100 km from the nearest treating medical or dental specialist or travels an average of 500 kms per week in a block of at least 5 weeks	Assistance provided for the most direct means of public transport (economy rate) Fuel subsidy of 14c/km for private car	Commercial: Up to \$30/night for a maximum of 120 nights in a treatment year Private: Not eligible	Patients who are not concession card holders will have the first \$100 deducted from their payment each treatment year	Referring practitioner and/or treating specialist state escort necessary or person under 18 years
Qld	Service must be more than 50 km from the patient's nearest public hospital Referred by medical practitioner or remote area nurse, dentist or optometrist	Assistance provided at the cost of the least expensive form of public transport from the town of local hospital to the transport terminal of the town the patient is travelling to Fuel subsidy of 10c/km for private car	Commercial: \$30/night for concession card holders; non-concession card holders must pay for the first four nights accommodation in a fiscal year Private: \$10/night for concession card holders; non-concession card holders to meet first four nights accommodation	Nil	If hospital medical officer decides it is medically necessary
SA	Patient must live more than 100 km from the nearest treating specialist	Assistance provided at economy rate for bus/ferry/train less a patient contribution of \$30 Fuel subsidy of 16c/km for private car	Commercial: Up to \$33/night, no reimbursement on first night for non-concession card holders Private: Not applicable	Patient contribution of \$30 deducted from total travel benefits: means tested exemption for genuine hardship	Need for escort medically endorsed or person under 17 years

WA	Patient must live more than 100 km from the nearest treating specialist or 70kms to access renal dialysis or oncology treatment	Assistance provided at economy rate for bus or train Air only if required by medical condition or journey by road over 16 hrs Fuel subsidy of 13c/km for private car	Commercial: Up to \$35/night. Non-concession card holders are required to pay for the first three nights accommodation Private: \$10/night	Non-concession card holders pay the first \$50 for a maximum of 4 trips in a financial year	If deemed medically necessary or person under 18 years
Tas	Patients must live more than 75 km from the nearest treating specialist or medical services not available in Tasmania Referral by a medical specialist or oral/maxillofacial surgeon or a rural GP	Assistance provided at economy bus travel from patient's residence Fuel subsidy of 13c/km for private car	Commercial: up to \$30/night Patients not on a pension are required to pay for the first two nights Private: not applicable Limit of \$2000 travel and accommodation costs/patient paid each year by Government	Card holders: \$15/trip; maximum contribution \$120/fiscal year Non card holders: \$75/trip; maximum contribution \$300/fiscal year	If referring specialist certifies escort necessary to provide active assistance while travelling or for specific medical reasons relating to treatment or under 18 years
NT	Patient must live more than 200 km from the nearest treating specialist or to interstate specialist when no specialist available in NT. Referral by medical or dental practitioner	Assistance provided at the cost of an economy return bus trip from the bus depot closest to the patient's residence. Air for Alice Springs/Darwin and interstate Fuel subsidy of 15c/km for private car	Commercial: Up to \$30/night Private: \$10/night	Nil	If necessary to assist with patient care and support services at place of treatment cannot provide adequate assistance or person under 16 years (individual approval for under 18 years)
ACT	Available to permanent residents of the ACT who are required to travel interstate for specialist medical treatment which is not available in the ACT Referral by specialist or GP	A maximum entitlement for travel by coach/train (Can/Syd/Can) is \$40/adult and \$20/child Greater reimbursement for travel to cities other than Sydney Travel by private car receives \$40/trip (Can/Syd/Can)	Commercial: up to \$30/night Private: \$10/night	Nil	Referring specialist certifies escort necessary for medical reason or person under 17 years

Source: Clinical Oncological Society of Australia, The Cancer Council Australia and the National Cancer Control Initiative, Optimising Cancer Care in Australia, p.116; NSW Health, Transport for Health.

Accessing patient assistance

I had my first blood tests on a Tuesday morning and that afternoon I was told I had cancer. During my first few nights in the hospital my husband slept in a chair beside my bed. My parents were forced to stay in a guesthouse nearby at \$120 per night. My sister lived 40 minutes from the hospital, so her household grew from three to 10 people...tension was high and relationships strained. These living arrangements meant that no one had any routine or normality to their lives. It would have been a load off my mind had my family been able to stay somewhere close by, without being a burden on anyone, or one their savings. I went from wondering if I had many tomorrows left, to stressing about where my family would stay.¹²⁰

4.151 During the inquiry, the Committee received extensive evidence on the inadequacy of current arrangements to assist patients who need to travel to large centres for assessment and to receive treatment. Because of the lengthy treatment cancer patients must undertake, many patients remain at treatment centres for long periods of time which not only places a financial burden on families but also causes further disruption to family life. The Country Women's Association NSW graphically portrayed the problems of those needing to travel to access treatment:

One of our members knows of a cancer patient from the Cooma area who chose to die rather than going all the way to Sydney (Westmead) regularly for treatment. She stated it was just too much effort and energy to make the trips and be away from the family. This would not be an isolated case, and in a country of our supposed standard of living it is a disgrace.¹²¹

4.152 Many witnesses also emphasised that improved outcomes for women with gynaecological cancers have been shown for women who receive timely referral and treatment by a gynaecological oncologist supported by a full multidisciplinary team. This care is only available in large centres. To ensure that all women have access to multidisciplinary teams, financial assistance is often required for them to travel. Associate Professor David Allen, representing the commented:

If we are really serious about bringing multidisciplinary care and the best possible care to these women, and if we are going to bring them to a metropolitan area for that care we really need to fund them fully for transport, meals and accommodation for them and their support people. As you say, if you are moving a doctor – a gynaecological oncologist for example – out to a remote area there is only so much they can do outside of the multidisciplinary team and the supports that they use every day in a big hospital. So they are still not going to get the full benefit of the treatment that is given in a metropolitan area or big city. But it is a trade-off. Is it more disruptive to have them come down to a city or to stay in the remote area? But if they are going to come down I think we need to support them a

120 National Health Priority Action Council, *National Service Improvement Framework for Cancer*, 2006, p.43.

121 *Submission 16*, p.4 (Country Women's Association NSW).

lot more than we are at the moment. There is support, but I do not think it is enough.¹²²

4.153 In its 2005 report into services and treatment options for persons with cancer, *The cancer journey-informing choice*, the Committee noted the difficulties facing those who must access patient travel and accommodation schemes. During this inquiry, the same difficulties were raised and the same criticisms were made. These criticisms focussed on the level of reimbursement for travel and accommodation, the requirement to access the nearest specialist and the lack of support for patient escorts.

4.154 The existing schemes all provide reimbursement for accommodation but generally in the range \$30 or \$35 in commercial accommodation. Some schemes also provide for a small payment for private accommodation. Witnesses noted that this is a subsidy only and does not cover all costs.¹²³ Some accommodation is provided by organisations such as state cancer councils and at hospitals which generally only charge around the price of the accommodation subsidy.¹²⁴ However, it was emphasised that there is still a large amount of unmet need. The Cancer Council of Western Australia commented that it was turning away about 50 country people a month who were seeking accommodation. To address the shortage a further building was being converted to accommodate rural patients.¹²⁵

4.155 Professor Hacker also noted that changes to admission practices have added to the level of unmet need. He noted that patients travelling to a major centre are not admitted straight to hospital as there is often a need to do investigations and therefore they must come to the city for two or three days before their operation. Professor Hacker also explained that hospital administrators want day-of-surgery admissions:

That means they cannot come down and be admitted to hospital, they have to come down and stay in a motel or somewhere. You really need, particularly for the lower income patients, some cheap accommodation associated with the major hospitals, major cancer centres, where patients can come and be investigated, be counselled and then be admitted on the day of surgery to the hospital for their operation.¹²⁶

4.156 Most States and Territories require that a patient see the nearest specialist. The Health Consumers Council WA commented that the imposition of this provision limits the choice for rural women and therefore limits the opportunity for women to build a partnership with their treating physician as 'PATS only subsidises under

122 *Committee Hansard* 3.8.06, p.83 (The Cancer Council Victoria and Victorian Cooperative Oncology Group).

123 *Submission* p.23 (The Cancer Council of Western Australia).

124 *Committee Hansard* 2.8.06, p.28 (Cancer Voices Australia).

125 *Committee Hansard* 4.8.06, p.10 (The Cancer Council Western Australia).

126 *Committee Hansard* 1.8.06, p.16 (Royal Hospital for Women).

certain criteria'.¹²⁷ Other witnesses also commented that such requirements may have an adverse outcome for women with gynaecological cancers as general surgeons may not have the expertise to treat the very complex cases that some women present with. Associate Professor Margaret Davy commented:

There is a strong need for the Multidisciplinary Group approach to gynaecological cancer care, so that it is not possible, nor even desirable that women are offered a poorer standard of care, just to make it closer to home.¹²⁸

4.157 A further matter raised in evidence was access to funding for an escort to accompany a woman to a treatment centre. In most States, an escort may accompany a patient if there is a medical need. Associate Professor Davy also noted that the Northern Territory will not permit an escort for a patient unless they are Aboriginal, whereas, South Australia and NSW will permit an escort to attend.¹²⁹ Witnesses argued that an escort should not be limited to only these circumstances. Women, and indeed all patients travelling to receive medical treatment, need psychological support as well as medical assistance. Professor Hacker commented:

When you mention the word cancer, any patient turns off and they do not hear very much of what is said thereafter. It is important that there is somebody with them just to take in the information that is given. To say you need a valid medical reason is very disappointing.¹³⁰

4.158 While schemes may make provision for funding for escorts, reimbursement is not always provided. ASGO commented:

You write these things, but it is not guaranteed. Whether or not a support person will be funded to come down often depends on who the administrative officer is.¹³¹

4.159 As the travel and accommodation schemes are administered by the States and Territories, the scheme may only fund for travel within that particular jurisdiction and patients in the same hospital may be funded to different levels. Cancer Voices of Australia commented:

When New South Wales patients have to go to Queensland and when Victorian patients have to go to New South Wales and vice versa, there are different rules. There should be one rule for all so that it does not matter where you get cancer, as it comes under the same rule.¹³²

127 *Committee Hansard* 4.8.06, p.56 (Health Consumers Council Western Australia).

128 *Submission* 46, p.4 (Associate Professor Margaret Davy).

129 *Submission* 46, p.4 (Associate Professor Margaret Davy).

130 *Committee Hansard* 1.8.06, p.16 (Royal Hospital for Women).

131 *Committee Hansard* 2.8.06, p.53 (ASGO).

132 *Committee Hansard* 2.8.06, p.27 (Cancer Voices Australia).

4.160 Many witnesses concluded that there is an urgent need to improve the system of travel and accommodation assistance. Professor Hacker commented that:

To avoid discrimination against rural patients, travel should be provided free of charge (at least for low income earners) and patients and carers need appropriate, cheap accommodation close to the hospital.¹³³

4.161 The Committee agrees that improvements to the patient assisted travel schemes are urgently required. The need for many people facing major illness to travel to major centres adds to the trauma of their situation as inadequate subsidy for accommodation and travel expenses is generally the norm. The problems with the current arrangements have been highlighted in a number of reports including the Radiation Oncology Jurisdictional Implementation Group (ROJIG) Committee Inquiry and the Committee's report, *The cancer journey: informing choice*.¹³⁴ The issues have also been canvassed at a number of meetings and conferences including National Rural Health conferences. However, apart from a change to the NSW distance eligibility requirement (patients may now access the scheme if they live more than 100 kilometres from a treatment centre rather than 200 kilometres as previously required), benefits have largely remained unchanged for some time and do not reflect real costs or meet demands for services.

Other treatment and health support programs

Alternative and Complementary

4.162 The Committee received evidence on the provision of alternative and complementary therapies for women with gynaecological cancers. The issues included inability to access these therapies and a lack of regulation to ensure that such services are appropriate.

4.163 Cancer Voices Australia commented on complementary therapies or programs, such as art therapy and music therapy programs and said that the best example is the Browne's Institute in Western Australia:

The Cancer Council of New South Wales, in its latest round of clinical trials, has just issued money to a music therapist in one of the hospitals in Sydney to undertake a clinical trial on the benefits of music through the cancer pathway. It will be very interesting to see what that trial presents. The issue of complementary therapies will never go away. If you have cancer and something is perceived to be the silver bullet, people will go for it. People will hear from one person or one group or other that: 'This is the best treatment for you.' We certainly do support clinical evidence to support complementary therapies and we would look to have a lot more regulation in this area.¹³⁵

133 *Submission 40*, p.5 (Professor Neville Hacker).

134 Radiation Oncology Jurisdictional Implementation Group, *Final Report*, September 2003, p.10.

135 *Committee Hansard 2.8.06*, p.26 (Cancer Voices Australia).

4.164 Mrs Sharma, an ovarian cancer survivor and advocate, representing The Cancer Council Western Australia commented on the lack of accreditation of suppliers of these therapies and the need for more integrated medicine institutes in Australia. Mrs Sharma commented:

At the moment, in Australia, there is no credentialing or accreditation of people who offer alternative or complementary therapies. Obviously, a lot of these people end up with charlatans who steal not only their valuable time but their money as well. I do not see why this should be happening in a country like ours. We should really be providing secure, updated information for these people and telling them where they can go, instead of just offloading them and saying, 'Sorry, we can't do anything more for you.'

My last point is that there is no integrated medicine institute in Australia. There are clinics in Europe, like Paracelsus and Dr Issel's clinic. There is one in Switzerland and one in Germany but in Australia we do not have an approach like that and I do not see why not.¹³⁶

Menopause

4.165 Menopause, particularly, early onset menopause is a problem for women who receive treatment for gynaecological cancers. The Committee visited the Menopause Symptoms after Cancer Clinic in Western Australia and gained an insight to issues relating to menopause.

4.166 Evidence cited in submissions indicated that women with a diagnosis of cancer have a more troublesome experience with menopause than do other women. Approximately 40 per cent of women diagnosed with cancer experience a physical or emotional problem related to menopause and women who experience treatment-related menopause report a higher incidence and greater severity of tiredness, hot flushes and night sweats. These symptoms can persist for three or more years following diagnosis.¹³⁷

Lymphoedema

4.167 Evidence from survivors of cancers, women living with lymphoedema as well as gynaecological oncologists and other health specialists indicated that lymphoedema is a real problem and can have serious implications for a woman's health.

4.168 The Australian Physiotherapy Association explained what lymphoedema is:

Lymphoedema is swelling in one or more parts of the body which occurs when the lymphatic system does not work properly. People who have lymphoedema, as a result of gynaecological cancer treatment, may notice swelling that they cannot explain in the leg, lower abdomen, genital and buttock areas. The area may feel heavy, painful or uncomfortable. Unlike

136 *Committee Hansard* 4.8.06, p.3 (The Cancer Council Western Australia).

137 *Submission* 20, p.4 (CNSA).

breast cancer, most gynaecological cancer surgeries have a bilateral risk for lymphoedema – i.e. no "control" limb.¹³⁸

4.169 Research cited in submissions indicated that lymphoedema is a chronic and irreversible condition and the incidence of lower-limb lymphoedema in women who have been treated for gynaecological cancers ranges from 18 per cent to 41 per cent. Lower-limb lymphoedema causes problems with mobility, clothing and footwear and can significantly affect occupational and social activities.¹³⁹

4.170 Professor Hacker from the Royal Hospital for Women provided the following statistical information.

Patients with bad lower limb lymphoedema, which occurs in 50 per cent to 60 per cent of patients who have surgery for vulva cancer and groin node dissection and in about 20 per cent of patients who have surgery for cervical or endometrial cancer and have their pelvic lymph nodes removed, often need to spend a week in hospital while they undergo massage and bandaging.¹⁴⁰

4.171 Effective treatment for lymphoedema most often requires the use of specialised lymphoedema pressurised garments (compression stockings), regular massage and physiotherapy. The Lymphoedema Association of Western Australia stated that one compression stocking can cost \$800.00 and it is not unusual to require four of these stockings to receive adequate pressure.¹⁴¹ Also, due to the high cost, these stockings are often washed and used over and over again, which is not the most optimal solution.

4.172 Evidence received indicated that private health fund reimbursements and the ability to access public health subsidised compression stockings varies throughout Australia. The Australian Physiotherapy Association (APA) commented:

...the information that we do have indicates that patients receive very little reimbursement from health funds for garment provision. The APA contends that funding programs for garments such as those in Victoria and Tasmania would address some of the cost burden to the patient and could be emulated by other state governments, or a federal program could be introduced.

In 2002...a nationwide survey of garment provision...found no consistency between hospitals, between private and public sectors, or between states...Variability ranged from full cost borne by the patient to full subsidy by the government. Some equity is needed to provide fairer health care to those with lymphoedema.¹⁴²

138 *Submission 47*, p.3 (Australian Physiotherapy Association).

139 *Submission 20*, p.4 (CNSA).

140 *Committee Hansard 1.8.06*, p.17 (Royal Hospital for Women).

141 *Committee Hansard 4.8.06*, p.18 (Lymphoedema Association of Western Australia).

142 *Submission 47*, p.5 (Australian Physiotherapy Association).

4.173 The Gynaecological Oncology Unit at the Monash Medical Centre stated that they experienced serious deficiencies in service provision due to a lack of funding. One deficiency identified is the Unit's inability to provide a dedicated lymphoedema service for patients.

Currently in our Institution there is only provision for upper limb lymphoedema management under the auspices of Breast Care. A significant proportion of our Gynaecological cancer patients suffer from lower limb lymphoedema and they do not have access to the current service and are thus severely disadvantaged by this glaring deficiency. Provision of easy access to a fully effective and co-ordinated lymphoedema management service should be a major priority and would benefit Gynaecological cancer patients throughout the state.¹⁴³

4.174 The Lymphoedema Association of Western Australia commented on the compounded cost of treating lymphoedema in patients who have not received prior treatment.

The outcome is that many lymphoedema patients do not receive any treatment and go onto suffer chronic thickening of their lower limbs and recurring infection (cellulitis). Treatment for cellulitis may require hospitalisation and the use of expensive intravenous antibiotics, which is a strong indicator that withholding treatment is false economy for everybody.¹⁴⁴

4.175 The CNSA suggested that preventative education is probably the best way to address the problem, including early recognition of lymphoedema.

We are fortunate...that we have a well-established lymphoedema service which includes a preventative service, so every patient that is at risk of lymphoedema with breast cancer or a gynaecological cancer is seen by an occupational therapist prior to discharge to talk about preventative measures to try to address that.¹⁴⁵

4.176 In addition to preventative education to inform patients, The Australian Physiotherapy Association recommended that to effectively treat and manage lymphoedema, the following strategies need to be implemented:

All public sector patients with lymphoedema should have free access to specialised lymphoedema garments if these are required to manage their condition. For private patients, these garments should be fully subsidised by their health insurance fund.

Access to publicly funded lymphoedema management services should be increased to reduce waiting times.¹⁴⁶

143 *Submission 13*, pp.3-4 (Monash Medical Centre).

144 *Submission 17*, p.2 (The Lymphoedema Association of WA).

145 *Committee Hansard 1.8.06*, p.78 (CNSA).

146 *Submission 47*, pp.5-6 (Australian Physiotherapy Association).

Support groups

4.177 The use of support groups to provide information, a meeting place and a common understanding of the experience of gynaecological cancers is well established within Australia. There are many support groups around Australia that offer different services and levels of support. The Cancer Council New South Wales funded a survey of the cancer support groups in NSW and there were 173 of which only three were specific to gynaecological cancers.¹⁴⁷

4.178 The National Ovarian Cancer Network commented that through funding by public donation and commercial sponsorships they have:

...established peer support groups through their own facilities in Melbourne and is currently expanding this initiative through to Western Australia and Queensland. The Network provides the accommodation for patients to meet, along with a facilitator to provide a secure and welcoming environment for patients.¹⁴⁸

4.179 Dr Wain of the GMCT, commented that the survey indicated that patients who attend support groups get substantial benefits, have better quality of life and better outcomes—better depression or anxiety scores—and everything else along the way about people attending support groups.¹⁴⁹

Support for women during and after treatment

4.180 Dr Ryan from the CNSA commented on the need for support to be available so that women feel that they can continue to contribute to society, including sustaining some form of appropriate employment if desired by the woman.

I see it as our role to assist these women to go on living with this disease but also to continue contributing to society. I have become aware that, while women are living longer and it has become almost a chronic illness, there is a lot of uncertainty surrounding the illness and the treatment schedules that these women may be on. Therefore they have had to leave positions of employment because of their inability to give a guarantee to their employers. A challenge that we need to face is somehow keeping these women active in society because, while they are receiving treatment, they are still living with a certain quality of life.

By way of example, a young woman I am treating is a lawyer who had a position as an academic at a university. She had to leave because she could not guarantee how often she would be able to go into the university or how often she would be having treatment, and while she is still has a good quality of life she wants to contribute to society. She feels unable to, and I think that there is probably a large group of women now who are faced with

147 *Committee Hansard* 1.8.06, p.40 (GMCT).

148 *Submission* 33, p.9 (National Ovarian Cancer Network).

149 *Committee Hansard* 1.8.06, p.40 (GMCT).

this circumstance. Our challenge is to come up with creative ways to benefit from the expertise of these women, because for the majority of the women a major goal was to inhibit the disruption the cancer made to their lives in an effort to achieve some sense of normality.¹⁵⁰

Conclusion

4.181 Women with gynaecological cancers do not have equal access to services in Australia. Variation occurs in many settings and this is most evident in rural and remote areas of Australia, for Indigenous women and women from culturally diverse populations. Differences in service provision also occurred between treating hospitals and the public and private health systems. These issues all contributed to the ability of women to access multi-disciplinary care, adequate psychosocial and psychosexual support as well as the extent of coordination and wider support services available.

4.182 As a priority, strategies need to be developed and funding needs to be allocated to address these issues of variability. Many solutions were raised and strategies canvassed including extending the role of rural and regional nurses and Aboriginal health workers and incorporating e-medicine and telecommunications to support practitioners working in isolated areas. Although health delivery is primarily a State and Territory issue, the imperative to deliver high quality cancer care remains important. The need for the Commonwealth, State and Territory governments to work collaboratively to develop and implement strategies is necessary to achieve positive outcomes.

Recommendation 8

4.183 The Committee recommends that Cancer Australia work with the gynaecological cancer sector on an ongoing basis to develop national strategies improving the visibility of, and access to, screening, treatment and support services for women with gynaecological cancers.

Recommendation 9

4.184 The Committee recommends that the Commonwealth Government's funding and leadership of the National Cervical Screening Program continue and that strategies be implemented to improve screening participation rates for Australian women, particularly for Indigenous women.

4.185 The Committee further recommends that the Commonwealth work collaboratively with State and Territory Governments to promote the National Cervical Screening Program for all Australian women.

4.186 The Committee further recommends that the Commonwealth Government explore the extension of Medicare rebates for Pap tests performed by nurse practitioners, regional nurses and Indigenous health workers who are suitably trained.

