

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 Gynaecologic 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 sub-speciality 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

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- **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.

