

## **CHAPTER 3**

### **ADEQUACY OF RESEARCH FUNDING FOR GYNAECOLOGICAL CANCERS**

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

#### **Introduction**

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

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

#### **Gynaecological cancer research**

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

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

#### ***Clinical trials***

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

---

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

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

---

*The role of Australia New Zealand Gynaecological Oncology Group*

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

### **Where is the research money coming from?**

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

### ***Commonwealth funding for gynaecological cancer research***

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

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

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

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

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

---

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

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

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

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

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

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

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

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

#### *Other Commonwealth research funding*

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

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

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

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

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

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

#### *The priority of research funding*

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

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

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

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

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

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

---

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

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

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

---

the existence of benign conditions. The Ovarian Cancer Program commissioned the AIHW to develop the first national report about ovarian cancer which includes data on incidence, mortality and survival. This report is due for release later in 2006.<sup>11</sup>

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

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

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

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

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

### ***Community funding for gynaecological cancer research***

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

---

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

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

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

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

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

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

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

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

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

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

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

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

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

---

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

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

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

---

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

*Cancer Councils' funding of gynaecological cancer research*

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

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

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

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

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

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

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

---

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

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

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

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

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

### ***Pharmaceutical company funding for gynaecological cancer research***

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

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

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

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

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

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

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

### ***International funding for gynaecological cancer research***

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

---

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

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

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

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

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

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

#### *Australian Ovarian Cancer Study*

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

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

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

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

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

---

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

27 AOCs, *Funding*, [http://www.aocstudy.org/org\\_funding.asp](http://www.aocstudy.org/org_funding.asp).

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

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

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

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

### ***Incentives for research contributions***

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

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

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

### **Adequacy of research funding for gynaecological cancers**

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

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

---

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

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

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

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

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

For example, in the Commonwealth 2005-06 budget initiative 'Strengthening Cancer Care' \$189.4 million was allocated over five years to enable 'the Australian Government deliver its election commitment to help reduce the burden of cancer'. Of this funding, \$5 million was specifically allocated to breast cancer initiatives while other types of cancer did not receive any block grants. Organisations for other forms of cancer were only able to apply for seeding grants of up to \$90,000.<sup>32</sup>

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

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

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

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

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

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

---

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

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

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

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

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

### **Barriers to adequate gynaecological cancer research funding**

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

#### ***Duplication and an uncoordinated approach***

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

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

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

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

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

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

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

---

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

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

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

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

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

### ***Lack of academic research positions***

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

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

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

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

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

---

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

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

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

### ***Lack of clinical trial funding***

#### *The importance of clinical trials*

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

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

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

#### *Australia's experience with gynaecological cancer clinical trials*

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

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

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

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

---

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

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

---

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

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

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

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

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

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

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

---

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

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

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

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

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

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

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

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

#### *Adequacy of funding for clinical trials*

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

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

---

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

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

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

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

---

of recurrent funding to support infrastructure as well as funds for specific trials.<sup>50</sup>

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

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

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

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

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

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

#### *Adequacy of NHMRC funding for clinical trials*

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

---

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

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

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

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

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

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

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

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

### ***Link between research funding and intellectual interest***

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

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

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

---

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

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

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

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

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

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

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

### **Recommended funding levels for gynaecological cancer research**

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

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

---

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

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

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

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

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

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

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

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

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

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

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

---

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

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

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

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

## Future gynaecological cancer research needs

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

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

### *The priority of research*

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

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

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

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

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

---

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

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

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

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

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

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

### *A commitment to ongoing funding*

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

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

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

---

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

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

---

### ***The continued need for collaboration***

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

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

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

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

### ***The need for a national approach***

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

---

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

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

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

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

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

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

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

### ***A screening test for ovarian cancer***

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

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

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

---

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

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

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

---

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

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

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

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

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

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

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

---

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

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

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

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

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

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

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

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

### ***Understanding the symptoms and causes of gynaecological cancers***

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

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

---

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

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

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

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

---

## **Conclusion**

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

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

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

## **Recommendation 6**

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

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

## **Recommendation 7**

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

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