150 *Committee Hansard* 1.8.06 p.76 (CNSA)

Recommendation 10

4.187 The Committee recommends that, as a priority, State and Territory Governments provide further funding so that all women being treated for gynaecological cancers have access, based on need, to clinical psychologists or psychosexual counsellors.

Recommendation 11

4.188 The Committee recommends that Commonwealth, State and Territory Governments work collaboratively to ensure adequate funding for health and support programs in rural and remote areas, such as increased funding for specialist outreach clinics and for the use of modern telecommunications technologies.

Recommendation 12

4.189 The Committee recommends that the Council of Australian Governments, as a matter of urgency, improve the current patient travel assistance arrangements in order to:

- establish equity and standardisation of benefits;
- ensure portability of benefits across jurisdictions; and
- increase the level benefits to better reflect the real costs of travel and accommodation.

Recommendation 13

4.190 The Committee recommends that the Commonwealth Government consider a Medicare Item Number for lymphoedema treatment by accredited physiotherapists and the provision of subsidised lymphoedema compression garments, based on need, for women as a result of cancer treatment.

Recommendation 14

4.191 The Committee recommends that the Commonwealth Government through the Medical Services Advisory Council (MSAC), review the MSAC's decisions on the use of liquid-based cytology (LBC) and high risk human papilloma virus (HPV) DNA testing in cervical screening processes.

Recommendation 15

4.192 The Committee recommends that the Commonwealth Department of Health and Ageing, as a priority, develop national strategies surrounding HPV vaccines and testing. Specifically, targeted and customised strategies to:

- highlight the benefits of HPV vaccines;
- provide easy access to the vaccines and appropriate educational resources, particularly for Indigenous Australians and people from culturally and linguistically diverse backgrounds; and

-
- **develop and encourage the use of self-testing for high risk HPV**

Recommendation 16

4.193 The Committee recommends that the Commonwealth Government, in collaboration with Cancer Australia and the Centre for Gynaecological Cancers, develop strategies and targets to improve referral rates from general practitioners to gynaecological oncologists for women with ovarian cancer.

Recommendation 17

4.194 The Committee recommends that the Commonwealth Government, as a priority, assume responsibility for the funding, development and implementation of a national data collection and management system to ensure the appropriate and accurate collection of gynaecological cancer data.

Recommendation 18

4.195 The Committee recommends that the Commonwealth Government in conjunction with the State and Territory Governments to expand the roles and responsibilities of specialist breast cancer nurses to include gynaecological cancers through cooperation with multidisciplinary gynaecological cancer centres.

Recommendation 19

4.196 The Committee recommends that the Commonwealth Government explore the need for Medicare rebates for MRI scans of pelvic, abdominal and breast areas.

Recommendation 20

4.197 The Committee recommends that Commonwealth, State and Territory Governments commit urgently needed funding and increased specialist resources to reduce current waiting times for women seeking the services of gynaecological oncologists and their multidisciplinary teams.

4.198 The Committee further recommends that maximum surgery waiting times are defined by key performance indicators agreed by treating physicians as not putting patients at risk.

CHAPTER 5

GYNAECOLOGICAL CANCERS EDUCATION FOR THE MEDICAL COMMUNITY

Introduction

5.1 One of the key issues in improving gynaecological cancer care is the management of the disease by the medical community and their level of knowledge about gynaecological cancers.

5.2 Members of the medical community and individuals spoke about the ongoing need for better information about gynaecological cancers and improved educational opportunities for all professionals.

5.3 Education for the medical community was identified as a priority by many and an effective way to tackle the issues that caused delays between symptom presentation and definitive treatment.¹ The Committee heard that one of the biggest challenges was targeting information about gynaecological cancers more appropriately and making it more visible and accessible.

5.4 Education for the medical community on gynaecological oncology matters was argued to be particularly important because it is a relatively new sub-specialty. Although there was some indication that awareness of the sub-specialty was growing, evidence to the Committee suggested that whilst medical professionals knew about gynaecological cancers, many lacked understanding regarding appropriate referrals to gynaecological oncologists, optimal treatment and associated issues that women may experience.² This lack of knowledge could be attributed to the fact that women with gynaecological cancers often present with non-descript symptoms which in turn could delay diagnosis in a large proportion of cases.

5.5 Dr Lewis Perrin, Secretary and Treasurer of the Australian Society of Gynaecologic Oncologists (ASGO) argued that improving the knowledge of the medical profession, particularly general practitioners, was just as important as public education.

I do not think the practitioners are deliberately poorly treating their patients, but they are not aware of the now documented evidence showing significant improved survival going into one of these units. Of course education is needed for the public, but I would say it is mainly for the medical profession.³

1 *Submission 51*, p.26 (The Cancer Council Western Australia); *Submission 44*, p. 9 (NBCC).

2 *Committee Hansard 2.8.06*, p.63 (ASGO); *Committee Hansard 1.8.06*, p.65 (NBCC).

3 *Committee Hansard 2.8.06*, p.63 (ASGO).

The importance of education

5.6 Women turn to medical professionals for certainty about uncertain aspects of their health. Professionals, particularly general practitioners, play a pivotal role in providing care and advice to women. It is therefore critical that they have the knowledge and resources necessary to give the best possible care to women with, or at risk of, gynaecological cancers.

5.7 Although there is a lower incidence of gynaecological cancers in Australia relative to other tumour types, the Committee heard that education was vital in ensuring that the professionals themselves maintained and expanded their knowledge of, and core skills in, gynaecological oncology. With evidence informing best practice constantly evolving and changing, it was argued that the medical profession needed to keep pace with the standards and mechanisms to ensure that women could access quality treatment and care.⁴

5.8 The Committee was told that education about gynaecological cancers should not only focus on technical medical concepts and developments, but should improve awareness of the psychosocial and emotional needs of women and hone other professional skills, such as communication with patients.

5.9 Witnesses and submitters emphasised that a measured approach to education was needed to:

- ensure delivery of programs and information in a timely fashion;
- match the messages and activities with the needs of the target audience;
- improve retention of key messages;
- increase rates of participation in continuing professional education activities; and
- to improve service delivery for women.

The medical community

5.10 The extent to which members of the medical profession required education of risk factors, symptoms and treatment of gynaecological cancers varied across the professions and across the individuals within those professions.

5.11 Some educational issues were profession-specific, hence some professions have been examined separately. Some issues – such as the need for improved coordination of educational strategies – apply across the board and have been considered in the latter part of this chapter.

5.12 Particular attention was given to the education of general practitioners and nurses because of the roles they play in the detection of gynaecological cancers and

4 *Submission 56*, p.30 (The Cancer Council Australia, COSA and NACCHO).

referral to specialist care. Education for allied health professionals, gynaecologists and gynaecological oncologists is also considered briefly.

General practitioners

Role

5.13 In the context of gynaecological cancer, general practitioners practise in a very different setting and context to other medical professionals, and as such have different relationships with patients and different learning and educational requirements.

5.14 General practitioners were described as the 'gatekeepers' of the medical profession because of their role in detection, referral, follow up and care for women.⁵ In this role, it has been said that they need to be masters of uncertainty because symptoms were ill-defined and infrequently presented (perhaps one or two per year).⁶ Mr John Gower, Chief Executive of the Gynaecological Cancer Society argued:

The GPs have a hell of a job to do and they are not used to seeing gynaecological cancer, which can be 50 other things...They know their stuff; they know the symptoms; it is just not front of mind.⁷

5.15 In the case of ovarian cancer, the Committee heard stories of women for whom the diagnostic process was long, leading to delayed treatment and poorer survival rates.⁸ The Committee also heard similar experiences from women diagnosed with other gynaecological cancers.

5.16 The Committee heard that general practitioners experienced the following problems surrounding the management of women with gynaecological cancers:

- given the breadth of clinical encounters in general practice, general practitioners often did not have ready access to detailed information about gynaecological cancers and their treatment;
- general practitioners needed to be more aware of gynaecological oncology resources in their region and the evidence associated with treatment, to minimise referrals being made on less evidenced-based approaches;
- insufficient education about the benefits of treatment by a gynaecological oncologist, compounded by the lack of an academic base in the sub-specialty and resultant inadequate undergraduate training;

5 *Submission 44*, p.9 (NBCC).

6 *Committee Hansard 2.8.06*, p.38 (Gynaecological Cancer Society).

7 *Committee Hansard 2.8.06*, p.38 (Gynaecological Cancer Society).

8 *Committee Hansard 3.8.06*, p.4 (The Royal Women's Hospital).

- the structure of general practice itself often does not allow much time for, and unless the general practitioner is very motivated, investigation and management of vague and ill-defined symptoms; and
- insufficient support and incentives for the average general practitioner to up-skill in gynaecological cancer related issues as he or she only sees one or two new cases of a gynaecological cancer a year (particularly when so much of the person's care is undertaken by others medical professionals, such as gynaecological oncologists).

5.17 The referral process gave rise to particular concerns. It was argued that opportunities to improve referral pathways through education were important as the initial referrals of women to specialist services (widely agreed to be a critical role for general practitioners) were not always made. A number of reasons were put forward, with the main one being a lack of available information about referral pathways to specialist services. It was argued this meant general practitioners did not necessarily know who to refer patients to or they simply continued referring them to specialists to whom they had historical referral patterns.

Current education strategies

5.18 A large proportion of the educational material and programs produced for professionals by government, non-government and community-based organisations were aimed at general practitioners. The Commonwealth Department of Health and Ageing (the Department) and the National Breast Cancer Centre (NBCC) emphasised that their activities and efforts to raise awareness about gynaecological cancers had targeted general practitioners because they were the first point of contact for women with symptoms.⁹

5.19 The NBCC has produced various educational programs and products on ovarian cancer for general practitioners. In 2005, the NBCC developed a guide – *Assessing symptoms that may be ovarian cancer* – to assist general practitioners to assess women with a step-by-step process to follow in the investigation of symptoms. According to the NBCC:

This guide was disseminated to over 22,000 GPs across Australia. It continues to be the most widely disseminated guide from the whole NBCC resource list, with nearly 2,000 copies disseminated in 2005-06. It is regularly requested as the key resource for GP education sessions...¹⁰

5.20 The NBCC has also provided input into national seminars and a range of products, such as fact sheets, clinical practice guidelines and development packages, which target general practitioners and medical professionals more generally. Of note, is the *Directory of Gynaecological Cancer Services* which is an online resource that

9 *Committee Hansard* 1.8.06, p.59 (NBCC); *Committee Hansard* 23.6.06, p.42 (Commonwealth Department of Health and Ageing).

10 *Committee Hansard* 1.8.06, p.59 (NBCC).

provides general practitioners with contacts for referrals to gynaecological treatment centres and gynaecological oncologists.¹¹

5.21 The Cancer Council Australia and its State and Territory bodies also have educational strategies for general practitioners. In recognition of the fact that general practitioners are an important source of information for women, the Cancer Council Western Australia has held many GP cancer education programs events since 2001 with a gynaecological focus.¹²

5.22 Many community-based organisations and professionals acting in a volunteer capacity also conduct educational activities. For example, the NSW Psychosocial Support Project at the Westmead Hospital developed a new learning course for general practitioners with seven modules on psychosocial issues.¹³ Dr Yee Leung, a Western Australian gynaecological oncologist, said he and his colleagues made efforts to inform general practitioners on gynaecological cancers through lectures, workshops and seminars.¹⁴

5.23 ASGO also said that most gynaecological cancer centres in Australia run education programs on an 'ad-hoc basis' for general practitioners in their catchment area which were 'usually extremely well attended and very successful'.¹⁵

Is the current level of education appropriate?

5.24 The Committee heard that if the right decision regarding referral was to be made the right information needs to be available to general practitioners. General practitioners need to know what information is available, what information to seek and where to seek it.

5.25 It was difficult to judge the success of current education strategies without the presentation of empirical evidence, but anecdotally, the NBCC said that it had received positive feedback on its ovarian cancer guidelines from general practitioners.

5.26 Dr Helen Zorbas, Director of the NBCC said that one way to measure the success of the NBCC's approach was to examine changes in the referral patterns of general practitioners. Anecdotal evidence from one gynaecological oncologist suggested that the referrals he had been getting over recent times were growing in number and were 'much more appropriate'.¹⁶ Dr Zorbas argued:

11 *Submission 44*, pp.9-10 (NBCC).

12 *Submission 51*, p.25 (The Cancer Council Western Australia).

13 *Committee Hansard* 1.8.06, p.33 (NSW Psychosocial Support Project).

14 *Committee Hansard* 4.8.06, p.63 (Western Australian Gynaecologic Cancer Service).

15 *Submission 24*, p.11 (ASGO); *Submission 25*, p.9 (Hunter New England Centre for Gynaecological Cancer).

16 *Committee Hansard* 1.8.06, p.64 (NBCC).

It would seem to us from the feedback that we are getting that, drip by drip, we are getting through to the general practitioners, and they are vital in this process.¹⁷

5.27 A number of comments were made in relation to the barriers that general practitioners faced specifically in absorbing the information provided and/or pursuing educational opportunities.

- It is hard to educate general practitioners about something with vague symptoms, particularly when many diseases have similar symptoms.
- General practitioners are trained to look at the 'most likely cause of the disease before looking at the least common cause of the symptoms', which could be a gynaecological cancer.¹⁸
- ASGO argued that education programs were often conducted on an ad hoc basis by individuals and organisations in addition to their already heavy workload.¹⁹
- Gynaecological cancer education is usually a sub-set of cancer education and current gynaecological cancer educational strategies often focused on ovarian cancer and cervical cancer.
- Most general practitioners generally do not see a large number of individual patients with cancer, let alone gynaecological cancers, so it is hard to put a numerically uncommon tumour on the work plans of the Australian Divisions of General Practice.²⁰
- General practitioners are inundated with information on a daily basis and it is hard for them to make sense of it all.
- Educational opportunities are difficult to take due to lack of available time. When it is taken, technical training is generally more attractive to general practitioners than communication skills training.²¹
- There is a lack of communication between professionals from the gynaecological oncologists down about gynaecological cancers preventing education on-the-job.

5.28 On this last point about communication, Mrs Vickie Hardy from the National Ovarian Cancer Network (ACT and region) argued:

There is a lack of communication between all the agencies, from your gynaecologist down. Your GP is your first port of call and he has to be

17 *Committee Hansard* 1.8.06, p.64 (NBCC).

18 *Committee Hansard* 23.6.06, p.19 (National Ovarian Cancer Network – ACT and region).

19 *Submission* 24, p.11 (ASGO).

20 *Committee Hansard* 1.8.06, p.53 (GMCT).

21 *Committee Hansard* 4.8.06, p.7 (The Cancer Council Western Australia).

informed but quite often the GP was not informed on anything; he did not get information. So there are a lot of areas that need to improve, to help the patient.²²

5.29 The broad message to the Committee was that although current educational strategies were well-intentioned and executed, much more needed to be done to support general practitioners.

The way forward

5.30 Dr Zorbas from the NBCC argued that 'educating general practitioners is No. 1'.²³ Many also argued that educating general practitioners was equal in priority to educating women and the broader community.

5.31 Evidence to the Committee cautioned that a number of changes were needed to improve the effectiveness of future educational strategies and therefore maximise the health outcomes for women.

5.32 ASGO stressed that increased funding was needed to ensure that general practitioners had sufficient and current knowledge of gynaecological cancers, had access to a referral system and had access to educational material and the support they needed to care for patients.²⁴

5.33 The Cancer Council Australia stressed that research into getting the message across to general practitioners should be a high priority. It was argued that feedback and input from general practitioners should guide the content and direction of future activities, particularly because of the many different methods of delivery available.²⁵ Professor Ian Olver, Chief Executive Officer of The Cancer Council Australia said:

The difficulty these days is that there are so many methods to choose from in terms of web-based things and pod casts and whatever, but nobody knows what the most effective method is. People sort of guess and go along a line, but there needs to be research done. At least, if you get funding to disseminate information some of that funding should be used...to evaluate the impact that information.²⁶

5.34 Professor Olver and Dr Kendra Sundquist, also representing The Cancer Council Australia, emphasised the importance of coordination and planning in overcoming the current challenges posed by ad hoc approaches.²⁷ They argued that the development of nationally coordinated targeted messages for general practitioners on

22 *Committee Hansard* 23.6.06, p.21 (National Ovarian Cancer Network – ACT and region).

23 *Committee Hansard* 1.8.06, p.65 (NBCC).

24 *Submission 24*, p.11 (ASGO).

25 *Committee Hansard* 2.8.06, p.13 (The Cancer Council Australia).

26 *Committee Hansard* 2.8.06, p.13 (The Cancer Council Australia).

27 *Committee Hansard* 2.8.06, p.13 (The Cancer Council Australia).

gynaecological cancers would bring many advantages.²⁸ In relation to ovarian cancer, representatives from the National Ovarian Cancer Network argued strongly for an awareness campaign for general practitioners. Mrs Erica Harriss from the National Ovarian Cancer Network (ACT and region) argued:

...it needs to be a nationally coordinated ovarian cancer awareness campaign to make sure that GPs are very aware and consider the possibility of ovarian cancer. I was told my symptoms were vague, and that is what they say about ovarian cancer. But nobody considered it, and I knew nothing about ovarian cancer.²⁹

5.35 ASGO also argued that existing programs needed to be better coordinated, better advertised, and more frequent. Whilst there were some gaps in the current approach (for example, referral guidelines for general practitioners), it was argued that the present distribution and communication channels needed to be fine-tuned.

5.36 Witnesses also stressed the importance of leveraging existing processes to maximise access and penetration in the general practice community.³⁰ Recently, The Cancer Council Western Australia used the Royal Australian College of General Practitioners' (RACGP) web-based learning tool to give general practitioners messages about gynaecological cancers as part of their continuing medical education.

5.37 The Cancer Council Victoria suggested that the NBCC guide, *The investigation of a new breast symptom – a guide for General Practitioners*, was a 'highly commended' resource that could be used for general practitioners to assist them in identifying, investigating and appropriately referring women with a suspected gynaecological cancer.³¹

5.38 Where possible, advances in technology (particularly web-based) should be utilised to assist in message delivery to general practitioners, whilst remembering the value in face-to-face discussions.³²

5.39 To address concerns that referrals were largely ad hoc, the development of referral guidelines for general practitioners with information on who best to refer women to should be investigated. The NBCC's online directory of gynaecological oncology services was thought to be a valuable resource, but that more was needed to increase the profile and use of this product and the sub-specialty more generally amongst general practitioners.

28 *Committee Hansard* 2.8.06, p.13 (The Cancer Council Australia).

29 *Committee Hansard* 23.6.06, p.18 (National Ovarian Cancer Network – ACT and region).

30 *Committee Hansard* 4.8.06, p.7 (The Cancer Council Western Australia).

31 *Submission* 48, p.2 (The Cancer Council Victoria).

32 *Committee Hansard* 4.8.06, p.7 (The Cancer Council Western Australia).

5.40 The overall aim of general practitioner education is to bring gynaecological cancers to 'front of mind' and where a general practitioner suspects a gynaecological cancer is present, he or she has the knowledge to refer the woman to a gynaecological oncologist for further assessment (including diagnosis) and treatment.

Nurses

Role

5.41 Nurses from a very wide range of practice settings care for and support women with gynaecological cancers. Ms Tish Lancaster from Cancer Nurses Society of Australia (CNSA) argued:

...that the intimate nature of nursing care that is involved for women with gynaecological cancer well places nurses to identify the needs of women, to address some of those needs and to make appropriate referrals to other health practitioners that may also assist in addressing those needs.³³

5.42 Among their many roles, nurses provide education to women about gynaecological cancers and Ms Lancaster said that 'nurses are very well placed in a health promotion role for all gynaecological cancers'.³⁴

Current education about gynaecological cancers

5.43 The Committee heard about a number of educational programs for nurses on gynaecological cancers.

5.44 Since 2004, the Greater Metropolitan Clinical Taskforce (GMCT) in New South Wales has conducted 'highly successful' annual nurses' study days that were 'well attended by hundreds of nurses from both metropolitan areas and the country'.³⁵

5.45 Another successful initiative for nurses developed by the CNSA was the publication of a textbook on gynaecological cancers for nurses and allied health professionals.³⁶ In highlighting the positive feedback on this product, Ms Lancaster said:

...it has not just been a local thing. It has had this enormous spin-off that we did not ever anticipate. The nurses who come to the study days, the nurses who work in our units and even the junior medical staff really love it, because it is a practical, evidence based, woman centred approach to gynaecological cancer.³⁷

33 *Committee Hansard* 1.8.06, p.71 (CNSA).

34 *Committee Hansard* 1.8.06, p.73 (CNSA).

35 *Committee Hansard* 1.8.06, p.44 (GMCT).

36 *Committee Hansard* 1.8.06, pp.77-78 (CNSA).

37 *Committee Hansard* 1.8.06, p.78 (CNSA).

5.46 Representatives from the National Ovarian Cancer Network also told the Committee about a resource kit that was initially prepared for women recently diagnosed with ovarian cancer, but has also been of considerable use for oncology nurses. Ms Jane Harriss, Director of National Ovarian Cancer Network (ACT and region) said that nurses:

...were crying out for that information themselves. We talked with them about it, and they said that they were ready and waiting for us to provide them with that level of support.³⁸

5.47 The Committee heard from the CNSA and the GMCT that there was no specific formal education in gynaecological oncology offered for nurses and that the current post graduate studies, at least in New South Wales, tended to focus on cancer nursing more generally. Ms Jayne Maidens the GMCT's Gynaecological Oncology Group said:

Currently there is a graduate oncology nursing certificate that is run by the College of Nursing in Sydney. Some of the universities also have graduate certificates. They cover cancer nursing under a large umbrella, but there is nothing that is specific to gynaecological cancer...³⁹

Is the current level of education appropriate?

5.48 Evidence to the Committee showed that nurses wanted more education in gynaecological oncology and many nurses funded themselves to go on courses and attend conferences. Ms Lancaster from the CNSA argued:

I think nurses in general are very keen for educational opportunities and it is something that, in general, they do not get. They more junior you are the less likely you are to get out to those sorts of things.⁴⁰

5.49 The results of a 2004 study of 150 nurses (from a variety of settings in New South Wales) who attended the GMCT's nurses' study day showed that 66 per cent of nurses were either very or moderately confident about talking to women about gynaecological cancers in general and also about 'common practical issues', such as bladder and bowel problems.⁴¹ However, results showed that many nurses lacked confidence in their ability to manage more complex, yet still common issues experienced by women such as infertility, lymphoedema and psychosexual dysfunction.⁴²

38 *Committee Hansard* 23.6.06, p.22 (National Ovarian Cancer Network – ACT and region).

39 *Committee Hansard* 1.8.06, p.52 (GMCT).

40 *Committee Hansard* 1.8.06, p.79 (CNSA).

41 *Committee Hansard* 1.8.06, p.74 (CNSA).

42 *Committee Hansard* 1.8.06, p.74 (CNSA).

5.50 Despite the 'considerable experience and formal qualifications' of the nurses surveyed, many did not feel confident in addressing specialised gynaecological cancer issues. The CNSA said:

...only 12% felt very confident in discussing the management of gynaecological cancers, while 5% felt very confident in addressing genetic susceptibility, 8% for fertility issues, 12% for lymphoedema prevention and 15% for sexuality and body image (Maidens et al. 2004). Reports suggest that health care professionals require development of skills in psychosocial assessment and care. Nurses, like other health professionals require development of competency in this area...⁴³

5.51 The CNSA noted that the nurses who cared for women outside of specialist cancer centres indicated that they wished to provide better supportive care for women but that 'inadequate education hinders their efforts to do so'.⁴⁴

5.52 The CNSA argued that there was a clear demand for better educational opportunities for nurses. It stressed that when looking at offering skilling opportunities for nurses, a number of barriers existed, including:

- workforce shortages, high workloads and competing demands leading to problems associated with back-filling positions;⁴⁵
- poor links between education and career pathways;
- the cost of further education at university;
- the geographical location of nurses (greater barriers for nurses in rural areas); and
- insufficient training places, especially in the university system.⁴⁶

5.53 The Committee also heard that the formality of training to become a specialist gynaecological oncology nurse could be a barrier to many nurses who would be competent at the role. Ms Elizabeth Chatham, Director of Women's Services at The Royal Women's Hospital stated:

The hurdles to get over to be able to become a gynae-onc nurse are so high that they actually cut out a lot of the people that may be interested; but it still has to be credible and structured.⁴⁷

43 *Submission 20*, p.3 (CNSA).

44 *Submission 20*, p.3 (CNSA).

45 *Committee Hansard 1.8.06*, p.75 (CNSA).

46 *Submission 20*, p.3 (CNSA).

47 *Committee Hansard 3.8.06*, p.28 (The Royal Women's Hospital).

The way forward

5.54 To ensure that nurses have the skills required to give women optimal care and to work effectively within the gynaecological oncology system, including knowledge of appropriate referral and communication pathways, the current educational strategies for nurses need to be reviewed. Nurses caring for women with gynaecological cancers need to be adequately prepared to assess the physical as well as emotional needs of women and thus be able to collaborate with other medical professionals. Education is the key to achieving this outcome.

5.55 Formal education for nurses is currently tailored to general cancer issues, with very little focus on gynaecological oncology.⁴⁸ The CNSA argued that steps ought to be taken to examine the content of curricula at undergraduate and graduate levels of training to better prepare nurses.⁴⁹ The CNSA noted that Commonwealth government funding for nursing training through a program called 'EdCaN' is 'going a long way' towards addressing current training issues.

5.56 The Royal Women's Hospital argued that 'post-graduate specialist gynaecology nursing courses significantly improve workforce capacity'.⁵⁰

5.57 Ms Jayne Maidens said that work by the GMCT was already underway to raise the profile of gynaecological oncology in tertiary nursing curricula.

We hope to have some affiliation with either one of the universities or the College of Nursing to promote a package specific to gynae-oncology so that at the end of the day they will come out with a certificate or with some sort of recognition that they have this speciality in gynae-oncology. We are working through that at the moment.⁵¹

5.58 The CNSA argued that the specific needs of nurses need to be taken into account in the development of future educational strategies in gynaecological oncology. Ms Lancaster highlighted that the needs of specialist nurses would differ from the needs of nurses in non-specialist and rural settings.

As I said, the difficulty is probably in finding something that is tailored to the needs of a particular nurse. And to be fair, nurses in specialist gynaecological cancer centres will be looking at very specific educational opportunities but those in rural centres are probably seeing not just women but all sorts of patients with all sorts of cancers, so their needs are broader.⁵²

48 *Committee Hansard* 1.8.06, p.77 (CNSA).

49 *Committee Hansard* 1.8.06, p.81 (CNSA).

50 *Submission* 37, p.4 (The Royal Women's Hospital).

51 *Committee Hansard* 1.8.06, p.52 (GMCT).

52 *Committee Hansard* 1.8.06, pp.76-77 (CNSA).

5.59 Opportunities to pursue training to become specialist gynaecological oncology nurses was also supported by the CNSA, particularly because of the successful care coordinator role that specialist breast cancer nurses play for breast cancer patients.

While the evidence that specialist nurses contribute to improve patient outcomes comes from the field of breast cancer, it is likely that the same outcomes could be achieved if specialist nurses roles are supported for women with gynaecological cancers.⁵³

5.60 Nurses are an important source of information for women with gynaecological cancers and according to the CNSA there are 'no nursing education programs relating specifically to gynaecological cancer in Australia'.⁵⁴ For nurses to provide the required support, it is important that they are supported to pursue educational opportunities, and have better access to appropriate, authoritative information. The Committee heard that this would not only bring professional gains to the nurses, but also benefit women with, or at risk of, gynaecological cancers.

Allied health professionals

5.61 Allied health professionals have a significant role in treating and caring for women with gynaecological cancers. Professionals such as psychologists, social workers and physiotherapists, have contact with women at different points along their journey with gynaecological cancers, but not at the same level of frequency or closeness as others. Nevertheless, some level of interaction necessitates a degree of awareness and understanding of the symptoms, treatment and the latest developments in gynaecological oncology, and oncology more generally.

5.62 The Cancer Council Australia, the Clinical Oncological Society (COSA) and the National Aboriginal Community Controlled Health Organisation (NACCHO) argued that general education programs for allied health professionals should include a focus on cancer management:

...particularly as incidence rates rise and as the trend towards multidisciplinary care creates increased opportunities for a wider range of healthcare professionals to participate in patient care.⁵⁵

5.63 The Committee heard that many of the allied health professions were experiencing funding and resource shortages and this impacted their ability to pursue clinical and other education.

5.64 The evidence presented suggested that education about gynaecological cancers was not an area of significant focus for government and organisations that instead targeted their educational activities and programs at general practitioners and nurses. The GMCT emphasised it sponsored once or twice yearly educational sessions

53 *Submission 20*, p.2 (CNSA).

54 *Submission 20*, p.3 (CNSA).

55 *Submission 56*, p.32 (The Cancer Council Australia, COSA and NACCHO).

for 'health care practitioners' on gynaecological oncology, but little else was presented during the inquiry about education for allied health professionals.⁵⁶

5.65 The Royal Women's Hospital argued that 'allied health staff working in cancer services would benefit from structured training and professional development programs' in gynaecological oncology.⁵⁷

5.66 It was thought that education of members of more specialised health disciplines (that have small numbers in comparison to medicine and nursing) was still critical to the system's ability to provide a comprehensive level of care for women.

Gynaecologists

5.67 The Committee received little evidence on the educational needs of gynaecologists, however it heard it was important for them to develop sub-specialised skills in gynaecological cancers to ensure appropriate referral to a gynaecological oncologist and their multidisciplinary team.

5.68 Professor David Allen, representing The Cancer Council Victoria's Gynaecological Cancer Committee and Victorian Cooperative Oncology Group, said that it was 'not uncommon' for gynaecologists or general surgeons to refer women with a gynaecological cancer to a medical oncologist rather than a gynaecological oncologist.⁵⁸ He argued that national protocols be established to counter this.

I mentioned in the opening statement getting rid of a lot of the variation in the current practice. Only state-wide or national protocols and expectations and outcomes that can be written into practice are going to get rid of those variations and get people to the right centres.⁵⁹

5.69 The GMCT said some of its educational sessions on gynaecological oncology were targeted at gynaecologists.⁶⁰

Gynaecological oncologists

5.70 A gynaecological oncologist is a specialist in obstetrics and gynaecology, who has been assessed as being competent in the comprehensive management of women with a gynaecologic cancer, awarded the Fellowship of the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (FRANZCOG), completed a

56 *Committee Hansard* 1.8.06, p.44 (GMCT).

57 *Submission* 37, p.4 (The Royal Women's Hospital).

58 *Committee Hansard* 3.8.06, p.88 (The Cancer Council Victoria and Victorian Cooperative Oncology Group).

59 *Committee Hansard* 3.8.06, p.88 (The Cancer Council Victoria and Victorian Cooperative Oncology Group).

60 *Committee Hansard* 1.8.06, p.44 (GMCT).

formal three year training program in gynaecological cancer care, and passed the examination for the Certificate of Gynaecological Oncology.⁶¹

5.71 Evidence to the Committee suggested that gynaecological oncologists did not have any specific or urgent educational needs pertaining to risk factors, symptoms and treatment of gynaecological cancers.

5.72 The Royal Women's Hospital did argue though that gynaecological oncology suffered from a lack of academic support.

There are only two full professorial positions in gynaecological oncology in New South Wales, one in Victoria, one in Western Australia and none in Queensland, South Australia or Tasmania.⁶²

General issues

5.73 A number of issues apply more generally across the medical and allied health communities and these warrant separate discussion.

5.74 The following were presented as barriers to the success of current education strategies:

- poor coordination and communication leading to duplication and gaps; and
- high workloads and workforce shortages that increased the burden of training.

5.75 The following were issues that needed to be considered in the development and direction of future education strategies:

- development and distribution of new clinical practice guidelines;
- dissemination of messages and awareness about medical advances;
- improvements to professional communication skills through more attractive training packages;
- short-term skills enhancement training; and
- the role of the Internet in the provision of education.

Coordination and communication

5.76 To achieve better education and training outcomes, improved coordination of organisations within the gynaecological oncology sector, and between this sector and health and educational institutions were thought to be needed.

5.77 There was also a clear need for individuals and groups with responsibility for education planning and delivery to improve communication with relevant players in

61 NBCC, *Directory of Gynaecological Oncology Services* (<http://www.ovariancancerprogram.org.au/dir/gynonc.html>).

62 *Submission 37*, p.4 (The Royal Women's Hospital).

order to ascertain: who was doing what; what was actually working and what needed to be done in future. A complete picture across the board was needed. There was widespread recognition of the need for improvements in the information base to better coordinate and manage activities.

5.78 The fragmented approach has meant that the medical community, particularly general practitioners, cannot easily receive and retain educational messages. Disconnected strategies in the delivery of education and training have had a negative effect on the capacity of the medical community to pursue skilling opportunities in the sub-specialty of gynaecological oncology.

5.79 The extent to which the medical community has input into the development of educational programs was also seen as important for ensuring the capacity of medical professionals to recognise and deal with gynaecological oncology issues.

5.80 Opportunities to improve coordination could also be made during the consultation and planning stages to enhance the effectiveness of material and the effort that groups put in (particularly community-based groups operating on minimal funds).

Workforce shortages

5.81 The Committee heard that the gynaecological cancer care workforce was not immune to the workforce shortages that exist in almost every medical and allied health professional field at the moment. The shortages in the gynaecological cancer sector often reflected the more general shortage, for example, in the nursing profession, but were also caused by the nature of gynaecological oncology training and time required to complete formal training.⁶³

5.82 Workforce shortages have meant that medical professionals typically have less time outside of their normal working hours to absorb information and also fewer opportunities to pursue further education. The shortages, particularly of gynaecological oncologists, have shown themselves more acutely in areas outside of capital cities, particularly Sydney and Melbourne.⁶⁴

Clinical practice guidelines

5.83 The *Guidelines for the management of women with epithelial ovarian cancer* were widely distributed to medical professionals. The Cancer Council of Australia, COSA and NACCHO argued that similar guidelines should be developed for other gynaecological cancers.

63 *Committee Hansard* 2.8.06, p. 87 (Royal Prince Alfred Hospital); *Submission* 39, p.2 (RANZCOG and Mercy Hospital for Women).

64 *Submission* 24, p.14 (ASGO).

5.84 It was also suggested that a quality assurance framework be put in place to ensure that the management of gynaecological cancers followed a national evidence-based and patient-centred approach.⁶⁵

Education on emerging issues

5.85 Educating the medical profession about 'breakthroughs' and other emerging issues in a timely fashion was argued to be important, particularly to:

- ensure changes to best practice are known as early as possible and to increase acceptance and compliance of the changes;
- enable delivery of accurate and consistent messages;
- educate women; and
- encourage broad uptake of new medicines, such as the HPV vaccine.⁶⁶

Communication skills

5.86 Encouragement and incentives for all care providers to undertake training and education to improve communication skills – from gynaecological oncologists to general practitioners – was argued to be a priority. The Committee heard it was essential that members of the medical community improve their ability pick up relevant cues from women, particularly in response to psychosocial and psychosexual effects of treatment.

5.87 Mr Terry Slevin, Director of Education and Research at The Cancer Council Western Australia commented:

We have programs in place where we try and bring people in and weave in communication skills, listening skills, as part of the more technical training that we offer. Certainly, it is the technical training that is generally more attractive to general practitioners. Those who are interested in communication skills training tend to be the ones who are at the higher end of that skill spectrum anyway.⁶⁷

5.88 The Committee heard that formal communication training would make a positive difference to the ability of professionals to recognise and respond to patient needs, particularly emotional issues.

5.89 Ms Connie Nikolovski, an ovarian cancer survivor, stressed the importance for medical professionals to have strong communication skills in order to draw information from their patients.

65 *Submission 56*, p.30 (The Cancer Council Australia, COSA and NACCHO).

66 *Submission 27*, p.18 (Ms Margaret Heffernan).

67 *Committee Hansard 4.8.06*, p.7 (The Cancer Council Western Australia).

Medical people do not extract enough information; maybe they are not educated to. So perhaps there is the need for more education about people skills; I understand that they are skilled at what they do, but that is just another area I noticed when my mother was being cared for that needed to improve.⁶⁸

5.90 Communication skilling should include a focus on catering for cultural sensitivities to raise awareness of the needs of people from culturally and linguistically diverse backgrounds.

Skills enhancement training

5.91 Given it takes many years to train in gynaecological oncology, the importance of providing opportunities for short-term fellowships for those wanting to improve their knowledge was recommended. Professor J Norelle Lickiss, a palliative medicine specialist, argued this short-term measure would have high yield.⁶⁹ Professor Lickiss also suggested:

...there should be clinical fellowships in improving understanding of symptoms alone...If we had those we would actually get some advance, because that is the bottom line. The rest can build on that.⁷⁰

The Internet

5.92 More recently, the Internet has created an additional source of medical and general information that medical professionals can look to and rely on. The Committee heard that there were credible information sites developed by government and non-government health organisations for medical professionals that contain freely available information on gynaecological cancers.

5.93 This rich resource of information is presently under-utilised by both women and professionals. In assisting women who choose to access online information distinguish between unbiased information and the information designed to push a product or service, professionals themselves need to feel comfortable enough with the Internet to guide their patients' online searches for medical information. As such, there is a clear need for professionals to be educated about, and be aware of, trusted and quality information websites.

5.94 Future education strategies need to empower professionals and women to use the Internet as part of a total health care strategy. For professionals, where possible, education should be as interactive and personalised as possible.

68 *Committee Hansard* 3.8.06, p.77 (Ms Connie Nikolovski).

69 *Committee Hansard* 2.8.06, p.72 (Professor J Norelle Lickiss).

70 *Committee Hansard* 2.8.06, p.81 (Professor J Norelle Lickiss).

Roles and responsibilities

5.95 Evidence to the Committee suggested that the 'plethora of funders and providers of health promotion...has resulted in some confusion about roles and responsibilities, and about leadership'.⁷¹ In evidence, the need for coordination of education was argued to be a priority because at the moment 'everybody is doing a little bit of everything'.⁷²

5.96 It was argued that educational initiatives and formal training opportunities would continue to occur in a piecemeal fashion without the establishment of a national framework or body to provide direction and oversight. A national approach would provide an avenue for existing players from across jurisdictions – governments, non-government organisations and community-based organisations – to come together to review the current approach and to develop new initiatives and practical implementations plans as required.

5.97 There was uncertainty expressed about the direction and leadership that Cancer Australia would provide in this area due to lack of understanding about its roles and responsibilities.

5.98 Evidence to the Committee suggested an expansion of the NBCC's role to cover education about other gynaecological cancers would be a viable approach.⁷³ However, the majority of witnesses and submitters thought that funding to set up a national centre would be an effective mechanism for better coordination of gynaecological oncology education across Australia. It was thought that a national centre could provide an overarching framework reflective of national priorities and the views of all stakeholders. Further discussion on a national approach is found in Chapter 2.

Conclusion

5.99 Associate Professor Anthony Proietto, Chairman of ASGO, argued that 'medical education is as important as public'.⁷⁴ Education is the key to telling the relevant people about the information they need to know.

5.100 The Committee heard that there was a varying degree of knowledge about gynaecological cancers within the medical community.⁷⁵ A low level of knowledge amongst professionals was linked to poor awareness of the symptoms and delayed or inappropriate referral of women to specialist care. Evidence to the Committee stressed

71 *Submission 27*, p.22 (Ms Margaret Heffernan).

72 *Committee Hansard 2.8.06*, p.89 (Royal Prince Alfred Hospital).

73 *Submission 56*, p.35 (The Cancer Council Australia, COSA and NACCHO).

74 *Committee Hansard 2.8.06*, p.63 (ASGO).

75 *Submission 28*, p.10 (Western Australian Gynaecologic Cancer Service).

that for women with gynaecological cancers, particularly ovarian cancer, these were barriers to effective diagnosis and care that could be minimised or overcome with better education.

5.101 As gynaecological oncology is a new sub-specialty, it was argued that its profile needed to be lifted amongst the medical community to ensure that professionals were aware of the benefits for women of referral to gynaecological oncologists. Out of all the professions, Dr Lewis Perrin from ASGO said that particular effort was needed to educate general practitioners who were not aware of the benefits.

5.102 The Gynaecological Awareness Information Network (GAIN) believed education and awareness was a two-way street – the public needed to be better informed, and the medical community needed greater education on how to diagnose, treat and manage women with gynaecological cancer.⁷⁶

Recommendation 21

5.103 The Committee recommends that an urgent review of the adequacy and provision of information to medical and allied health professionals about gynaecological cancers be undertaken by the Centre for Gynaecological Cancers.

5.104 The Committee further recommends that the gynaecological oncology medical and allied health communities, through the Centre for Gynaecological Cancers, have greater input into decisions about education strategies for professionals, women and adolescents.

Recommendation 22

5.105 The Committee recommends that the Centre for Gynaecological Cancers, with assistance from the gynaecological cancer community, develop culturally appropriate educational material focusing on the risk factors and symptoms of gynaecological cancers. Any such material should specifically meet the needs of general practitioners, nurses (including remote area nurses), Aboriginal health workers, gynaecologists and allied health professionals

5.106 The Committee further recommends that educational materials be provided to general practitioners to inform them about the sub-specialty of gynaecological oncology and the circumstances in which it is appropriate to refer women to gynaecological oncologists.

Recommendation 23

5.107 The Committee recommends that Cancer Australia formally investigate the referral patterns of general practitioners at a national level and devise appropriate strategies to address any concerning trends.

76 *Committee Hansard* 4.8.06, p.37 (GAIN).

5.108 The Committee further recommends that accurate and accessible service directories should be developed in all jurisdictions to support knowledge-based appropriate referrals.

Recommendation 24

5.109 The Committee recommends the development and distribution of clinical practice guidelines for all gynaecological cancers (or similar consistent and authoritative information) to ensure standard practice across the healthcare system.

5.110 The Committee further recommends that the Australian Divisions of General Practice include gynaecological cancer issues in at least one professional development seminar per year.

Recommendation 25

5.111 The Committee recommends that all gynaecologists involved in treating gynaecological cancers associate themselves with a recognised multidisciplinary specialist gynaecological cancer unit.

Recommendation 26

5.112 The Committee recommends that appropriate educational opportunities be offered to medical and allied health professionals from all settings to increase skills in gynaecological oncology. Appropriate financial incentives or assistance packages should be offered, and given where required.

Recommendation 27

5.113 The Committee recommends that doctors who are training to be general practitioners be exposed to the concept of multidisciplinary care and the sub-specialty of gynaecological oncology in their training.

5.114 The Committee further recommends that medical professionals receive instruction and experience, where relevant, in diagnosing malignant gynaecological cancers through educational programs.

CHAPTER 6

GYNAECOLOGICAL CANCERS EDUCATION FOR WOMEN AND THE COMMUNITY

Introduction

6.1 The Committee heard that information and education were critical for women with, or at risk of, gynaecological cancers. It was emphasised that women who were well-informed on issues relating to gynaecological cancers generally had better health outcomes than those who were poorly informed. Specifically, they:

- had a better understanding of their choices and what may happen to them;
- were more satisfied with their care, psychosocial wellbeing and compliance with their treatment; and
- experienced less anxiety and had better coping skills.

6.2 Information about gynaecological cancers, treatment and prognosis should be timely, reliable and accessible. The Committee heard that a commonly unmet need of women was the lack of appropriate information. As such, strong concern was expressed about the low levels of awareness and its flow on effects for the care of women.

6.3 The level of awareness of gynaecological cancers in the broader community, particularly of family members and carers, was also critical to the health outcomes of women. Evidence to the Committee indicated it was not only important to ensure that women themselves were adequately informed because the effect of a gynaecological cancer does not finish there – it was vital that the people around them received appropriate information as well.

The importance of education

6.4 Education is a wide-ranging term that encompasses a wide range of activities. This inquiry focused on education in the context of the provision of information for the purpose of raising awareness and understanding of gynaecological cancers. Currently, responsibility for educational initiatives and implementation is multi-layered and rests with government, non-government organisations and community-based organisations. The delivery of education about gynaecological cancers is done primarily through printed material, online resources, electronic media as well as face-to-face interaction.

6.5 At present, there is no national education strategy designed to increase the awareness and knowledge of the full range of gynaecological cancers. Some of the strategies for specific tumour types are discussed later in this chapter.

6.6 The Committee heard that education was important because many women with gynaecological cancers frequently seemed to know nothing about their condition, even though some considered themselves to be well-informed consumers and well-informed about their own health. The Committee heard that it was often distressing for women to discover that there was much they did not know about their condition, treatment and other services.

6.7 The Gynaecological Cancer Society argued:

In a perfect world specialist practitioners would have the time to discuss and ensure understanding of each detail of the treatment process. As this is not a perfect world, patients are most often left with unanswered questions that can lead to irrational fears. This situation, if left unchecked, can interfere with good treatment outcomes.¹

Awareness leads to empowerment

6.8 Education and information empower women and those in the broader community (such as family and friends) faced with uncertainty about decisions that need to be made in physically and emotionally-demanding situations.

6.9 Evidence suggested that women with gynaecological cancers seemed to go through a journey from starting to feel ill, to some form of medical intervention and then medical treatment. The Committee heard that access to appropriate treatment by a gynaecological oncologist (as part of a multidisciplinary team) sometimes had more to do with a woman's insistence that something was wrong rather than medical knowledge that something was wrong.

6.10 Mr John Gower, Chief Executive of the Gynaecological Cancer Society agreed with the need for showing assertiveness:

There is a lot of evidence where women have presented with symptoms and in truth the only reason that a final diagnosis of gynae cancer was made was because the patient sat there and said: 'That's not good enough. I don't have a cold.' ...There are a lot of women alive today who would not be if they had not been assertive about their symptoms.²

6.11 The Committee heard that awareness of the sub-speciality of gynaecological oncology and assertiveness were linked to earlier diagnosis of gynaecological cancers, which was particularly important in the case of ovarian cancer.³ It was argued that if women knew of the existence of gynaecological cancer centres and gynaecological oncologists there would be more consumer awareness, and therefore demand, to get the best treatment.

1 *Submission 7*, p.6 (Gynaecological Cancer Society).

2 *Committee Hansard 2.8.06*, p.42 (Gynaecological Cancer Society).

3 *Submission 33*, p.6 (National Ovarian Cancer Network).

Improving awareness of the sub-specialty of gynaecological oncology

6.12 Education is needed to inform women about the sub-specialty of gynaecological oncology which is generally not understood well by women. Professor Neville Hacker, Director of the Gynaecological Cancer Centre at the Royal Hospital for Women argued:

If you asked the average woman on the street whether she had ever heard of a gynaecological oncologist, she would say no.⁴

Eliminating the stigma associated with gynaecological cancers

6.13 The Committee also heard that gynaecological cancers and conditions were a sensitive issue for the great majority of Australians and that education was the key to overcoming some of the feelings of embarrassment, guilt and fear about the conditions.⁵ Ms Natalie Jenkins, Chairperson of the Gynaecological Awareness Information Network (GAIN) said:

GAIN continues to be surprised and dismayed at the lack of knowledge and awareness of gynae conditions amongst the general populace. We believe this is the result of the social taboo surrounding the subject.⁶

6.14 Ms Sally Crossing from Cancer Voices Australia agreed and cautioned that 'loneliness, embarrassment and stigma may hinder women from taking action' in relation to their health.⁷

6.15 Professor Barbara Andersen, a Professor at the Department of Psychology and the Department of Obstetrics and Gynecology at The Ohio State University, told the Committee that information for women was particularly important at the time of diagnosis because:

...everybody has very high levels of stress and anxiety, and interventions at that time would probably be best focused on delivering understandable information to patients.⁸

Women and the broader community

Women

6.16 Women affected by gynaecological cancers not only experience impacts to their physical health, but also to their social, psychological and economic wellbeing. It

4 *Committee Hansard* 1.8.06, p.11 (Royal Hospital for Women).

5 *Committee Hansard* 4.8.06, p.36 (GAIN).

6 *Committee Hansard* 4.8.06, p.37 (GAIN).

7 *Committee Hansard* 2.8.06, p.24 (Cancer Voices Australia).

8 *Committee Hansard* 12.9.06, p.2 (Professor Barbara Andersen).

is therefore important that women are educated about the risk factors, symptoms and treatment options available. This information needs to be easily available and visible.

6.17 In relation to education, witnesses and submitters told the Committee that women wanted information to:

- better understand the risks of developing gynaecological cancers and to know how to reduce their risk of gynaecological cancers;
- be able to access highly credible and nationally consistent evidence-based information about the symptoms of gynaecological cancers; and
- if they are diagnosed with a gynaecological cancer, to:
 - be told appropriately and provided with supportive care services and information about their treatment;
 - know who is coordinating their care and who can answer their questions;
 - have information about and help to minimise any uncertainty following the completion of treatment;
 - have information about prevention and the ongoing side effects of treatment; and
 - know how to take care of themselves and to maintain optimal health.

6.18 The Committee heard from women and representative groups that the current approach to health education needed to be improved in order to provide better support through the provision of information to women.

Broader community

6.19 Education and awareness about gynaecological cancer issues are not only important for women.⁹ Evidence to the Committee suggested that education is important for members of the broader community – which could include family members, friends, carers or colleagues – so they can better understand the physical and emotional journey that women with gynaecological cancers are experiencing in order to provide the necessary support. To illustrate this point, GAIN noted that if partners are unable to discuss matters of concern, such as sexual dysfunction, women can become isolated emotionally.¹⁰

It can have devastating effects on whole families, which means men too need to have awareness, so they can develop understanding and cope with the unforeseen side effects. Most medical practitioners and support services do not acknowledge this and there are very few support services available for partners and families.¹¹

9 *Submission* 14, p.6 (GAIN).

10 *Submission* 14, p.6 (GAIN).

11 *Submission* 14, p.6 (GAIN).

6.20 Gynaecological cancers are physically and emotionally debilitating for women, their partners and families. Mr John Stubbs, Executive Officer of Cancer Voices Australia argued that partners of women with gynaecological cancers should be encouraged to be more involved and should be provided with evidence-based information.¹²

Current education strategies

Current activities

6.21 A range of communication and education resources are available for women for gynaecological cancers. Many organisations produce material for women.

Commonwealth Department of Health and Ageing

6.22 Information links for women on gynaecological cancers are available through the Commonwealth Government's information portal, HealthInsite.

6.23 The Commonwealth Department of Health and Ageing (the Department) said that HealthInsite is designed to provide all consumers with easy access to reliable, high quality and relevant information about health and wellbeing.¹³ It works by linking users to specific information on the websites of approved information partners. It links to a number of resources about cancer and includes information about diagnosis, treatment options, support services, latest research and statistical information. The Committee noted that the only gynaecological cancers listed were cancer of the uterus, cervical cancer and ovarian cancer.

National Breast Cancer Centre's Ovarian Cancer Program

6.24 The National Breast Cancer Centre's (NBCC) Ovarian Cancer Program produces a number of resources designed to provide information to women and the wider community.¹⁴

6.25 Products developed by the NBCC include:

- a web-based national directory of gynaecological oncology services;
- a guide titled *Epithelial ovarian cancer: understanding your diagnosis and treatment* to provide information to women diagnosed with ovarian cancer, their family, partners and friends;
- a web-based fact sheet about the tumour marker CA125 for women who have been referred for a blood test during the diagnostic process; and
- a fact sheet for the general public about ovarian cancer.¹⁵

12 *Committee Hansard* 2.8.06, p.35 (Cancer Voices Australia).

13 *Submission* 52, p.12 (Commonwealth Department of Health and Ageing).

14 *Submission* 44, pp.11-12 (NBCC).

6.26 The NBCC also raises awareness of ovarian cancer through national forums, an electronic bi-monthly newsletter *Ovarian e-upd@te* and through working with the National Ovarian Cancer Network in promoting Ovarian Cancer Awareness Week.¹⁶

Cancer Councils

6.27 The Cancer Council Australia told the Committee that the State and Territory Cancer Councils disseminate a range of resources aimed at raising women's awareness of gynaecological cancer symptoms or indications of precancerous conditions.¹⁷

6.28 For example, The Cancer Council Western Australia produces a women's cancers speaker's kit covering gynaecological cancers (including cervical, ovarian, uterine, vulval and vaginal). It also produces a brochure on gynaecological cancers, booklets on uterine cancer and cervical cancer and provides public and health professional talks on gynaecological cancers.¹⁸

6.29 The Cancer Council Australia also highlighted that its Help Line provides telephone counselling and referral to appropriate professionals and that its work with National Aboriginal Community Controlled Organisation (NACCHO) helps to promote and raise awareness of the signs of gynaecological cancers amongst Indigenous women.¹⁹

Community Organisations

6.30 A number of community organisations also provide education to women and the broader community. In commenting on the role that they played, Australian Society of Gynaecologic Oncologists (ASGO) said that 'these organisations admirably perform a much-needed function with little or no support'.²⁰

6.31 Many of these organisations develop pamphlets, information packages and websites to inform and support women and their families with their experience with gynaecological cancers.²¹ Many also endeavour to gain a media profile and involve themselves in media events to increase the community awareness of gynaecological cancers.²²

15 *Submission 44*, p.11 (NBCC); *Committee Hansard 1.8.06*, p.59 (NBCC).

16 *Submission 44*, p.12 (NBCC); *Submission 52*, p.13 (Commonwealth Department of Health and Ageing).

17 *Submission 56*, p.34 (The Cancer Council Australia, COSA and NACCHO).

18 *Submission 51*, p.29 (The Cancer Council Western Australia).

19 *Submission 56*, p.34 (The Cancer Council Australia, COSA and NACCHO).

20 *Submission 24*, p.12 (ASGO).

21 *Submission 7*, p.6 (Gynaecological Cancer Society); *Submission 6*, p.1 (NSW Psychosocial Support Project); *Submission 14*, p.8 (GAIN).

22 *Submission 24*, p.12 (ASGO).

6.32 Some examples include:

- the development of the *Directory of gynaecological oncology treatment and support services* (NSW Psychosocial Support Project, NSW Health and Life Force Foundation);²³
- the establishment a national gynaecological awareness day in Perth on 10 September 2006 (GAIN);²⁴
- the launch of an online patients' forum to encourage interaction between women with gynaecological cancers (National Ovarian Cancer Network);²⁵
- the adaptation of the Breast Cancer Network of Australia's *My Journey Kit* for gynaecological cancers (Ms Margaret Heffernan);²⁶ and
- the development of a supporting partners program focusing on women with gynaecological cancers (Gynaecological Cancer Society).²⁷

Success of current activities

6.33 The Committee heard from witnesses that despite the efforts and enthusiasm of governmental and other organisations in developing and disseminating education nationally and locally, the level of awareness and understanding of gynaecological cancers remained low in Australia. The Western Australian Gynaecologic Cancer Service said:

There is a paucity of knowledge in the general community regarding the risk factors, symptoms, signs and treatment of gynaecological cancers.²⁸

6.34 Ms Carmen Duncan, Fundraising Manager for the GO Fund, commented that when she approached the corporate sector for donations, she found there was 'widespread ignorance about ovarian cancer in particular and gynaecological cancer in general'.²⁹

6.35 Gynaecological cancer control can be measured by success in prevention, reduction in incidence, increasing survival and improving quality of life. These factors are all linked to the level of education and awareness that women and the broader community have about these cancers.

23 *Submission 6*, p.1 (NSW Psychosocial Support Project).

24 *Committee Hansard* 4.8.06, p.40 (GAIN).

25 *Committee Hansard* 3.8.06, p.103 (National Ovarian Cancer Network).

26 *Committee Hansard* 3.8.06, p.51 (Ms Margaret Heffernan).

27 *Submission 7*, Attachment 1 B (Gynaecological Cancer Society).

28 *Submission 28*, p.11 (Western Australian Gynaecologic Cancer Service).

29 *Committee Hansard* 1.8.06, p.4 (GO Fund).

6.36 In examining current educational activities, it was hard to measure the success of the activities themselves without mechanisms for review and feedback from women and the community. Whilst this occurred on an informal and ad hoc basis, no detailed national studies on the adequacy of current approaches to education in Australia have been undertaken to date.

6.37 The Committee considers the following issues raised throughout the inquiry are important and must be considered in further detail.

Vagueness of symptoms

6.38 As noted many times throughout the inquiry, symptoms of some gynaecological cancers are vague.³⁰ This is particularly the case for ovarian cancer as its symptoms can be easily confused with variation in normal function, leading to delay in presentation to a medical practitioner for evaluation.³¹

6.39 The Cancer Council Western Australia stressed that distinguishing the symptoms of ovarian cancer from those that normally occur was problematic, for women and also health professionals. Ms Crossing from Cancer Voices Australia agreed that women were largely ignorant of the connection between known risk factors and the symptoms of some gynaecological cancers. She argued 'there is less than easy access to reliable information for women'.³²

Disproportionate focus on other cancers

6.40 The extent to which women currently received and retained appropriate information and education on gynaecological cancers was thought to be influenced by the focus on other types of cancer. The Committee heard that information was generally more accessible for some cancers than others and that women with breast cancer could access much more information about aspects of their disease and its management than women with gynaecological cancers. The clear message from submitters and witnesses was that a strategy to increase women's awareness and knowledge of gynaecological cancers was required to ensure it was 'higher on the radar'.³³

6.41 The Committee also noted that a large proportion of the information and awareness raising efforts in Australia have tended to focus on cervical cancer screening programs and ovarian cancer (through the NBCC's Ovarian Cancer Program). It is important to raise the profile of all gynaecological cancers.

30 *Submission 24*, p.12 (ASGO).

31 *Submission 28*, p.11 (Western Australian Gynaecologic Cancer Service).

32 *Committee Hansard 2.8.06*, p.24 (Cancer Voices Australia).

33 *Committee Hansard 1.8.06*, p.62 (NBCC).

Fragmented approach

6.42 Many witnesses and submitters commented on the fragmented and uncoordinated approach to education, particularly at the community level.³⁴ This influenced the ability of women and the broader community to receive and retain educational messages. The following were identified as the consequences of this fragmentation:

- duplication of resources and effort, often by people and professionals working in a volunteer capacity;³⁵
- increased potential for confusion over responsibility for initiatives;³⁶ and
- untargeted dissemination of large volumes of information and other products, leading to gaps in delivery and lack of readily available information.³⁷

Personal experiences needed

6.43 The Committee heard that women generally seemed to be poorly informed about gynaecological cancers until they were touched by it in one way or another, either personally or through someone close to them.³⁸

6.44 Dr Helen Zorbas, Director of the NBCC, agreed that most people were not interested in something until it came close to home. She argued that because breast cancer affected a greater number of women it was higher on the radar than ovarian cancer 'which touches relatively fewer people in the community'.³⁹

6.45 Ms Tish Lancaster from the Cancer Nurses Society of Australia (CNSA) also acknowledged that gynaecological cancers were not high on women's radar.

We have also heard several times today about knowledge of gynaecological cancer and women saying that they had never heard of ovarian cancer until they got it or until they know somebody who gets it. I think that is not particular only to ovarian cancer; I actually think it is particular to many cancers.⁴⁰

34 *Submission 28*, p.11 (Western Australian Gynaecologic Cancer Service); *Submission 24*, p.12 (ASGO).

35 *Submission 10*, p.7 (Sydney Gynaecological Oncology Group).

36 *Committee Hansard 23.6.06*, p.55 (Senator Jeannie Ferris).

37 *Committee Hansard 2.8.06*, p.8 (The Cancer Council Australia).

38 *Committee Hansard 1.8.06*, p.62 (NBCC).

39 *Committee Hansard 1.8.06*, p.62 (NBCC).

40 *Committee Hansard 1.8.06*, p.73 (CNSA).

Misunderstanding about what Pap smears screen for (ie, only cervical cancer).

6.46 The Committee was told that women were getting the message about having Pap tests and that the current cervical cancer screening program was very successful, however it was evident that women commonly misunderstood that Pap smear testing did not screen for the full range of gynaecological cancers. Mrs Erica Harriss from the National Ovarian Cancer Network (ACT and region) made the following comment about the misunderstanding.

Senator FERRIS—Do you think there might be some confusion in the general umbrella of gynaecological cancer between pap smears and the protection that they might offer?

Mrs Harriss—Yes, I have actually had it said to me, ‘You don’t need to worry about that. You have had a pap smear.’ And you have to say to that, ‘A pap smear does not detect ovarian cancer.’⁴¹

Lack of media profile

6.47 The media is a popular source of information for many Australians. The Committee heard that gynaecological cancers did not have a high media profile relative to other cancers, despite the efforts of many organisations.

Despite the efforts of established ovarian cancer organisations that are attempting to get this information out it does not get high media profile, and if it is available it is not being communicated effectively.⁴²

6.48 Ms Anne Mellon, a clinical nurse consultant from the Hunter New England Centre for Gynaecological Cancer, commented that breast cancer was in the public eye, whereas gynaecological cancers were not talked about as much in the media or by women publicly 'because it is stuff that happens "down there" and people do not want to bring it up'.⁴³

6.49 The Committee also noted that much of the media interest in gynaecological cancers was generally ad hoc and triggered by publicity regarding specific media 'breakthroughs' such as the recent release of a vaccine for the human papilloma virus.⁴⁴

Strategies for change

6.50 The provision of information on gynaecological cancers and support to the women and community should be a priority. In supporting this argument, Professor David Allen from The Cancer Council Victoria's Gynaecological Cancer

41 *Committee Hansard* 23.6.06, p.24 (National Ovarian Cancer Network – ACT and region).

42 *Committee Hansard* 3.8.06, p.74 (Ms Connie Nikolovski).

43 *Committee Hansard* 2.8.06, p.64 (Hunter New England Centre for Gynaecological Cancer).

44 *Submission* 28, p.11 (Western Australian Gynaecologic Cancer Service).

Committee and Victorian Cooperative Oncology Group argued that education of the public should be 'carefully considered and messages and advice must always be properly formulated and tested prior to being disseminated'.⁴⁵

6.51 In commenting on public education and cancer more generally, Mr Terry Slevin, Director of Education and Research at The Cancer Council Western Australia, said that a balance must be reached between getting a profile and getting the attention.

The notions of cut-through, as you will know from your own careers as politicians, of reaching your target audience, is an immediate challenge. Sometimes the way some organisations can achieve that is through hyperbole, if you like, so that it is a clear and dramatic statement of a problem. We have a clear and dramatic statement of a problem, but what we do not have is a clear and constructive solution to that problem.⁴⁶

Areas of focus

6.52 Witnesses called for new educational strategies to focus on all aspects of gynaecological cancer issues, ranging from identification of symptoms to the location of treatment facilities. Organisations such as GAIN said that issues must not be considered in isolation; rather they must be integrated with the larger, more challenging issues of gynaecological cancer care across the board. GAIN argued that education 'must also extend beyond the narrow realm of cancer education to education regarding the full range of gynaecological issues facing women in today's society'.⁴⁷

Education needs to focus on the holistic nature of risk factors, symptoms and treatment, in order that it is relevant to communities; accommodate the individual's preference for a range of treatment options (ranging from conventional to alternative); and be extended to include non-cancerous gynaecological conditions/issues.⁴⁸

6.53 It was noted that the need for information and the depth of information being sought would vary between women and would change throughout their cancer journeys. Commonly identified areas in need of greater attention included: psychosocial and psychosexual support; physical and daily living; patient care and support; services and resources; and complementary and alternative therapies and medicines.

Too much education?

6.54 It was suggested to the Committee that too much awareness generation and education could be counter-productive as it had the potential to unnecessarily scare

45 *Committee Hansard* 3.8.06, p.83 (The Cancer Council Victoria and Victorian Cooperative Oncology Group).

46 *Committee Hansard* 4.8.06, p.5 (The Cancer Council Western Australia).

47 *Submission* 14, p.8 (GAIN).

48 *Submission* 14, p.8 (GAIN).

women. GAIN refuted this argument saying this underestimated the ability of women to use knowledge in a way that is beneficial for them. Ms Jenkins from GAIN argued:

Our experience as a support organisation, from people that contact us on a daily basis, is that their lack of knowledge and awareness has contributed to whatever problem they have had, in that they often do not know how to describe their symptoms or indeed their gynaecological parts correctly; that they did not know that these things existed and how they could prevent transmission of them or how they could look after themselves; and that they feel ignorant when they go to their GP or gynaecologist, which no woman needs to feel about her body.⁴⁹

6.55 Ms Carolyn Walker, Director of the National Ovarian Cancer Network, also stressed that 'knowledge is power' and that it was important that organisations work together to 'get this vital and life-saving information out into the community'.⁵⁰

A new, coordinated approach

6.56 Many groups, such as the Sydney Gynaecological Oncology Group at the Royal Prince Alfred Hospital, did not make specific recommendations about the need for particular activities, but instead simply argued for a more coordinated approach and increased funding.

6.57 As such, the Committee has focused its attention on the key recommendation made during the inquiry – the need for a national public awareness campaign.

National Awareness Campaign

6.58 There was support for the development of a national awareness campaign to raise the profile of gynaecological cancers and to encourage women to present to general practitioners with symptoms earlier. It was also argued that a campaign would raise the level of awareness about gynaecological cancers in the community more generally.⁵¹

6.59 Mrs Lisle Fortescue, an ovarian cancer survivor, argued that because gynaecological cancers were a mystery to Australians, funding for an awareness campaign was needed.⁵² GAIN also recommended that awareness and education campaigns would enable women to take better control of their own gynaecological health.⁵³

49 *Committee Hansard* 4.8.06, pp.38-39 (GAIN).

50 *Committee Hansard* 3.8.06, p.94 (National Ovarian Cancer Network).

51 *Committee Hansard* 2.8.06, p.63 (ASGO).

52 *Committee Hansard* 1.8.06, p.28 (Mrs Lisle Fortescue).

53 *Committee Hansard* 4.8.06, p.37 (GAIN).

6.60 Of all the gynaecological cancers, a particular need to raise awareness about ovarian cancer was identified. Associate Professor Anthony Proietto, Chairman of ASGO, stated:

If we look at some of the other cancer sites, cervical cancer has a reasonable public profile, breast cancer certainly has an excellent public awareness profile and the profile of prostate cancer is getting better and better. We see this with our own patients. They often say: 'We didn't know anything about ovarian cancer. We didn't know it could exist. We didn't know that there were symptoms. We didn't know anything about it.' It is not talked about by the media, it is not talked about among women themselves and there is an awful lot of ignorance about some of the other sites, like ovary endometrial, vulval et cetera.⁵⁴

Whilst there was broad agreement about the need for a greater awareness, the detail of how a campaign would be executed or the cost were not examined in any depth by many.

6.61 In evidence, Dr Edward Trimble, Head of Gynecologic Therapeutics at the National Cancer Institute in the United States mentioned that the Centers for Disease Control and Prevention had conducted a public education that targeted ovarian cancer in the United States.

One of our sister agencies, the Centers for Disease Control and Prevention, has a public education campaign targeting ovarian cancer and the vague symptoms that you have mentioned. They have worked with the society of oncologists and several of the ovarian cancer advocacy groups in helping to identify these symptoms and to develop a broad based educational campaign.⁵⁵

6.62 Professor Philip Di Saia, a gynaecological oncologist from the United States, also referred to a number of public education initiatives that had been successful in the United States. These included an ovarian cancer month (each September), marathons to raise funds and awareness and the development of brochures, guidelines and cervical cancer screening programs.⁵⁶

6.63 The Gynaecological Cancer Society presented the Committee with a detailed proposal for a national public awareness campaign and argued that an 'effective and efficient' example could be found by looking at the NBCC's approach to breast cancer.⁵⁷

54 *Committee Hansard* 2.8.06, p.63 (ASGO).

55 *Committee Hansard* 16.8.06, p.4 (United States National Cancer Institute).

56 *Committee Hansard* 10.8.06, p.4 (Professor Philip Di Saia).

57 *Submission* 7, Attachment 3 (Gynaecological Cancer Society).

Over the years many millions of dollars have been spent informing and educating the public on relevant breast cancer issues and we must be prepared to do the same if we expect to see similar results.⁵⁸

6.64 For an efficient and effective campaign, the Gynaecological Cancer Society stressed that all stakeholders needed to participate in a coordinated fashion, that it needed to be a long campaign and that all media streams should be involved. The Society estimated that their proposal would cost around \$19 million over five years.⁵⁹

6.65 Ms Connie Nikolovski, an ovarian cancer survivor, suggested that television would be the best medium to convey messages to a large number of people.

Definitely more television, because everybody watches TV—and communicating. And radio, in people’s own language—not just in the Australian language. We are a multicultural society, so we should cater for that. I know that people stick in their own little groups. As soon as you have a representative of one community, that flourishes throughout that whole community.⁶⁰

6.66 In agreeing that raising awareness was a positive step, witnesses cautioned that education needed to be carefully tailored so as not to create a scare campaign and to overload general practitioners.⁶¹ Mr Gower from the Gynaecological Cancer Society stated:

My only fear with a national campaign is that it has to be done sympathetically so that we do not have all of our GPs and our treatment centres totally overwhelmed by six million women who are sure they have one of the six gynaecological cancers, but that can be done.⁶²

6.67 The Committee heard that because of the vague nature of the symptoms for gynaecological cancers, in particular ovarian cancer, effort was needed to strike an appropriate balance between providing women with useful and timely information (from a more medical perspective), and not scaring them into confusing a gynaecological cancer with, for example, their normal monthly menstrual cycle.⁶³ Mr Slevin from The Cancer Council Western Australia argued that greater investment in research was needed to better shape the messages provided to women.⁶⁴

58 *Submission 7*, Attachment 3 (Gynaecological Cancer Society).

59 *Submission 7*, Attachment 3 (Gynaecological Cancer Society).

60 *Committee Hansard* 3.8.06, p.76 (Ms Connie Nikolovski).

61 *Committee Hansard* 1.8.06, p.75 (CNSA).

62 *Committee Hansard* 2.8.06, p.43 (Gynaecological Cancer Society).

63 *Committee Hansard* 4.8.06, p.5 (The Cancer Council Western Australia).

64 *Committee Hansard* 4.8.06, p.6 (The Cancer Council Western Australia).

6.68 Not all witnesses supported a campaign, nor saw it as a priority, instead choosing to direct resources and funding on more focused educational activities. The main reason cited was summed up by The Cancer Council Western Australia.

The promotion of such generalised symptoms in relation to gynaecological cancer has significant potential to generate high levels of anxiety, and potentially promoting significant increase in health service seeking, with little evidence to suggest that such anxiety and further investigation will result in improved detection or ultimately better health outcomes.⁶⁵

6.69 The Department and the NBCC agreed with the position of The Cancer Council Western Australia.

6.70 Dr Zorbas from the NBCC argued that the lack of a clear, simple message about ovarian cancer symptoms meant that there was not a strong evidence base present for a viable campaign and as such it had 'not been identified as a priority area' by the NBCC's stakeholders.⁶⁶ Dr Zorbas stated:

If we could find a particular group of symptoms, for example, that were more significant when pooled together, that could give us an important key message. The message around early detection is around symptoms that are vague and common, and it is not a simple, clear message about awareness or screening or anything that you could put into a clean package for women. Unfortunately, that is the case at the moment.⁶⁷

6.71 The Department also agreed that the lack of a simple message or slogan similar to those developed for breast cancer and for cervical cancer (such as 'have a Pap smear'), prevented the viability of a public awareness campaign.

6.72 On this point, Professor Ian Olver, Chief Executive Officer of The Cancer Council Australia, said that the 'one thing that ovarian cancer shares with other cancers is that the symptoms are persistent'. He argued that a message about persistency of symptoms should be investigated further and could also be given to the community and reinforced without creating 'public panic'.⁶⁸

6.73 The NBCC highlighted its work with the National Ovarian Cancer Network, particularly around Ovarian Cancer Awareness Week and an upcoming awareness road-show focusing on regional centres, were effective avenues for spreading some of its key messages in both breast cancer and ovarian cancer.⁶⁹

65 *Submission 51*, p.29 (The Cancer Council Western Australia).

66 *Committee Hansard 1.8.06*, p.62 (NBCC).

67 *Committee Hansard 1.8.06*, p.63 (NBCC).

68 *Committee Hansard 2.8.06*, pp.8-9 (The Cancer Council Australia).

69 *Committee Hansard 1.8.06*, p.62 (NBCC).

6.74 The NBCC and the Department emphasised that they had instead focused their attention on working with general practitioners to raise awareness on ovarian cancer issues.

We have put a lot of energy into that because we want them to have it on their radar, to think, 'Maybe this woman could have ovarian cancer and we should be appropriately investigating her.'⁷⁰

Broader education about cancer

6.75 Witnesses suggested that improvements to gynaecological cancer awareness could be made as part of a broader strategy to increasing education about cancer. Professor Olver considered that the whole cancer community, including the sub-specialty of gynaecological cancer, would benefit from information and awareness about all cancers, with priority put on disseminating messages about seeking advice on persistent symptoms.⁷¹

Factors to consider

One size does not fit all

6.76 When developing new initiatives, the Committee heard that it was important to recognise that women and the broader community have different information needs and different ways of absorbing information.

6.77 In considering the merits of particular educational strategies, Dr Sarah Pickstock, a Palliative Care Physician from the King Edward Memorial Hospital argued that 'we are all unique with our decisions in life and health decisions' and that the challenge for health care workers was to 'pick the right style for the right person'.⁷² The Committee heard that for some people, it was deleterious to give too much information, whereas this was not the case for others.

6.78 As a practical way of addressing this issue, Mr Michael Powell, Vice Chair of Cancer Voices Victoria suggested that setting a minimum information standard would be a positive step to overcoming inconsistencies in the amount of information given to women and the timing of it. Mr Powell argued:

Set a minimum, set a protocol and everyone has to be given this minimum information, which gives them the guidelines of where to go and is structured in such a way that country people have the phone numbers, toll free numbers, to talk to somebody, because they cannot go down to the corner and find someone. It has to be structured to suit all Australians.⁷³

70 *Committee Hansard* 1.8.06, p.63 (NBCC).

71 *Committee Hansard* 2.8.06, p.9 (The Cancer Council Australia).

72 *Committee Hansard* 4.8.06, p.76 (King Edward Memorial Hospital).

73 *Committee Hansard* 3.8.06, p.89 (Cancer Voices Victoria).

Overcome stigma and use terminology correctly

6.79 It was evident throughout the inquiry that in discussions about gynaecological cancers it was important to overcome any taboos that might exist.

6.80 Witnesses emphasised that women were more comfortable talking about breast cancer than ever before and that the same needed to occur for gynaecological cancers, particularly for women from culturally and linguistically diverse backgrounds. Ms Jenkins from GAIN said that if discussions about gynaecological cancers were more public and women became more comfortable with the language of gynaecological cancer, its profile would grow.

The terminology is not even being used correctly...Using 'gynae cancers' in itself as a catch-all is not providing the right levels of education. The media has to be on to it. We have to be talking about it in public forums and again at all levels—community, clinical and also government.⁷⁴

6.81 It was argued that education should aim to facilitate more open discussion about gynaecological cancers in order to overcome some of the stigma attached to the terminology and related issues. Ms Nikolovski argued that people should learn 'that cancer is a word that should not be avoided but must be discussed'.⁷⁵

6.82 Ms Michele Kosky, Executive Director of the Health Consumers Council Western Australia, argued that gynaecological health deserved more attention within Australia's sexual health framework in order to give it a higher profile alongside breast cancer.⁷⁶

Written information

6.83 There is a large amount of written information produced for women with gynaecological cancers and the broader community, including pamphlets, booklets and fact sheets. The Committee heard that high quality information should include evidence-based statements and be easily accessible. Also important is that information should be presented in a balanced way using concise, jargon-free language.

6.84 Traditionally, sources of written information have been medical and allied health professionals, family and friends and the publicly available media.

6.85 It was evident that many organisations produced well-written and appropriate information to assist women with gynaecological cancers, however the Committee heard that many women were not able to access the full range of information available necessary to make fully informed decisions about different treatment options.

74 *Committee Hansard* 4.8.06, p.40 (GAIN).

75 *Committee Hansard* 3.8.06, pp.74-75 (Ms Connie Nikolovski).

76 *Committee Hansard* 4.8.06, p.60 (Health Consumers Council Western Australia).

Online information and e-medicine

6.86 Some women have become more active managers of their health since the introduction of the Internet. The Internet has meant women can access information about gynaecological cancers and their specific conditions online in addition to information supplied by medical and other health professionals.

6.87 The Committee heard that women used information on the Internet as an educational tool to:

- obtain a range of opinions regarding gynaecological cancers, for themselves, family or friends;
- search directly for health information, health organisations or providers;
- participate in support groups; and
- consult with health professionals.

6.88 The Internet, particularly in the context of psychosocial support, can be helpful for women in many respects as it is a convenient, anonymous and cost effective source of information.

6.89 For health providers and government, the Internet can be a very effective tool for disseminating health information, health education and services.

6.90 Though the Internet is highly visible and accessible to many Australians, there is an enormous volume of information online meaning that it is potentially confusing to navigate through. Often individuals might not get to the right website or get conflicting information. A coordinated and visible approach is needed.

6.91 Although many organisations provide high quality information, there is no comprehensive site which details information on types of gynaecological cancers as well as treatment options, treatment facilities and Government assistance (for example, patient travel schemes) in Australia. In New South Wales there is a directory of gynaecological oncology treatment and support services that is available online, but a national approach is needed with a broad focus that includes all aspects of gynaecological cancer care.

Face-to-face contact important.

6.92 Despite the prevalence of health information on the Internet, women still value face-to-face interaction.⁷⁷

6.93 Ms Jenkins from GAIN pointed out that the Internet 'is not the be-all and end-all'.⁷⁸ It is used a lot because it is accessible, cheap and gives immediate access, but

77 *Committee Hansard* 1.8.06, p.33 (Mrs Lisle Fortescue).

78 *Committee Hansard* 4.8.06, p.43 (GAIN).

any coordinated approach to information provision must include human interaction, particularly for those that are not computer literate.

Consideration of population differences

6.94 As the incidence of gynaecological cancers as a group continues to rise, with a disproportionate rate in disadvantaged groups including Aboriginal and Torres Strait Island populations and those in rural and remote areas, special consideration of women from culturally and linguistically diverse backgrounds must be taken into account by decision-makers.

6.95 Furthermore, given the ageing of the population and the fact that gynaecological cancers are mainly a disease of older people, incidence is expected to continue to rise in the future. This trend will pose an ongoing challenge in the delivery of optimal gynaecological cancer education – both about prevention and detection and also throughout the cancer journey.

Roles and responsibilities

6.96 The need for a better coordinated approach to promoting awareness and conducting education about gynaecological cancers was thought to be a high priority by many witnesses and submitters. It was argued that a powerful voice was required to implement a national campaign and associated programs along similar lines to that of the successful breast cancer movement, which achieved a great deal for the Australian community.⁷⁹

6.97 Many suggested that the establishment of a national body to provide this coordination and to centralise resources would represent a significant advance for women and an important strategic investment for Australia as a whole.⁸⁰ A national body would provide efficient and timely mechanisms to produce up-to-date educational material and to consolidate and integrate the current ad hoc development and delivery of support and information resources.⁸¹ The proposal for a national centre is discussed further in Chapter 2.

6.98 The Australian Society of Gynaecologic Oncologists (ASGO) indicated its support for such a national approach. It argued that the formation of a National Gynaecological Cancer Centre (NGCC) would mean that education was better coordinated, diversity catered for, a higher audience reach achieved and better support for existing organisations already providing education.⁸²

79 *Submission 7*, Attachment 3 (Gynaecological Cancer Society).

80 *Committee Hansard* 1.8.06, p.2 (Royal Hospital for Women).

81 *Submission 27*, p.26 (Ms Margaret Heffernan); *Submission 10*, p.6 (Sydney Gynaecological Oncology Group); *Submission 48*, p.3 (The Cancer Council Victoria).

82 *Submission 24*, p.12 (ASGO).

6.99 Others, such as The Cancer Council Australia, recommended that the NBCC's existing role in disseminating community information should be expanded beyond ovarian cancer to focus on all gynaecological cancers.⁸³

6.100 It was also thought that Cancer Australia was an authoritative body that could coordinate educational strategies to ensure that information is available and visible.

Conclusion

6.101 Gynaecological health is a complex area and education is essential to ensure that women and the broader community:

- are aware of the risk factors and symptoms that may indicate the presence of gynaecological cancers; and
- make informed choices about the treatment and management of their particular health and medical issues.

6.102 The Committee heard that through education, women with gynaecological cancers are generally better informed about all aspects of their health and care. Information based on quality evidence led to improved referrals, better knowledge of treatment options and more realistic outcome expectations. The key is reliable information that is available and accessible to women and the broader community. It is also important that health providers (for example, general practitioners) play a role in encouraging women to take full advantage of the information available to them.

6.103 Better coordination of existing resources and providing the necessary support to organisations and primary healthcare providers were important pre-conditions to ensuring that women and the community were supported and educated about gynaecological cancers.

6.104 It was argued that responsibility for coordination and strategic planning of educational initiatives could lie with one of a number of bodies, including the newly established Cancer Australia, the NBCC, the proposed NGCC or another national body (under the umbrella of Cancer Australia). Whilst witnesses and submitters diverged on the appropriate body to take responsibility, an overwhelming number considered that a national approach would ensure a suitable body provided leadership and a nationally consistent source of information on services, treatment options, government assistance and links to appropriate support groups which can be made readily available in different forms.

83 *Submission 56*, p.34 (The Cancer Council Australia, COSA and NACCHO).

Recommendation 28

6.105 The Committee recommends that Cancer Australia, in conjunction with the Centre for Gynaecological Cancers, be given wide-ranging responsibility for the management of coordinated national education strategies targeting women and their families, friends, carers and the broader community about gynaecological cancers.

6.106 The Committee further recommends that a review of all existing gynaecological cancer educational material targeting women and the broader community be undertaken by Cancer Australia, in conjunction with a Centre for Gynaecological Cancers, to review the currency of the content and the appropriateness for the audience.

Recommendation 29

6.107 The Committee recommends that Cancer Australia and the Centre for Gynaecological Cancers work together to develop a resource pack be developed and disseminated to give women and the broader community consolidated and consistent information about gynaecological cancers, treatment options, support groups and other services.

Recommendation 30

6.108 The Committee recommends that Cancer Australia and the Centre for Gynaecological Cancers work together to ensure that medical facilities and support organisations have visible and current information on-site in the form of posters and pamphlets about gynaecological cancers and related services.

Recommendation 31

6.109 The Committee recommends that Cancer Australia analyse and assess the approach taken in the United States in the following areas:

- public education (for example, the strategies of the Centres for Disease Control in relation to ovarian cancer);
- advocacy by gynaecological cancer groups; and
- service provision by support groups.

CHAPTER 7

EXPERIENCE, EXPERTISE AND REPRESENTATION OF GYNAECOLOGICAL CANCER ISSUES

Introduction

7.1 There are a multitude of individuals and organisations in Australia with experience and expertise in gynaecological cancer that strive to improve all aspects of care and support for women.¹

7.2 This chapter examines where the expertise and experience is found and the extent to which it is represented in the priorities and directions of:

- national health agencies, including Cancer Australia; and
- key advisory bodies and Commonwealth government forums that shape health priorities.

7.3 This chapter considers the appropriateness of the level of representation and the extent to which initiatives, programs and services address gynaecological cancers and related issues.

Experience and expertise in gynaecological cancers

7.4 The Committee heard that there was a considerable amount of expertise and experience in gynaecological cancer matters in Australia.² This resides with gynaecological oncologists and other members of the medical and allied health communities, the women who have, or have survived, gynaecological cancers and with the professional bodies, organisations and community-based groups that represent and promote matters relating to women with these types of cancers.

7.5 The extent to which this knowledge and 'know-how' has been successfully utilised by, and incorporated into the decision-making of, national health agencies was a matter of some contention, with some arguing that gynaecological cancers were often over-shadowed by other tumour types with a higher public profile, particularly breast cancer.

Medical community and allied health community

7.6 Members of the medical community and allied health professionals have close relationships with women who have, or are at risk of, gynaecological cancers. Professionals that form multidisciplinary care teams include (but are not limited to)

1 *Committee Hansard* 16.8.06, pp.1-2 (United States National Cancer Institute).

2 *Committee Hansard* 1.8.06, p.2 (Royal Hospital for Women).

gynaecological oncologists, medical oncologists, radiation oncologists, palliative care specialists, specialist gynaecological cancer nurses, dedicated physiotherapists, clinical psychologists, dieticians, social workers, supportive care and pastoral care workers.

7.7 With gynaecological cancer care moving to a more patient-centred approach, professionals are uniquely placed to provide their perspectives on issues relating to the adequacy of treatment, care and support systems and future priorities in gynaecological oncology. It was argued that representation of their views would help to better address the individual physical and emotional needs of women and better shape policies and strategies designed to improve care for women.

Gynaecological cancer organisations

7.8 There are many established and emerging professional and consumer non-government organisations that advocate for improvements in all aspects of gynaecological cancer care. These organisations operate on a national, as well as a state and local level.

7.9 The existence of many organisations is indicative of the high level of enthusiasm and importance that individuals and professionals place on working collaboratively to promote and advance gynaecological cancer care.

Professional bodies

7.10 A number of organisations represent and support the work of gynaecological oncology professionals, including the Australian Society of Gynaecological Oncologists (ASGO) and the Australia New Zealand Gynaecological Oncology Group (ANZGOG).

7.11 ASGO was founded in 1985 and is an organisation of Australian and New Zealand gynaecological oncologists. Its role is to promote 'improvement in the service delivery' in Australia, including in the area of patient care.³

7.12 ASGO is the closest organisation to a national body representing gynaecological cancer issues in Australia. By virtue of its national status, ASGO has assumed a limited coordination role, but it said its ability to perform effectively was hampered by resource (human and financial) constraints.⁴

7.13 The ANZGOG has a narrower remit than ASGO. It was established in 2000 to facilitate a collaborative and coordinated approach to gynaecological cancer clinical trials in Australia and New Zealand.⁵ Professor Michael Friedlander, Chairman of

3 *Committee Hansard* 2.8.06, p.50 (ASGO).

4 *Submission* 24, p.7 (ASGO).

5 *Submission* 55, p.1 (ANZGOG).

ANZGOG, stated that it has developed a viable and effective clinical trials group because it has 'very close working relationships' with all of the Australian gynaecological cancer units and international gynaecological cancer groups.⁶

7.14 ANZGOG commented that its most critical issue was the lack of recurrent funding to support infrastructure and specific clinical trials. To date, it has received 'limited' financial support from the Commonwealth government, through the Strengthening Cancer Care initiative and a grant from the Cancer Institute of New South Wales.⁷

Community organisations

7.15 Australia has a large number of community-based organisations that work on gynaecological cancer issues. Depending on their size, and geographical region, the Committee heard that some organisations tended to focus on a broad range of issues associated with gynaecological cancers, whereas others narrowed their activities to specific tumour types. Evidence received during the inquiry indicated that more groups focused on ovarian cancer than for any other gynaecological cancer.

7.16 Many of these organisations coordinate, conduct or provide a broad range of activities, support and other services often on a volunteer basis with minimal funding. These include (but are not limited to):

- to act as a clearinghouse for information on gynaecological cancer issues for women, carers, professionals, government, community organisations and those who support women;
- to be a 'voice' for patients;
- to raise awareness of gynaecological cancers amongst women and the medical community;
- to consult with identified interest groups and stakeholders; and
- to raise funds to support gynaecological cancer control.

7.17 There is a vast amount of expertise that these groups bring, or could potentially bring, to national health agencies and other government decision-making bodies. Many past and present gynaecological cancer patients work actively in these organisations and bring their personal experiences and expertise to their work.

The Cancer Councils

7.18 The Cancer Council Australia is Australia's national non-government cancer control organisation. It has eight State and Territory cancer organisations that work

6 *Committee Hansard* 1.8.06, p.43 (ANZGOG).

7 *Committee Hansard* 1.8.06, p.43 (ANZGOG).

together to undertake and fund cancer research, to prevent and control cancer and to provide information and support for people affected by cancer.⁸

7.19 The Cancer Council Australia acts nationally to advise governments and other bodies on appropriate practice and policies for the prevention, detection and treatment of cancer and is an advocate for the rights of cancer patients to best treatment and supportive care.

7.20 Although the Cancer Councils do not specifically focus on gynaecological cancers, those tumours fit within their broad remit.

National health agencies, bodies and initiatives

7.21 In Australia, a mix of government, non-government and community sectors shape health priorities and deliver and fund health services.

7.22 The Commonwealth Government – through the Commonwealth Department of Health and Ageing (the Department), Cancer Australia, the National Breast Cancer Centre (NBCC) and other bodies and initiatives – is responsible for setting national health policies and service delivery for those with gynaecological cancers through funding for research, policy and program implementation. The Department also has responsibility for building strong partnerships with stakeholders.⁹

7.23 Although the Government's various bodies, policy forums and initiatives focused on gynaecological cancers, it appeared that gynaecological cancers were only a sub-set of a wider focus on cancer. The extent to which representative and community groups, and the experience and expertise they represent, had access to government decision-making bodies was often difficult to gauge. The level of involvement of 'experts' and those with experience, particularly consumers, remained somewhat vague and uncertain to many witnesses and submitters.

Commonwealth Department of Health and Ageing

7.24 The broad role of the Department is to:

- provide expert policy advice and analysis to the Commonwealth Government;
- manage the Commonwealth Government's health programs to ensure the provision of quality, cost effective care to Australians; and
- promote healthy living and communicate information about health services to Australians.

7.25 In providing leadership for gynaecological cancer matters, the Department works with consumers, communities, health providers, peak bodies, industry groups,

8 The Cancer Council of Australia, *About Us*, (<http://www.cancer.org.au/content.cfm?randid=325412>).

9 *Submission 52*, p.5 (Commonwealth Department of Health and Ageing).

professional organisations, State and Territory governments and portfolio agencies. The NBCC's Ovarian Cancer Program is largely funded by the Commonwealth Government to undertake activities in relation to ovarian cancer.

7.26 The Department also administers the ongoing funding provided for initiatives aimed at improving the prevention, detection, treatment and management of cancer more generally for the Australian community. Whilst the Department funds and oversees many initiatives, the few that focus on gynaecological cancers appear largely limited to ovarian cancer control (through the NBCC) or cervical cancer screening programs. It was unknown whether this lack of focus was due to little gynaecological cancer representation on decision-making bodies or whether other tumour types warranted greater priority.

7.27 To help reduce the burden of cancer the Commonwealth Government allocated \$189.4 million over the five years to 2008-09 through the Strengthening Cancer Care initiative.¹⁰ The initiative aims to ensure:

- better coordination of the national cancer effort;
- more research funding for cancer care;
- enhanced cancer prevention and screening programs; and
- better support and treatment for those living with cancer.

7.28 One of the most significant elements in this initiative is the establishment of a new national cancer agency, Cancer Australia.

Cancer Australia

7.29 The Commonwealth Government announced its intention to establish Cancer Australia as part of its Strengthening Cancer Care initiative. According to the Government's 2004 Federal election policy, a body such as Cancer Australia was needed to ensure that 'the entire spectrum of cancer care services throughout Australia are evidence based and consumer focused'.¹¹

7.30 Cancer Australia's role is to:

- provide national leadership in cancer control;
- make recommendations to the Commonwealth Government about cancer policy and priorities;
- guide scientific improvements to cancer prevention, treatment and care;
- coordinate and liaise between the wide range of groups and providers with an interest in cancer; and

10 Commonwealth Department of Health and Ageing, *Budget 2005-06* (www.health.gov.au/budget2005).

11 Dr Angela Pratt, *Bills Digest – Cancer Australia Bill 2006*, 1.3.06, p.2.

- oversee a dedicated budget for research into cancer.¹²

7.31 The Committee understands that Cancer Australia will have four priority areas in which it will take leadership: research and clinical trials; quality; consumers; and policy. Each of these areas will have a national reference group to support it and consumers and cancer experts to inform and drive priorities.

7.32 Cancer Australia is expected to spend \$16.663 million in grants in 2006-07 to support the following Strengthening Cancer Care measures:

- clinical trials;
- cancer research;
- cancer support networks;
- mentoring for regional hospitals and cancer professionals; and
- developing training courses for cancer nurses.¹³

7.33 Cancer Australia will comprise of a Chief Executive Officer (CEO), an Advisory Council and support staff. The CEO, medical oncologist Professor David Currow, will head the agency and will report to the Minister for Health and Ageing.¹⁴ The Advisory Council, chaired by former Australian Medical Association president Dr Bill Glasson, will be advisory to the CEO and will consist of a Chair and a maximum of 12 other members.¹⁵

Issues regarding the operation of Cancer Australia

7.34 The establishment of Cancer Australia appears to be supported by cancer groups and others in the gynaecological cancer community.¹⁶

7.35 Professor Ian Olver, Chief Executive Officer of The Cancer Council Australia, was a strong advocate of Cancer Australia's formation and saw the organisation as having the potential to make a significant impact on controlling cancer, including gynaecological cancers, in Australia.¹⁷ The Cancer Council Western Australia and Professor Christobel Saunders, Acting Director of the Cancer and Palliative Care Network, also welcomed its establishment and argued it provided a

12 Portfolio Budget Statements 2006-07 – Health and Ageing Portfolio, p.299.

13 Portfolio Budget Statements 2006-07 – Health and Ageing Portfolio, p.303.

14 Minister for Health and Ageing, the Hon. Tony Abbott MP, *Media Release* (ABB124/06), 25.8.06.

15 Minister for Health and Ageing, the Hon. Tony Abbott MP, *Media Release* (ABB025/06), 7.3.06.

16 *Submission 56*, p.35 (The Cancer Council Australia, COSA and NACCHO).

17 *Committee Hansard* 2.8.06, pp.3-4 (The Cancer Council Australia).

good opportunity for gynaecological cancer work to be undertaken by one entity and in concert with other more general developments in cancer control.¹⁸

7.36 Professor Olver said the following about Cancer Australia's formation:

...one of the difficulties in Australia is there are little bits of organisations and people doing things all over the place, and not only in organisational things—supportive things and research. Something that could focus that in would be a good idea. We see Cancer Australia as a portal of entry into government—into the minister's office, if you like—and the exit portal of government communicating with the community.¹⁹

7.37 A number of witnesses and submitters expressed uncertainty about Cancer Australia's operation in practice and questioned its capacity to address issues specific to gynaecological cancers.²⁰

7.38 First, there was concern about the low profile gynaecological cancer issues might receive once Cancer Australia was operational. Associate Professor David Allen, representing The Cancer Council Victoria's Gynaecological Cancer Committee and Victorian Cooperative Oncology Group, argued that gynaecological cancer representation on decision-making and policy development bodies was important. Associate Professor Allen said that this representation was lacking on Cancer Australia's Advisory Council.

But if you look at that committee...it has no real gynaecological representation. I do not know if the idea is to try to represent most of the cancer entities on that committee or not. It seems to have a lot of breast input and interests. Certainly we believe, and I know that ASGO, the Australian Society of Gynaecologic Oncologists, believes as well that we should have some sort of voice or connection with that, even if it is in the form of a subcommittee, or whether some national gynaecological body should be aligned to the Cancer Australia. But we believe that sitting in or around councils like that is very important.²¹

7.39 The Queensland Centre for Gynaecological Cancer highlighted that breast cancer was represented on the Advisory Council with 'at least three members', whereas gynaecological cancer was not represented at all.²²

18 *Submission 51*, p.31 (The Cancer Council Western Australia); *Committee Hansard* 4.8.06, p.26 (Cancer and Palliative Care Network).

19 *Committee Hansard* 2.8.06, p.3 (The Cancer Council Australia).

20 *Committee Hansard* 4.8.06, p.58 (Health Consumers Council Western Australia); *Committee Hansard* 2.8.06, p.26 (Cancer Voices Australia).

21 *Committee Hansard* 3.8.06, p.85 (The Cancer Council Victoria and Victoria Cooperative Oncology Group).

22 *Submission 11*, p.9 (Queensland Centre for Gynaecological Cancer).

7.40 In response, the Department maintained that Cancer Australia's formation would mean that 'all cancers, including gynaecological cancers, continue to be a focus for the Commonwealth Government'.²³ In addition, The Cancer Council Australia, the Clinical Oncological Society of Australia (COSA) and the NBCC all emphasised that through their representatives on Cancer Australia's Advisory Council there would be a strong commitment to ensuring that gynaecological cancer issues were afforded appropriate priority. They argued that they would:

...convey the concerns of our gynaecological cancer stakeholders and work to help ensure that relevant issues receive due prominence in discussion around the agency's strategic directions.²⁴

7.41 Second, some witnesses had difficulty commenting on the role Cancer Australia would play, or the difference it could make, to gynaecological cancer control because of the lack of information or communication about its operations.²⁵ At the time of writing its submission, the Gynaecological Cancer Society stated:

...we have absolutely no first-hand knowledge regarding the organisation, its intended function or its membership. Certainly the Society has never been approached to participate nor offered any information regarding the activities of Cancer Australia.²⁶

7.42 Third, there were concerns about the lack of direct representation of experts in gynaecological cancers and consumers on the Advisory Council and its impact on the ability of professionals and women to access Cancer Australia.²⁷

7.43 The Sydney Gynaecological Oncology Group felt that there was no appropriate clinician appointed to Cancer Australia despite the prevalence of gynaecological cancers in Australia.²⁸

Clinicians involved with these diseases feel that representatives for other disease groupings do not adequately consider the importance of gynaecological cancers.²⁹

7.44 Cancer Voices Australia, a body representing the views of consumers, said it was involved in some consultation with Cancer Australia during its developmental phases, but that contact was a 'one-off'.³⁰ Although Cancer Voices Australia was

23 *Submission 52*, p.5 (Commonwealth Department of Health and Ageing).

24 *Submission 56*, p.36 (The Cancer Council Australia, COSA and NACCHO).

25 *Committee Hansard 3.8.06*, p.85 (The Cancer Council Victoria and Victoria Cooperative Oncology Group).

26 *Submission 7*, p.3 (Gynaecological Cancer Society).

27 *Committee Hansard 2.8.06*, pp26-27 (Cancer Voices Australia).

28 *Submission 10*, p.11 (Sydney Gynaecological Oncology Group).

29 *Submission 10*, p.11 (Sydney Gynaecological Oncology Group).

30 *Committee Hansard 2.8.06*, p.26 (Cancer Voices Australia).

advised that one or two of the members of the Advisory Council would be a conduit for consumers into the organisation, it stressed that representation of women's views would be more meaningful if consumer representatives were directly appointed to the Council.

7.45 The Gynaecological Cancer Society also argued for meaningful commitment to consumer involvement.

As a matter of principle the Society strongly endorses a policy of inclusiveness for any organisation that purports to represent the interests of cancer stakeholders in Australia.³¹

7.46 In relation to the composition of Cancer Australia's Advisory Council, Professor Olver argued that the membership included a wide range of expertise and experience in cancer control and that the lack of direct representation would not necessarily preclude gynaecological oncology interests being put forward:

...all of us who were approached to sit on that council were not approached with any designation at all. I wear a number of hats, I guess, in the cancer community and I have no idea which of them, if any of them, I was specifically appointed to that council for. I think the idea was to develop a body of expertise that covered quite a wide spectrum.

...

So it is highly unlikely that there can be a representative of particular tumour types—lung cancer, breast cancer and so on, although breast cancer is represented, as it happens.³²

7.47 Despite the concerns put forward by some witnesses about Cancer Australia's ability to focus on, and address, gynaecological cancer issues, the establishment of a national government agency was widely agreed to be essential.

7.48 Dr Robert Rome, a Melbourne gynaecological oncologist, argued:

There certainly needs to be a more coordinated effort to improve gynaecological cancer and this would best be done through a Federal initiative rather than at a state level.³³

7.49 The suggestion by many to establish a national body with a national approach and focus for gynaecological cancers, such as the National Gynaecological Cancer Centre (NGCC), is considered in further detail in Chapter 2.

31 *Submission 7*, p.3 (Gynaecological Cancer Society).

32 *Committee Hansard 2.8.06*, p.3 (The Cancer Council Australia).

33 *Submission 32*, p.2 (Dr Robert Rome).

National Breast Cancer Centre

7.50 The NBCC is currently Australia's peak body for breast and ovarian cancer control.³⁴ It was established in 1995 by the Commonwealth Government in response to community concerns about the human cost of breast cancer. In September 2001, in recognition of the impact of ovarian cancer on Australian women, the Commonwealth Government provided funding to the NBCC to manage the Ovarian Cancer Program.³⁵

7.51 The work of the Ovarian Cancer Program covers many aspects of ovarian cancer control, from risk factors, symptoms and diagnosis to the multidisciplinary treatment of women with ovarian cancer.

7.52 The NBCC told the Committee its Ovarian Cancer Program works in partnership with women, health professionals, cancer organisations, researchers and governments to improve the ovarian cancer outcomes for women.³⁶

7.53 The NBCC stated it has ensured clinical and consumer representation of ovarian cancer issues on its relevant Advisory and Working Groups.³⁷ For example:

- a clinical advisor in ovarian cancer is a member of the NBCC's Clinical Expert Advisory Panel providing advice to the NBCC on emerging and current issues in research and treatment; and
- the NBCC works closely with the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) and with ANZGOG involving them in development and implementation of initiatives in ovarian cancer control.

7.54 It is acknowledged that there is only one clinical advisor in ovarian cancer and none in other gynaecological cancers and the Committee considers this gives good reason for a separate focus through a stand-alone body.

7.55 The NBCC works closely with women who have ovarian cancer and it argued that their insights and understanding of the disease and its impact on women and their families enriched the overall approach taken in its ovarian cancer activities.

The involvement of both clinical and consumer experts is vital to the way NBCC develops and delivers on a relevant and informed business plan in ovarian cancer.³⁸

34 *Submission 52*, p.5 (Commonwealth Department of Health and Ageing).

35 *Submission 44*, p.12 (NBCC).

36 *Submission 44*, p.3 (NBCC).

37 *Submission 44*, p.13 (NBCC).

38 *Submission 44*, p.13 (NBCC).

7.56 In turn, the NBCC incorporates the expertise, views and interests it gathers through consultative processes at the National Cancer Strategies Group and the Australian Screening Advisory Committee (ASAC).³⁹

7.57 The NBCC addresses ovarian cancer through its Ovarian Cancer Program, but it does not address education, research and management issues pertaining to other gynaecological cancers.⁴⁰ The Committee noted that although the NBCC utilised much gynaecological oncology expertise, its remit is limited to ovarian cancer.

Roles and responsibilities in advising the Commonwealth Government

7.58 At the Canberra hearing, the Committee sought clarification from the Department about how it, Cancer Australia and the NBCC worked together in practice to provide advice to Government. The Department was questioned about the responsibility of each organisation in the development of new initiatives, such as a national awareness campaign. The Committee was concerned that the Department did not provide a clear answer about the delineation of the respective roles between the three organisations.

7.59 The Department commented that each agency was responsible for making recommendations to the Commonwealth Government about cancer policy and priorities and that Government would take into account the views of each body, but that 'there is no neat formula' and that ideas could be initiated by any of the three.⁴¹

7.60 As key advisers to Government, this has the potential to cause gaps and to send mixed messages.

Policy advisory structures

7.61 As cancer was established as a National Health Priority area in 1996 by Commonwealth, State and Territory health ministers, the Commonwealth Government established a number of health advisory committees to inform policy development (in addition to the Department, Cancer Australia and the NBCC). Some are discussed below.

7.62 Many of the national health agencies and policy advisory structures have gynaecological cancer expertise in their membership or committee membership – such as the ASAC – but due to the terms of reference of such committees, this has largely involved expertise related to cervical cancer.

39 NBCC, *Annual Report 2004-05*, p.4.

40 *Submission 40*, p.6 (Professor Neville Hacker).

41 *Committee Hansard 23.6.06*, pp.56-57 (Commonwealth Department of Health and Ageing).

Australian Health Ministers' Conference and Australian Health Ministers' Advisory Council

7.63 The Australian Health Ministers' Conference (AHMC) and its Australian Health Ministers' Advisory Council (AHMAC) are the key coordinating bodies comprising all Australian and New Zealand Ministers with direct responsibility for health matters.

7.64 The AHMC examines matters concerning health policy, health services and programs with the aim of promoting a consistent and coordinated national approach to health policy development and implementation.⁴² The AHMAC advises the AHMC on strategic issues relating to the coordination of health services across Australia and operates as a national forum for planning, information sharing and innovation.

7.65 In 2002, the AHMAC agreed to the development of a National Service Improvement Framework for cancer. The content of this Framework was drawn from existing cancer plans and policies, including those developed at the State and Territory level. It also drew on a number of other documents developed including *Optimising Cancer Care in Australia* and the *Priority Actions for Cancer Control*. Examination of the Framework did not show specific policies for, or references to, gynaecological cancers but it addressed the general issues of detection, treatment and cancer management that are important across the cancer spectrum.

National Cancer Strategies Group and National Health Priority Action Council

7.66 The National Cancer Strategies Group was established in 1998 to provide expert advice to the Commonwealth Government on strategies to improve the prevention, detection, treatment and management of its National Health Priority Areas.⁴³ Its membership includes clinicians, consumers, epidemiologists, general practitioners, peak cancer bodies, Aboriginal and Torres Strait Islander representatives, and government representatives.

7.67 The National Cancer Strategies Group was formed under the auspices of the National Health Priority Action Council (a sub-committee of the AHMAC). The purpose of the Council is to drive health service improvements to achieve better health outcomes for all Australians for the national health priority chronic conditions.⁴⁴ This Council is chair by the Commonwealth Government's Chief Medical Officer and comprises representatives from each jurisdiction, as well as consumer representatives and an Aboriginal and Torres Strait Islander representative.

42 AHMAC, *The Australian Health Ministers' Advisory Council*, (<http://www.ahmac.gov.au/site/home.asp>).

43 Commonwealth Department of Health and Ageing, *National Cancer Strategies Group*, <http://www.health.gov.au/internet/wcms/publishing.nsf/Content/pq-cancer-ncsg>

44 The National Health Priority chronic conditions are cancer, diabetes, asthma, cardiovascular disease and stroke, and arthritis and musculoskeletal conditions.

The Australian Screening Advisory Committee

7.68 The Australian Screening Advisory Committee was established in 2004 as a national body to provide advice to the Commonwealth, State and Territory governments on national screening programs, including existing programs, those under consideration and emerging screening issues.⁴⁵ ASAC replaced a number of previous advisory committees including the National Advisory Committee to the National Cervical Screening Program. Members of ASAC are drawn from Commonwealth government agencies, State and Territory health departments, and epidemiology, population health, gastroenterology, gynaecological oncology, general practice, consumer and Aboriginal and Torres Strait Islander groups.⁴⁶ The NBCC is also represented.

National Cancer Control Initiative

7.69 As mentioned above, many submitters and witnesses from the health and medical sector welcomed Cancer Australia's formation, however the announcement in 2004 caused a lot of uncertainty over the future of the Commonwealth's previous expert advisory body on cancer, the National Cancer Control Initiative (NCCI). The NCCI was established in 1997 to advise the Commonwealth government on all aspects of cancer control including prevention, early detection, treatment and palliative care.⁴⁷ A comparison of the terms of reference of NCCI and those of Cancer Australia show a great deal of similarity.

7.70 Following the announcement of the formation of Cancer Australia, many assumed that the NCCI would be subsumed into Cancer Australia, given the similarities between the advisory work of the NCCI, and the roles and functions of Cancer Australia.⁴⁸ However, because of the uncertainty over the NCCI's future in the Cancer Australia structure (as well as uncertainty over the NCCI's short term Commonwealth funding), the NCCI ceased to operate on 31 May 2006.⁴⁹

7.71 Whilst operational, the NCCI managed a range of Commonwealth-funded projects focusing on cancer. Of the projects that focused on specific cancer types (approximately half by number), none focussed on gynaecological cancers (though the Committee acknowledged that many other tumour types were also not included).⁵⁰ Of the remaining projects, more general health topics were covered including screening

45 AIHW, *Cancer Committees*, (<http://www.aihw.gov.au/cancer/committees.cfm>).

46 AIHW, *Cancer Committees*, (<http://www.aihw.gov.au/cancer/committees.cfm>).

47 Commonwealth Department of Health and Ageing, *Initiatives*, (<http://www.health.gov.au/internet/wcms/publishing.nsf/content/pq-cancer-init>).

48 Dr Angela Pratt, *Bills Digest – Cancer Australia Bill 2006*, 1.3.06, p.4.

49 Dr Angela Pratt, *Bills Digest – Cancer Australia Bill 2006*, 1.3.06, p.4.

50 The NCCI's projects focussed on colorectal (bowel) cancer, lung cancer, melanoma and non-melanoma skin cancer, prostate cancer and familial cancers.

and early detection, supportive care, service improvement and research. The Committee noted that these are areas of great importance to women with gynaecological cancers. By way of example the NCCI worked with the NBCC to develop the first guidelines about psychosocial care for adults with cancer.⁵¹

Representation of gynaecological oncology issues

The need for greater representation

7.72 The NBCC noted that although many aspects of care were generic, there were also important aspects which were specific to individual cancers.⁵²

7.73 The Cancer Council Australia, COSA and NACCHO agreed and emphasised that representation was critical in order to raise the profile of tumour types.⁵³

Diverse representation on policy-making and service planning bodies is critical to providing equity in the development and implementation of cancer prevention, treatment and care services.⁵⁴

7.74 Evidence from submitters and witnesses presented an overwhelming view to the Committee that experience and expertise in gynaecological cancers was not appropriately represented on national health agencies (and their initiatives) and in other policy development bodies.⁵⁵ The Queensland Centre for Gynaecological Cancer strongly argued that the issues were 'grossly underrepresented' and that this underrepresentation seemed to be a 'continuing theme involving the setting of health priorities and the distribution of (research) funds'.⁵⁶

7.75 Professor Neville Hacker, Director of the Gynaecological Cancer Centre at the Royal Hospital for Women, argued that the incidence of gynaecological cancers justified direct representation.

Gynaecological cancers represent 9.6% of cancers in women, which should be sufficient justification for representation on national cancer agencies.⁵⁷

7.76 The Cancer Council Australia, COSA and NACCHO did not support a quota-system approach to representation on national health agencies and in other policy-making bodies based on particular tumour types.

51 *Submission 44*, p.10 (NBCC).

52 *Submission 44*, p.12 (NBCC).

53 *Committee Hansard 2.8.06*, p.14 (The Cancer Council Australia).

54 *Submission 56*, p.35 (The Cancer Council Australia, COSA and NACCHO).

55 *Submission 28*, p.12 (Western Australia Gynaecologic Cancer Service); *Submission 10*, p.11 (Sydney Gynaecological Oncology Group).

56 *Submission 11*, p.9 (Queensland Centre for Gynaecological Cancer).

57 *Submission 40*, p.6 (Professor Neville Hacker).

If such an approach were taken, efforts to systematically reform cancer services would be fragmented; and people with cancers that cause relatively low incidence and mortality might struggle to find a voice.⁵⁸

7.77 Professor Olver from The Cancer Council Australia cautioned against a tumour-specific approach because it would not be practical for rarer malignancies to have their own national organisation. Where no direct gynaecological cancer expertise was present, he argued that it was still expected that those professionals would consider, represent and support the needs of women at risk or living with gynaecological cancers.

7.78 The Cancer Council Australia, COSA and NACCHO supported broad representation from groups with a wide range of cancer experience and skills, including oncologists, population health experts, consumers and allied health professionals. Specific representation was thought to be necessary though for population groups that face barriers to equitable service provision, such as Indigenous people and people in remote communities.⁵⁹

Improved coordination and leadership

7.79 Evidence to the Committee suggested that the existence of a large number of organisations meant there was no unified voice coming from the gynaecological oncology profession or consumers. A lack of coordination was described at many levels, including at the policy level, and within professional and community organisations.

7.80 Professor Michael Quinn, Director of Oncology/Dysplasia at The Royal Women's Hospital stressed the need for better cooperation within the gynaecological oncology community.

We have got a bigger picture about what is important in gynaecological cancer as opposed to the small, local issues that we all face on a day to day basis. I think there is a commitment from gynaecological cancer specialists to talk to each other, to talk to the community, and therefore they are an excellent model. The value-add, from my point of view, is the cooperation that we can all give together because we are a subspecialty that is very well organised. That is the way I would answer that question.⁶⁰

7.81 Professor Quinn made the following remarks to the Committee about the present state of cancer leadership in Australia:

...there is a feeling amongst the cancer community in Australia that there is a vacuum in cancer leadership. I think the reasons for this—and we can observe this—are that the Cancer Strategies Group has not met for two

58 *Submission 56*, p.35 (The Cancer Council Australia, COSA and NACCHO).

59 *Submission 56*, p.35 (The Cancer Council Australia, COSA and NACCHO).

60 *Committee Hansard 3.8.06*, p.36 (The Royal Women's Hospital).

years, the National Cancer Control Initiative has been disbanded, the Australian Cancer Society has just appointed a new CEO, who is obviously trying to find his feet, and there has been an inordinate delay in the formation of Cancer Australia. That was part of the present government's election platform in 2004 and so far more than \$5 million of budgeted funds have not been used.⁶¹

7.82 Professor Quinn's views were echoed by others and many agreed with the need for a central body to ensure collaboration and a unified voice for policy development and funding allocation.⁶² There was a difference of opinion amongst witnesses as to the means by which this is to be achieved. Some witnesses – notably the Cancer Council Australia – argued that Cancer Australia was the appropriate body, whilst the vast majority recommended the formation of a separate national gynaecological cancer centre.⁶³

Conclusion

7.83 The incidence of gynaecological cancers in women is growing and so are the flow-on impacts for others in the community. Evidence to the Committee questioned the extent to which expertise and experience in gynaecological cancers is being utilised effectively by national health agencies in Australia. Particular concerns were expressed about the extent to which Cancer Australia would successfully incorporate the concerns and needs of those in the gynaecological cancer community with experience and expertise.

7.84 Experience and expertise in gynaecological cancers is found in many different individuals and organisations. From individual gynaecological oncologists and other medical and allied health professionals and researchers, to consumers and community-based organisations – all bring unique and valuable perspectives, knowledge and experiences to the table. It is vital that these are utilised and that information flows to the national agencies, particularly the Department, Cancer Australia and the NBCC, which advise the Government and other decision-making bodies to ensure that gynaecological cancer interests are taken into account.

7.85 The key challenges for guaranteeing an appropriate level of representation were a lack of cooperation between the players and the lack of a unified approach to representational activities in the gynaecological cancer sector. As a result, there were high expectations about the unifying role Cancer Australia was expected to play, but also doubts about whether its stated objectives would be achieved in practice for gynaecological cancer issues.

61 *Committee Hansard* 3.8.06, p.2 (The Royal Women's Hospital).

62 *Committee Hansard* 3.8.06, p.5 (Monash Medical Centre).

63 *Submission* 40, p.6 (Professor Neville Hacker); *Submission* 24, p.3 (ASGO); *Submission* 27, p.20 (Ms Margaret Heffernan).

7.86 As a result, many submitters and witnesses suggested that a national centre focusing on gynaecological cancers be established to provide a strategic framework, to increase efficiencies through coordinated action and to develop a better understanding of gynaecological cancer issues at the political and policy level.

7.87 The Committee acknowledges the complexity of the health system and the delineation of responsibility across all levels of government and other organisations have posed challenges to identifying activities and directions that would deliver better outcomes for the future.

Recommendation 32

7.88 The Committee recommends that Cancer Australia collaborate with individuals and groups to identify the best ways to ensure that expertise and experience in gynaecological cancer is represented on national health agencies, particularly Cancer Australia.

7.89 The Committee further recommends that consumer and community representatives have greater involvement in the decision-making of national health agencies.

7.90 The Committee further recommends that when membership of Cancer Australia's Advisory Council is due for review, one or more consumer representatives from the reproductive cancer sector be appointed to maintain the confidence of groups within those areas.

Recommendation 33

7.91 The Committee recommends that the Commonwealth Department of Health and Ageing, Cancer Australia and the Centre for Gynaecological Cancers communicate with each other about the content of future work plans in order to avoid confusion over responsibility for the development of initiatives and program delivery.

Recommendation 34

7.92 The Committee recommends that the Centre for Gynaecological Cancers put arrangements in place to ensure continuity between the work of the now defunct National Cancer Control Initiative and Cancer Australia, particularly in relation to gynaecological cancers.

APPENDIX 1

LIST OF PUBLIC SUBMISSIONS AND TABLED DOCUMENTS AUTHORISED FOR PUBLICATION BY THE COMMITTEE

- 1 Howat, Dr Paul
- 2 Binns, Professor Colin and Lee, Professor Andy (WA)
- 3 Australian Institute of Health and Welfare (ACT)
- 4 Gynaecological Cancer Service, Peter MacCallum Cancer Centre (VIC)
- 5 Fortescue, Mrs Lisle (NSW)
- 6 Psychosocial Support Project (NSW)

Supplementary information

Provided at hearing 1.8.06:

- NSW Health, *Directory of gynaecological oncology treatment and support services*, 2004
- Promotional brochure for www.gynaecancersupport.org.au
- Westmead Centre for Gynaecological Cancer, *Comprehensive Team Care of Gynaecological Oncology Patients*
- R McQuellon, G Hurt, P DeChatelet, 'Psychosocial Care of the Patient with Cancer', *Cancer Practice*, Nov/Dec 1996, Vol 4, No 6
- S Heiney et al, 'Planning and Organising a Multidisciplinary Psychosocial Oncology Service', *Cancer Practice*, Nov/Dec 1995, Vol 3, No 6
- J Owen et al, 'Psychosocial Interventions for Cancer: Review and Analysis using a three-tiered Outcomes Model', *Psycho-Oncology*10, 2001
- M Fitch, Supportive Care for Cancer Patients, *Hospital Quarterly*
- P Harnett, et al, *Certain Death in Uncertain Time: A Qualitative Study of the Experience of Advanced Ovarian Cancer*, Overview of research project
- J Ussher et al, *An evaluation of concerns, self-perceived needs, and supportive interventions, for informal cancer carers*, Overview of research project
- P Butow et al, Medical Psychology Research Unit, *Supporting the supporters: A randomized controlled trial of interventions to support leaders of cancer support groups*
- The Cancer Council (NSW) Support Groups Empower Cancer Patients: New Study, *Media release*, 4 April 2004
- Clinical Oncological Society of Australia, *Psycho-Oncology Cooperative Research Group*

Provided following hearing 1.8.06:

- Additional information received 3.8.06 (satellite symposium)
- Response to questions regarding workforce issues following hearing 1.8.06, dated 29.8.06

7 Gynaecological Cancer Society (QLD)

8 Nikolovski, Ms Concetta

9 Rosengarten, Ms Alexa (VIC)

Supplementary information

Provided at hearing 3.8.06

- A Rosengarten, 'Sex and sex-ability: Sex, illness and disability' from *Sexual Health: an Australian perspective*, M Temple-Smith & s Gifford (eds)
- Dr R King, 'Pursuer/distancer – A vicious cycle in action' from *Good Loving Great Sex*, Arrow, 1997
- Possible sexuality issues involved with gynaecological cancer surgery
- Opening remarks – references
- G Tan, K Waldman, R Bostick, 'Psychosocial Issues, Sexuality and Cancer', *Sexuality and Disability*, Vol 20, No 4, Winter 2002
- B Schantz Laursen, K Overvad, A schou Olesen, C Delmar, L Arendt-Nielsen, 'Ongoing Pain, Sexual Desire, and Frequency of Sexual Intercourses in Females with Different Chronic Pain Syndromes', *Sexuality and Disability*, Vol 24, No 1, Spring 2006
- K Booth, K Deaver, H Kitchener, J O'Neill, C Farrell, 'Women's experiences of information, psychological distress and worry after treatment with gynaecological cancer', *Patient Education and Counseling*, 56 (2005)
- R Petersen, K Ung, C Hollnad, J Quinlivan, 'the impact of molar pregnancy on psychological symptomatology, sexual function, and quality of life', *Gynecologic Oncology*, 97, 2005
- C Warnock, 'Patients' experiences of intracavity brachytherapy treatment for gynaecological cancer', *European Journal of Oncology Nursing*, 9, 2005

10 Sydney Gynaecological Oncology Group, Sydney South West Area Health Service NSW (NSW)

Supplementary information

- Additional information provided following hearing 2.8.06, received 3.8.06

11 Queensland Centre for Gynaecological Cancer (QCGC) (QLD)

12 Bancroft, Ms Ann (WA)

13 Monash Medical Centre - Gynaecological Oncology Unit (VIC)

14 Gynaecological Awareness Information Network Inc (GAIN)

15 Women's Health Queensland Wide Inc (QLD)

16 Country Women's Association of NSW (NSW)

17 The Lymphoedema Association of WA (WA)

Supplementary information

Provided at hearing 4.8.06

- Opening Statement by Mrs B White
- Commonwealth and other funding required for treatment costs
- A Bancroft – My wish list

-
- 18 Cancer Voices Australia (NSW)
Supplementary information
Provided at hearing 2.8.06:
- Cancer Voices NSW, Charter of cancer consumer values, pamphlet
 - Cancer Voices NSW, *Position Statement on Complementary and Alternate Therapies in the Treatment of Cancer*
 - Cancer Voices Australia, Presentation to the Senate Inquiry into Gynaecological Cancer in Australia
- Provided following hearing:
- Additional information concerning psychosocial guidelines, Isolated Patients' Travel and Accommodation Assistance Schemes, role of cancer consumer groups, dated 3.8.06
- 19 Cancer Voices Victoria (VIC)
Supplementary information
- Supplementary submission provided at hearing 3.8.06
- 20 Cancer Nurses Society of Australia (NSW)
Supplementary information
Provided at hearing 1.8.06:
- M Ryan et al, 'Aetiology and prevalence of lower limb lymphoedema following treatment for gynaecological cancer', *Australian and New Zealand Journal of Obstetrics and Gynaecology*, 43, 2003
 - M Ryan et al, 'The experience of lower limb lymphedema for women after treatment for gynaecologic cancer', *Oncology Nurses Forum*, May-Jun;30 (3)
- 21 CSL Limited (VIC)
Supplementary information
- Cervical Screening Essentials
 - Guidelines (with Senator Moore)
 - Cervical Screening Seminar, NSW Cervical Screening Program
 - Gardasil, Product Information
- 22 Llewellyn, Dr Huw (ACT)
- 23 Northern Sydney Central Coast Health (NSCCH) Gynaecological Oncology Group (NSW)
- 24 Australian Society of Gynaecologic Oncologists (ASGO) (NSW)
- 25 Hunter New England Centre for Gynaecological Cancer (NSW)
- 26 Blomfield, Dr Penny (TAS)
- 27 Heffernan, Ms Margaret (VIC)
Supplementary information
Provided at hearing 3.8.06
- 'Celebrating 15 years of bug breakfast', *NSW Public Health Bulletin*, Vol 16, no 5-6
 - 'My Journey with Gynaecological Cancer' Information Kit: Budget: 1 year estimate

- 28 Hammond, Professor Ian
Leung, Dr Yee Chit
McCartney, Dr Anthony (WA)
- 29 Garvan Institute of Medical Research, Cancer Research Program (NSW)
- 30 GO Fund (NSW)
- 31 Name withheld (SA)
Supplementary information
- Additional information received 8.8.06 (availability of herceptin)
- 32 Rome, Dr Robert (VIC)
- 33 National Ovarian Cancer Network (VIC)
Supplementary information
- *Growing Awareness of Ovarian Cancer* pamphlet and postcard
 - *Ovarian Cancer – the journey* CD
 - *Ovarian Cancer – the journey Treatment*
- 34 Smith, Ms Tanya (WA)
- 35 Greater Metropolitan Clinical Taskforce (GMCT) Gynaecological Oncology Network (NSW)
Supplementary information
Provided at hearing 1.8.06
- Gynaecological oncology services for greater metropolitan Sydney - pamphlet
 - Gynaecological Oncology Services CD
 - Ms Mercia Bush, community representation on medical committees
- Provided following hearing
- Additional information provided following hearing, received 6.9.06 (WHO publication on HPV vaccines)
- 36 Lickiss, Professor J Norelle (NSW)
Supplementary information
- Notes for presentation at the hearing 2.8.06
 - Additional comments following hearing, received 14.8.06
- 37 Royal Women's Hospital (VIC)
Supplementary information
Provided at hearing 3.8.06
- Professor Quinn Opening remarks
 - BreaCanResource Centre – pamphlet & BreaCan – An Innovative Model of Support
 - *The Sexual and Reproductive Health of Young Victorians*, A collaborative project between Family Planning Victoria, Royal Women's Hospital and Centre for Adolescent Health
- Provided following hearing
- Additional information provided following the roundtable discussion 3.8.06 relating to models of care for women living in regional areas, received 29.8.06

- 38 OvCa (ACT & Region) (ACT)
- 39 Gynaecological Oncology Committee of the Royal Australian & New Zealand College of Obstreticians and Gynaecologists and Gynaecological Oncology Department, Mercy Hospital for Women, Heidelberg (VIC)
- 40 Hacker, Professor Neville (NSW)
Supplementary information
 Provided at hearing 1.8.06:
- Beth Y. Karlan, M.D., 'Evolution through intelligent design', Presidential Address International Gynaecologic Cancer Society, *Gynecologic Oncology*, 102, 2006
 - Society of Gynaecologic Oncologists: Statement on a Cervical Cancer Vaccine, June 2006, Statement on Use of Intraperitoneal (IP) Chemotherapy for Ovarian Cancer, January 2006; Statement on the Improved Detection of Abnormal Glandular Lesions, September 2005; and Statement on Early Detection Markers for Ovarian Cancer, March 2005
 - Neville F. Hacker, 'Organisation of gynecological cancer care; a time for change', Presidential Address International Gynaecologic Cancer Society', *International Journal of Gynecological Cancer*, 8, 1998
 - G Ronco et al, 'Human papillomavirus testing and liquid-based cytology in primary screening of women younger than 35 years: results at recruitment for a randomised controlled trial', *Lancet Oncology* 2006:7
 - M Inoue, J Sakaguchi, T Sasagawa, M Tango, 'The evaluation of human papillomavirus DNA testing in primary screening for cervical lesions in a large Japanese population', *International Journal of Gynecological Cancer*, 16, 2006
 - M Schiffman, D Solomon, 'Findings to date from the SCUS-LSIL Triage Study (ALTS)', *Archives of Pathology and Laboratory Medicine*, Vol 127, No 8
 - P Davis et al, 'A report on the current status of European research on the use of human papillomavirus testing for primary cervical cancer screening', *International Journal of Gynecological Cancer*, 118, 2006
- Provided following hearing
- Additional information provided relating to collection of data, dated 16.8.06
- 41 Health Consumers' Council WA (WA)
- 42 National Health and Medical Research Council (ACT)
Supplementary information
- NHMRC funded cancer research 2000-2006 provided at hearing 23.6.06
 - Response to questions following hearing dated 19.7.06
- 43 Federation of Ethnic Communities' Councils of Australia (FECCA) (ACT)
- 44 National Breast Cancer Centre (NSW)
Supplementary information
 Provided at hearing 1.8.06
- NBCC, *Assessment of symptoms that may be Ovarian Cancer: a guide for GPs*
 - NBCC, *Information about CA125 and Ovarian Cancer*
 - NBCC, *Ovarian Cancer in Australia*
 - NBCC, *Clinical practice guidelines for the psychosocial care of adults with cancer*

- NBCC, *Advice about familial aspects of breast cancer and epithelial ovarian cancer*
- NBCC, *Epithelial Ovarian Cancer: Understanding your diagnosis and treatment*
- CAN & NBCC, *Clinical practice guidelines for the management of women with epithelial ovarian cancer*
- CAN & NBCC, *Clinical practice guidelines for the psychosocial care of adults with cancer*

Provided following hearing

- Supplementary submission received 5.10.06

45 GlaxoSmithKline (GSK) (VIC)

46 Davy, A/Professor Margaret (SA)

47 Australian Physiotherapy Association (APA) (VIC)

Supplementary information

Provided at hearing 3.8.06

- Presentation
- A McAuliffe, A Cantlay, E Lassko, *A Review of Physiotherapy Services to Palliative Care Patients in Australia*, Vol 1, August 1997

48 Cancer Council Victoria (VIC)

Supplementary information

- Additional information received 11.9.06 (supportive of NBCC's work on ovarian cancer program)

49 Queensland Multicultural Health Network (QLD)

50 Diagnostic Technology Pty Ltd (NSW)

Supplementary information

- J Cuzick et al, 'Overview of the European and North American studies on HPV testing in primary cervical cancer screening', *International Journal of Cancer*, 119, 2006 provided at hearing 1.8.06
- M Schiffman and P E Castle, 'The Promise of Global Cervical-Cancer Prevention', *The New England Journal of Medicine*, November 17, 2005, received 22.8.06
- *HPV Today, Newsletter on Human Papillomavirus*, No.9 August 2006, received 22.8.06

51 The Cancer Council WA (WA)

Supplementary information

Provided at hearing 4.8.06

- M Grossi, M Quinn, V Thursfield, P Francis, R Rome, R Planner, G Giles, 'Ovarian cancer: patterns of care in Victoria during 1993-1995', *Medical Journal of Australia*, 1 July 2002
- Letter from Cancer Voices WA to the Minister for Health and Ageing, dated 27 July 2006;
- Letter from Ms B Cook to the Minister for Health and Ageing, dated 26 July 2006
- Western Australian Clinical Oncology Group, Recommendations for Screening for Specific Cancers: Guidelines for General Practitioners

-
- 52 Department of Health and Ageing (ACT)
Supplementary information
- Info on MBCC meeting to discuss multidisciplinary cancer item, assessment of ovarian cancer symptoms and Clinical practice guidelines for the psychosocial care of adults with cancer provided at hearing 23.6.06
- 53 Business and Professional Women of WA (WA)
- 54 South Australian Government (SA)
- 55 Australia New Zealand Gynaecological Oncology Group (ANZGOG) (NSW)
- 56 The Cancer Council of Australia; The Clinical Oncological Society of Australia and National Aboriginal Community Controlled Health Organisation (NSW)
- 57 The Royal College of Pathologists of Australasia (NSW)
Supplementary information
Provided at hearing 1.8.06:
- RCPA response to the inquiry's terms of reference
 - RCPA, *Fact File: Pathology Workforce in Australia*, July 2006
 - RCPA, *Position Statement: NHMRC guidelines for cervical cytology implementation and implications*, July 2006
 - Letter to Dr Martin Bernard Van der Weyden dated 10 April 2006 on Pap smears
 - RCPA, 'Manpower Crisis on Pathology', *PathWay*, Spring 2005
 - RCPA, *PathWay*, Jubilee Souvenir Issue, Autumn 2006
 - RCPA, *A career in Anatomical Pathology*, pamphlet
 - RCPA, *A career in Pathology*, pamphlet
- 58 Menzies School of Health Research (NT)
- 59 Queensland Government (QLD)
- 60 Department of Human Services' Victoria (VIC)
- 61 Carless, Dr Alan (NSW)
- 62 Baird, Dr Phillip
- 63 Northern Territory Government (NT)
- 64 Name withheld
- 65 DES Action Australia-NSW
- 66 Martin, Mr John (NSW)
- 67 Strutt, Dr Rebecca (NSW)
- 68 Robertson, Ms Rosalind (NSW)
- 69 Sevicke Jones, Ms Maggie (WA)
- 70 Bowtell, Professor David on behalf of the Australian Ovarian Cancer Study (AOCS) (VIC)
- 71 Gibbons, Ms Victoria (ACT)
- 72 Mid-Life & Menopause Support Group (WA)

Additional information

Menopause Symptoms after Cancer (MSAC) Service

Provided at hearing 4.8.06

- Information on service
- Menopause Service King Edward Memorial Hospital for Women pamphlet
- WA Department of Health, *WA Health Cancer Services Framework*, October 2005
- WA Department of Health, *Palliative Care in Western Australia: Final Report*, December 2005
- WA Cancer and Palliative Care Network, *Progress Report*

Dr Ted Trimble

NCI Initiatives in Palliative Care, June 2006 Update provided following video conference 16.8.06, received 17.8.06

APPENDIX 2

WITNESSES WHO APPEARED BEFORE THE COMMITTEE AT PUBLIC HEARINGS

Friday, 23 June 2006

Parliament House, Canberra

Committee Members in attendance

Senator Moore (Chair)

Senator Adams

Senator Allison

Senator Carol Brown

Senator Ferris

Senator Humphries

Senator Polley

Dr Huw Llewellyn

OvCa Australia (ACT and Region)

Ms Jane Harriss, Director

Mrs Erica Harriss

Mrs Vickie Hardy

Department of Health and Ageing

Mr David Learmonth, Deputy Secretary

Ms Linda Addison, Acting First Assistant Secretary, Acute Care Division

Dr Andrew Black, Medical Adviser, Office for Aboriginal and Torres Strait Islander Health

Mr Ian Kemp, Director, Cancer Section, Chronic Disease and Palliative Care Branch

Prof. Rosemary Knight, Adviser On Cancer Control

Ms Margaret Lyons, First Assistant Secretary, Health Services Improvement Division

Ms Linda Powell, Assistant Secretary, Chronic Disease and Palliative Care Branch

Dr John Primrose, Senior Medical Adviser, Medical and Pharmaceutical Services Division

Ms Samantha Robertson, Acting Assistant Secretary, Medicare Benefits Branch

Ms Carolyn Smith Assistant Secretary, Targeted Prevention Programs Branch

Australian Institute of Health and Welfare

Mr Ken Tallis, Acting Deputy Director

Mr John Harding, Head, Health Registers and Cancer Monitoring Unit

National Health and Medical Research Council

Ms Suzanne Northcott, Executive Director, Centre for Research Management and Policy

Tuesday, 1 August 2006
Parliament House, Sydney

Committee Members in attendance

Senators Moore (Chair)
Senator Adams
Senator Allison
Senator Carol Brown

Senator Ferris
Senator Humphries
Senator Webber

Professor Neville Hacker

Garvan Institute of Medical Research

Professor John Shine, Executive Director
Professor Rob Sutherland, Director, Cancer Research Program

GO Fund

Mr Aleco Vrisakis, Chairman
Ms Carmen Duncan, Fundraising Manager

Ms Rosalind Robertson

Psychosocial Support Project

Dr Gerry Wain, Director and Gynaecological Oncologist, Westmead Hospital
Ms Jane Mills, NSW Coordinator
Ms Kim Hobbs, Social Worker

Mrs Lisle Fortescue

Australia New Zealand Gynaecological Oncology Group

Professor Michael Friedlander, Chair
Dr Julie Martyn, Associate Program Manager, ANZGOG Coordinating Centre and
NHMRC Clinical Trials Centre

Greater Metropolitan Clinical Taskforce, Gynaecological Oncology Network

Professor Donald Marsden, Co-Chair, GMCT Gynaecological Oncology Network
Dr Gerry Wain, Former Co-Chair, GMCT Gynaecological Oncology Network and
Gynaecological Oncologist, Westmead Hospital
Ms Jayne Maidens, Member, GMCT Gynaecological Oncology Network and Clinical
Nurse Consultant, Royal North Shore Hospital
Ms Mercia Bush, Community Participant

National Breast Cancer Centre

Dr Helen Zorbas, Director
Ms Jane Francis, Program Manager, Ovarian Cancer

Cancer Nurses Society of Australia

Ms Tish Lancaster, Past Deputy Chair and Clinical Nurse Consultant, Gynaecological Oncology, Westmead Hospital

Ms Mary Ryan, Clinical Nurse Consultant, Gynaecological Oncology, Royal Hospital for Women

The Royal College of Pathologists of Australasia

Dr Debra Graves, Chief Executive Officer

Dr Gordon Wright, Queensland Medical Laboratory, Pathology Department, Gold Coast Hospital

Dr Gabriele Medley, Melbourne Pathology

Diagnostic Technology Pty Ltd

Mr Mark Van Asten, Managing Director

Dr Alan Carless**Dr Phillip Baird**

Wednesday, 2 August 2006

Parliament House, Sydney

Committee Members in attendance

Senators Moore (Chair)

Senator Adams

Senator Allison

Senator Carol Brown

Senator Ferris

Senator Humphries

Senator Webber

The Cancer Council of Australia, The Clinical Oncological Society of Australia and the National Aboriginal Community Controlled Health Organisation

Professor Ian Olver, Chief Executive Officer, The Cancer Council Australia

Dr Kendra Sundquist, Manager Supportive Care Development, The Cancer Council NSW

Dr Sophie Couzos, Public Health Officer, National Aboriginal Community Controlled Health Organisation

Cancer Voices Australia

Ms Sally Crossing, Chair, Cancer Voices NSW

Mr John Stubbs, Executive Officer

Gynaecological Cancer Society

Mr John Gower, Chief Executive Officer

Hunter New England Centre for Gynaecological Cancer

Associate Professor Anthony Proietto, President

Ms Anne Mellon, Nurse Consultant

Australian Society of Gynaecologic Oncologists

Associate Professor Anthony Proietto, President

Dr Lewis Perrin, Secretary

Professor J Norelle Lickiss**Dr Rebecca Strutt****Sydney Gynaecological Oncology Group, Sydney South West Area Health Service**

Professor Jonathan Carter, Head of the Sydney Gynaecological Oncology Group, Royal Prince Alfred and Liverpool Hospitals

*Thursday, 3 August 2006**Peter MacCallum Cancer Centre, Melbourne***Committee Members in attendance**

Senators Moore (Chair)

Senator Adams

Senator Allison

Senator Ferris

Senator Humphries

Royal Women's Hospital

Professor Michael Quinn, Director of Oncology and Dysplasia

Ms Liz Chatham, Director Women's Services

Monash Medical Centre

Associate Professor Tom Jobling, Head, Gynaecological Oncology Unit

Gynaecological Oncology Committee of RANZCOG and Gynaecological Oncology Department of Mercy Hospital

Dr Peter Grant, Head, Department of Gynaecologic Oncology, Mercy Hospital for Women

Gynaecological Cancer Service, Peter MacCallum Cancer Centre)

Associate Professor Kailash Narayan, Radiation Oncologist & Head of Gynaecology Unit, Peter Mac

Professor David Bowtell, Australian Ovarian Cancer Study

Margaret Heffernan**Ms Alexa Rosengarten**

GlaxoSmithKline

Mr Alex Gosman, Director of Government & Corporate Affairs
Dr Catherine Streeton, A/Medical Director Cervarix
Ms Danielle Moore, Advocacy Cervarix

CSL Limited

Dr Gerry Wain, Director, NSW Cervical Screening Program, Westmead Hospital
Dr Rachel David, Director of Public Affairs
Dr Jane Leong, Medical Director, CSL Pharmaceuticals Ltd

Ms Concetta Nikolovski**Cancer Council Victoria**

Professor David Allen, Victorian Cooperative Oncology Group, Gynaecological Cancer Committee
Ms Kate Broun, Manager, PapScreen Victoria, Cancer Education Unit

Cancer Voices Victoria

Mr Ian Roos, Chair
Mr Michael Powell, Vice Chair

National Ovarian Cancer Network

Mr Simon Lee, Chair and Director
Ms Karen Livingstone, CEO and Director
Ms Nicole Livingstone, Director
Ms Carolyn Walker, Director

Australian Physiotherapy Association

Ms Cathy Nall, President
Ms Robyn Sharpe, A/Assistant Director Physiotherapy, Royal Brisbane Women's Hospital

Friday, 4 August 2006
King Edward Memorial Hospital, Subiaco WA

Committee Members in attendance

Senators Moore (Chair)
Senator Adams

Senator Allison
Senator Ferris

Cancer Council WA and WA Clinical Oncology Group

Ms Susan Rooney, Chief Executive Officer, Cancer Council WA
Dr Paul Katris, Executive Officer, WACOG
Mr Terry Slavin, Education and Research Director, Cancer Council WA
Ms Sushama Sharma, Consumer

Lymphoedema Association

Mrs Barbara White, President

Mrs Ann Bancroft

Menopause Symptoms after Cancer (MSAC) Service

Ms Jane Gregson, Clinical Nurse Coordinator MSAC Service
Ms Yvonne McCall, Honorary Coordinator, Mid-life and Menopausal Support Group

Ms Robyn Collins

Professor Christobel Saunders

Professor John Newnham

Gynaecological Awareness Information Network (GAIN) Inc

Ms Natalie Jenkins, Chair
Ms Kath Mazzella, Founder
Ms Kylie Flaherty, Committee member
Mrs Kyle Flaherty, Committee member

Ms Tanya Smith

Health Consumers' Council WA

Ms Michele Kosky, Executive Director

WA Gynaecological Cancer Service, King Edward Memorial Hospital

Dr Yee Chit Leung, Gynaecologic Oncologist

Dr Sarah Pickstock, Medical Director, Palliative Care Unit, Hollywood Private Hospital

Ms Valda Duffield, Senior Social Worker, KEMH

Dr Barry Cassidy, Consultant Radiation Oncologist

Professor Michael Millward, Cancer Council Professor of Clinical Cancer Research and Chairman, WA Clinical Oncology Group

Thursday, 10 August 2006

Parliament House, Canberra – Teleconference

Committee Members in attendance

Senator Moore (Chair)

Senator Allison

Senator Ferris

Senator Humphries

Senator Polley

Senator Webber

Professor Philip Di Saia

The Dorothy Marsh Chair in Reproductive Biology

Professor, Department of Obstetrics and Gynaecology, University of California, and Director, Division of Gynaecologic Oncology, University of California, Irvine Medical Centre, USA

Wednesday, 16 August 2006

Parliament House, Canberra – Video Teleconference

Committee Members in attendance

Senator Moore (Chair)

Senator Adams

Senator Allison

Senator Ferris

Senator Humphries

Dr Edward Trimble

Head, Gynecologic Cancer Therapeutics, National Cancer Institute

National Institutes of Health

Department of Health and Human Services, USA

Tuesday, 12 September 2006
Parliament House, Canberra – Teleconference

Committee Members in attendance

Senator Humphries (Chairman)	Senator Ferris
Senator Moore (Deputy Chair)	Senator Webber
Senator Allison	
Senator Carol Brown	

Professor Barbara Andersen

Professor, Department of Psychology and Department of Obstetrics and Gynecology, The Ohio State University, USA.

Inspections

Friday, 4 August 2006
Margaret Smith Menopause Unit, Centenary Clinic, King Edward Memorial Hospital, Subiaco WA

Committee Members in attendance

Senators Moore (Chair)	Senator Allison
Senator Adams	Senator Ferris

The Committee inspected the Menopause after Cancer Clinic.

Wednesday, 27 September 2006
National Breast Cancer Centre, Level 4, 92 Parramatta Road, Camperdown NSW

Committee Members in attendance

Senators Moore (Chair)	Senator Allison
Senator Adams	

The Committee visited the National Breast Cancer Centre and had informal discussions with Dr Helen Zorbas, Director, and NBCC staff on the work of The Ovarian Cancer Program.

Private Discussion

Wednesday, 11 October 2006
Parliament House, Canberra

The Committee held private discussions with Professor David Currow, CEO, Cancer Australia.

APPENDIX 3

NHMRC FUNDING FOR GYNAECOLOGICAL CANCER IN AUSTRALIA 2000 – 2006

NHMRC funding for Gynaecological Cancer in Australia – 2000-2006

Program Grants (3)

Researcher	Institution	Project Title	Duration	Total Funding
Prof David de Kretser	Monash University	Control of reproductive processes	2000	\$4,322,218
Dr Georgia Chenevix-Trench	Queensland Institute of Medical Research	Towards an understanding of the genetic basis of breast and ovarian	2003-2007	\$4,284,405
Prof Adele Green	Queensland Institute of Medical Research	Towards cancer control: Population and molecular strategies	2002-2006	\$5,411,880
			TOTAL	\$14,018,503

Project Grants (51)

Researcher	Institution	Project Title	Duration	Total Funding
Prof Francis J Bowden	Australian National University	Screening for Chlamydia trachomatis with routine Pap smears in general practice: A randomised controlled trial	2005-2007	\$350,500
A/Pr Roger J Daly	Garvan Institute of Medical Research	Regulation of mitogenic signalling via the Gab2 docking protein	2003	\$141,750
Prof Judith M Lumley	La Trobe University	Perinatal outcomes following treatment for cervical dysplasia	2003-2004	\$98,600
A/Pr Michael A McCuckin	Mater Misericordiae Health Services Brisbane Limited	The muc1 epithelial mucin in breast and ovarian cancer	2000	\$355,548

Researcher	Institution	Project Title	Duration	Total Funding
A/Pr Martin Pera	Monash University	Regulation Of Human Multipotent Stem Cells By Membrane Bound And Soluble Factors	2000-2001	\$344,732
A/Pr Peter AW Rogers	Monash University	Regulation of endometrial angiogenesis and lymphangiogenesis	2006-2008	\$477,750
A/Prof Peter AW Rogers	Monash University	New blood vessel growth in the human uterus	2000-2004	\$744,219
Dr Caroline E Gargett	Monash University	A study of cells responsible for growth of the human uterus	2004-2006	\$409,575
Dr Jillian M Shaw	Monash University	Development of ovarian cryopreservation and autografting procedures	2000	\$264,367
Prof David A Jans	Monash University	Regulation of nuclear import of viral oncoproteins and transcription factors by protein-protein interactions	2001-2005	\$650,383
Prof Donald McNaughton	Monash University	Infrared spectroscopic imaging in the diagnosis of cervical cancer	2003-2005	\$291,600
A/Pr Freddy Sitas	NSW Cancer Council	The effect of exogenous hormones, smoking and HPV on the incidence of screen detected pre-invasive cervical cancer	2006-2010	\$1,151,625
Prof Mark S Baker	Peter MacCallum Cancer Centre	Understanding ovarian cancer metastasis	2000-2002	\$166,725
Prof Peter J Fuller	Prince Henry's Institute of Medical Research	Identification of Key Genes in Cancer of the Ovary	2000-2002	\$264,601
A/Pr Andreas Suhrbier	Queensland Institute of Medical Research	A new function for a known enzyme inhibitor- implications for cancer	2004-2006	\$463,500

Researcher	Institution	Project Title	Duration	Total Funding
A/Pr Andreas Subrbier	Queensland Institute of Medical Research	The human papilloma virus oncoprotein E7 degrades the retinoblastoma protein by enhancing calpain activity	2006-2008	\$252,500
Dr Amanda B Spurdle	Queensland Institute of Medical Research	Functional Evaluation of BRCA1 & BRCA2 Unclassified Sequence Variants and Identification of Critical Pathogenic Domains	2003-2005	\$331,313
Dr Amanda B Spurdle	Queensland Institute of Medical Research	Molecular Epidemiology of Endometrial Cancer	2005-2007	\$1,473,480
Dr Georgia A Chenevix-Trench	Queensland Institute of Medical Research	Microarray-targeted candidate gene approach to finding ovarian cancer susceptibility genes	2006-2008	\$601,250
Prof Judith Clements	Queensland University of Technology	Expression and functional studies on the novel ovarian-expressed serine protease, Kallikrein 4, in ovarian tumorigenesis	2003-2005	\$410,250
Prof Judith Clements	Queensland University of Technology	Role of Kallikreins in ovarian cancer progression	2006-2008	\$498,750
Prof Richard Ivell	University of Adelaide	Relaxin signalling in the endometrium and the regulation of early pregnancy	2005-2007	\$466,125
A/Pr Ian G Campbell	University of Melbourne	Cloning of chromosome 22 tumour suppressor genes	2004-2006	\$249,250
A/Pr Ian G Campbell	University of Melbourne	LOH in cancer associated stroma	2006-2008	\$392,500
A/Pr Ian G Campbell	University of Melbourne	Genome-wide study of loss of heterozygosity using high density SNP arrays to identify breast cancer predisposition genes	2006-2008	\$531,250

Researcher	Institution	Project Title	Duration	Total Funding
A/Pr Wayne A Phillips	University of Melbourne	Phosphatidylinositol 3-kinase mutations associated with ovarian, colon and breast tumour	2004-2005	\$154,000
A/Pr Wayne A Phillips	University of Melbourne	PI 3-kinase: a new player in human cancer	2006-2008	\$542,750
Dr Phillip K Darcy	University of Melbourne	Activation and expansion of gene-engineered killer T cells	2002	\$115,660
Dr Richard B Pearson	University of Melbourne	Biochemical analysis of Akt 3-specific signal transduction	2005-2007	\$349,375
Prof David DL Bowtell	University of Melbourne	Molecular Epidemiology of Ovarian Cancer: The Australian Ovarian Cancer Study National Clinical Follow-Up Core	2006-2010	\$830,000
Prof David DL Bowtell	University of Melbourne	Combined expression analysis and SNP-based measurement of copy number variation in ovarian cancer	2006-2008	\$432,500
Prof Joseph F Sambrook	University of Melbourne	kConFab - A Consortium for research on familial breast cancer	2000-2002	\$1,624,711
Prof Lenore H Manderson	University of Melbourne	Social aspects and cultural meanings of gynaecological cancer diagnosis, treatment and adjustment of Victorian women	2004-2005	\$158,500
Dr Bettina Meiser	University of New South Wales	A randomised trial of a decision aid for women at increased risk for ovarian cancer	2002-2003	\$115,110
Prof Robyn Ward	University of New South Wales	Germline epimutations of tumour suppressor genes in familial cancer	2005-2007	\$502,500
Dr Germain J Fernando	University of Queensland	How to induce a long lasting anti-tumour response	2000-2002	\$242,567

Researcher	Institution	Project Title	Duration	Total Funding
Dr Germain J Fernando	University of Queensland	Optimising immunity towards cancers by vaccination	2002-2004	\$211,320
Dr Graham R Leggatt	University of Queensland	CTL avidity as a determinant of the mature, antigen-specific immune repertoire	2000-2003	\$241,528
Dr Nigel AJ McMillan	University of Queensland	The role of the human papillomavirus in alpha-6 integrin activation and cell growth	2000-2001	\$229,217
Dr Nigel AJ McMillan	University of Queensland	NHPV and cervical carcinoma: Signalling and clinical responses to interferons	2002-2004	\$534,480
Dr Nigel AJ McMillan	University of Queensland	Treatment of virally-induced cancers by RNA Interference	2004-2006	\$389,250
Prof Ian H Frazer	University of Queensland	Determinants of effective immunotherapy for epithelial tumours	2000-2001	\$344,432
Prof Ian H Frazer	University of Queensland	How does papillomavirus regulate its late gene expression?	2000-2001	\$237,350
Prof Ian H Frazer	University of Queensland	Effective immunotherapy for HPV associated cervical cancer precursor lesions	2002-2004	\$482,640
Prof Ian H Frazer	University of Queensland	Immunoregulatory immune responses to a peripherally presented tumour antigen	2003-2005	\$219,750
Prof Robert W Tindle	University of Queensland	Immunological consequences of epithelial expression of a viral oncoprotein associated with cervical carcinoma	2000-2001	\$192,069
Prof Robert W Tindle	University of Queensland	A cervical cancer vaccine for the out-bred human population	2001-2002	\$214,697

Researcher	Institution	Project Title	Duration	Total Funding
Prof Robert W Tindle	University of Queensland	Overcoming immune response non-reactivity in cervical cancer	2001-2004	\$212,037
Prof Robert W Tindle	University of Queensland	Improving the efficiency of DNA vaccines	2005-2006	\$182,000
A/Pr Christine L Clarke	University of Sydney	Modulation of cytoskeletal structure by progesterone receptor isoforms	2002-2004	\$337,650
A/Pr Paul R Harnett	University of Sydney	Certain death in uncertain time: a qualitative study of the experience of advanced ovarian cancer	2006-2008	\$217,500
			TOTAL	\$20,695,736

Scholarships (16)

Researcher	Institution	Project Title	Duration	Total Funding
Ms Fiona J Bruinsma	La Trobe University	Perinatal outcomes following treatment for cervical dysplasia	2005-2008	\$52,121
Ms Kathryn A Morris	La Trobe University	Cancer screening: Is there a coherent ethical framework?	2001-2004	\$86,715
Dr Simon Chu	Prince Henry's Institute of Medical Research	Molecular pathogenesis of ovarian tumours	2000-2003	\$66,376
Dr Catherine M Olsen	Queensland Institute of Medical Research	Anthropometric indices, physical activity and ovarian cancer: causation, diagnosis and survival	2006-2008	\$63,693

Researcher	Institution	Project Title	Duration	Total Funding
Dr Stephen A Myers	Queensland University of Technology	Estrogen and progesterone regulation of tissue kallikrein gene expression in endometrial cancer cell lines	2000-2002	\$56,627
Dr Sally E Baron-Hay	Royal North Shore Hospital	The Role of the Insulin-like Growth factors and their Binding Proteins in the Pathogenesis of Ovarian Cancer	2001-2004	\$55,941
Miss Natalie Wray	University of Melbourne	Gynaecological Cancers: A study of the attitudes and experiences of Australian-born and immigrant Middle Eastern women	2001-2003	\$47,805
Miss Natalie Wray	University of Melbourne	The attitudes and understandings of women with gynaecological cancer.	2002	\$8,900
Miss Wen Qiu	University of Melbourne	Cellular, molecular & genetic characterization of breast & ovarian cancer-associated fibroblasts (CAFs)	2006-2009	\$63,693
Miss Chin-Yi Kan	University of New South Wales	Investigating the regions/functions of HPV E6 proteins required for immortalisation of normal cells	2005	\$20,484
A/Pr Sherry Wu	University of Queensland	Liposomal delivery of RNA inhibitory nucleotides for treatment of cervical cancer	2006-2008	\$80,451
Dr Jennifer Broom	University of Queensland	Optimising immunotherapy for chronic viral infection	2006-2008	\$91,800
Dr Elizabeth Davey	University of Sydney	How the prevention of cervical cancer can be improved by new methods of screening and testing	2004-2005	\$51,897

Researcher	Institution	Project Title	Duration	Total Funding
Dr Georgina E Hale	University of Sydney	The natural history of the physiological, hormonal, endometrial and ovarian dynamics during the perimenopause: A 3-yr lo	2001-2004	\$98,103
Dr Rohini Sharma	University of Sydney	Identification of novel molecular targets for antibody-directed therapy of ovarian cancer	2004-2006	\$89,517
Mr Anthony Newall	University of Sydney	A model for evidence based introduction of a new vaccine to Australia - human papillomavirus vaccine	2006-2007	\$42,462
			TOTAL	\$976,585

Strategic Awards (2)

Researcher	Institution	Project Title	Duration	Total Funding
Prof Joseph F Sambrook	University of Melbourne	Kathleen Cuningham Foundation Consortium for Research into Familial Breast Cancer	2003-2006	\$3,195,990
Prof Ian H Frazer	University of Queensland	Study of HPV 6 L1 virus like particles as Therapeutic vaccine for genital warts and recurrent respiratory papillomatosis.	2004-2008	\$615,608
			TOTAL	\$3,811,598

Career Awards (7)

Researcher	Institution	Project Title	Duration	Total Funding
A/Pr David Robertson	Prince Henry's Institute of Medical Research	NHMRC Career Awards	2001	\$86,574
A/Pr David Robertson	Prince Henry's Institute of Medical Research	NHMRC Career Awards	2002-2006	\$683,000
Dr David Whiteman	Queensland Institute of Medical Research	NHMRC Career Awards	2004-2008	\$590,250
Dr Georgia Chenevix-Trench	Queensland Institute of Medical Research	NHMRC Career Awards	2002-2003	\$235,000
Prof Judith Clements	Queensland University of Technology	NHMRC Career Awards	2006-2010	\$701,250
Prof Suzanne Garland	University of Melbourne	NHMRC Career Awards	2005-2009	\$386,925
Prof Simon Foote	Walter and Eliza Hall Institute	NHMRC Career Awards	2003-2004	\$250,000
			TOTAL	\$2,932,999

Training Awards (4)

Researcher	Institution	Project Title	Duration	Total Funding
Dr Penelope L. Jeffery	Mater Medical Research Institute	Cell surface mucins modulate epithelial cell growth and apoptosis of normal mucosal wound repair and epithelial cancers	2005-2009	\$264,000

Dr Marguerite S Buzza	Monash University	Studies on the role of Testisin in fertility & cancer using knockout mice	2006-2010	\$299,856
Dr Rachel E Neale	Queensland Institute of Medical Research	Smoking and Hormonally related cancers: Epidemiological Studies	2003-2007	\$330,186
Dr Susan M Shanley	Sydney West Area Health Service	Identification of putative tumour suppressor gene on chromosome 1p36 in breast and ovarian carcinomas	2001-2006	\$410,040
		TOTAL		\$1,304,082

Fellowship (2)

Researcher	Institution	Project Title	Duration	Total Funding
Dr Wenyi Gu	University of Queensland	Sensitise cervical cancer cells to shRNA-mediated gene silence	2006-2009	\$265,250
Dr Kirsten J McCaffery	University of Sydney	Women's understanding of cervical screening and human papillomavirus (HPV): development and evaluation of a decision aid	2001-2004	\$251,012
		TOTAL		\$516,262

Source: Submission 42, pp.5-11 (NHMRC).

APPENDIX 4

POSSIBLE SEXUALITY ISSUES INVOLVED WITH GYNAECOLOGICAL CANCER SURGERY



Possible Sexuality Issues Involved With Gynaecological Cancer Surgery

Treatment	Low Sexual Desire	Less Vaginal Moisture	Reduced Vaginal Size	Painful Intercourse	Trouble Reaching Orgasm	Infertility
Chemotherapy	Sometimes	Often	Rarely	Often	Rarely	Often
Pelvic radiation therapy	Rarely	Often	Often	Often	Rarely	Always
Radical hysterectomy	Rarely	Often *	Often	Rarely	Rarely	Always
Removal of the ovaries	Rarely	Often *	Always	Sometimes	Rarely	Always
Bowel resection	Sometimes	Often *	Sometimes	Sometimes	Rarely	Sometimes
Total pelvic exenteration with vaginal reconstruction	Sometimes	Always	Sometimes	Sometimes	Sometimes	Always
Radical vulvectomy	Rarely	Never	Sometimes	Often	Sometimes	Never
Conization of the cervix	Never	Never	Never	Rarely	Never	Rarely
Oophorectomy (removal of one tube & ovary)	Rarely	Never *	Never *	Rarely	Never	Rarely
Oophorectomy (removal of both tubes & ovaries)	Rarely	Often *	Never *	Rarely *	Rarely	Always
Progesterone therapy for uterine cancer	Sometimes	Often	Sometimes	Sometimes	Rarely	Always

* Vaginal dryness and size changes should not occur if one ovary is able to be retained or if hormone replacement therapy is undertaken.

Source: *Submission 9, Attachment 3, p.2 (Ms Alexa Rosengarten).*